



# EAPC 2013

13<sup>th</sup> WORLD CONGRESS OF THE EUROPEAN  
ASSOCIATION FOR PALLIATIVE CARE

30 May – 2 June 2013  
Prague Congress Centre

Palliative Care – the right way forward



EUROPEAN ASSOCIATION  
FOR PALLIATIVE CARE  
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# 8<sup>th</sup> World Research Congress of the European Association for Palliative Care



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**13th World Congress of the European Association for Palliative Care (EAPC)**  
Prague, Czech Republic, 30 May – 2 June 2013

## **Abstracts**

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Dear Congress participant,

### **Welcome to the EAPC World Congress in Prague!**

This Congress has all the ingredients that are needed to deliver high quality palliative care wherever you are in the world. Whether this is your first Congress or if you are a regular attendee, I am sure there will be much in the programme to whet your appetite. The beautiful old city of Prague is situated almost in the centre of Europe, where flavours from east and west mingle with those of the north and south.

If I can draw on a cooking analogy, it seems that to produce the best quality meal; it is essential to combine fresh, carefully selected ingredients, mixed with skill and knowledge, presented impeccably in a timely and well paced way, and tempered with love and passion. Moreover, the very best meals are individualised to the palate, preferences and appetite of the person. Likewise, in palliative care situations, the very best care is provided through a combination of knowledge, skills and careful adjustment to the individual needs of patients and their families, with sensitivity to timing (what is regarded as delicious for breakfast might not be so appetising for dinner). Sharing the production of food and eating together is one of the features that make hospices and specialist palliative care units so different from conventional clinical environments like hospitals. I have a memory of visiting hospices in many countries, where the smell of fresh baking permeates the atmosphere, evoking the essence of homeliness.

Family members and other visitors often appreciate opportunities to drink and eat with patients – a normal social ritual – that advanced disease can disrupt or destroy. It can provide opportunities to collectively mark symbolic occasions – birthdays, anniversaries and religious events. For example, a birthday cake may enable family members to gather at the bedside of the patient, including the dying person in the celebration – giving them both literally and metaphorically ‘a taste for life’. It is also one of the ‘simple things’ that family members remark upon as special about palliative care units and hospices compared to busy hospital wards. Palliative care is also building research and clinical expertise in dealing with the distress caused by reduced appetite, anorexia and cachexia which may be features of the final phase of life. In some parts of Africa, palliative care services provide access to essential food for patients and families who would otherwise go hungry.

Sharing food is a profoundly social and cultural experience. Food is culturally imbued with meaning; it is an easy way to learn more about the backgrounds and values of your fellow participants and of the Czech Republic. I hope you will celebrate the opening of the Congress on Thursday 30th May by participating in the Get Together where you can meet with old and new friends.

At the Congress, we will be launching the Prague Charter which calls for the acknowledgement of palliative care as a human right. This builds upon previous EAPC initiatives such as Budapest Commitments and the Lisbon Challenge. We welcome you to join with us in an international united effort to improve access to high quality palliative care.



**Professor Sheila Payne**

*President of the European Association for Palliative Care*

#### **Acknowledgements**

I want to offer special thanks to Professor Lukas Radbruch who has chaired the Scientific Committee and acknowledge the important contribution of the members of the Scientific Committee. I am indebted to our international advisory board that have provided detailed and insightful reviews on all the proffered abstracts. Special thanks go to the local organizing committee for their commitment to ensuring the success of this Congress. As always, Heidi Blumhuber and Amelia Giordano in the EAPC Head Office in Milano, Italy have supported the Congress. Thank you to our efficient congress organisers, Interplan. Finally I am constantly amazed and impressed by the tireless energy and enthusiasm of our congress officer, Farina Hodiament, without whom this Congress would not have happened.

### Dear Congress participant,

We are looking forward to meeting you in Prague, for the 13th World Congress of the European Association for Palliative Care. The congress theme is "Palliative Care – the right way forward", and the topic of access to palliative care as a human right will be visible throughout the scientific program as a major thematic thread.

The congress theme refers to the Prague Charter "Palliative Care: a human right" ([http://www.avaaz.org/en/petition/The\\_Prague\\_Charter\\_Relieving\\_suffering](http://www.avaaz.org/en/petition/The_Prague_Charter_Relieving_suffering)), which has been launched by the European Association for Palliative Care (EAPC), International Association for Palliative Care (IAHPC), Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch (HRW). These organizations are working together to advocate access to palliative care as a human right. The Prague Charter will be promoted throughout the congress program. The full text of the Prague Charter can be found on the EAPC Prague Charter website (<http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx>).

The Prague Charter urges governments to relieve suffering and ensure the human right of access to adequate palliative care. Please support and sign the Prague Charter, while you are visiting the congress. So far, the petition has been signed by more than 3000 persons, and we hope that this number can be increased considerably during the congress!

The congress programme will discuss the gaps where this human right is not yet available, but also will discuss different models and ways that are available in order to make palliative care available and accessible for everybody who needs it. This discussion touches ethical, legal, economical, medical, and social challenges which all need to be addressed. Plenary lectures will represent the user perspective, teamwork, culturally and economically appropriate palliative care and the full range of palliative care throughout the disease trajectory from early integration of palliative care to symptom control in the final phase of life, and from pediatric palliative care to palliative care in patients with dementia.

The congress theme "Palliative Care – the right way forward" also mirrors the direction palliative care is heading to: forward! Against the background of this forward movement topics such as new developments in symptom control and service provision will be covered.

We are happy to see this forward movement also in the growth of the palliative care community which is mirrored by the increasing number of congress participants and the quality of the submitted abstracts. As always the scientific content of the EAPC congress will be co-designed by the participants themselves, and we are very much looking forward to your input and the oral communication sessions and poster exhibition which will be building on these abstracts.

Over the last years the EAPC congress became a popular and renowned forum for palliative care professionals from all around the world. The internationality as well as the multi-professionalism of this forum calls for a scientific program which is as versatile as the audience it is designed for. We are happy and honoured to take up the task to create this program representing the many-sidedness of palliative care and we hope to meet the various interests of you – the congress participants.

We are looking forward to seeing you in Prague!



**Lukas Radbruch**  
*Chair of the Scientific Committee*



**Ladislav Kabelka**  
*Chair of the Organizing Committee*

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# Plenary sessions

PL 1.1

# Twenty-five years revisited: have we been faithful to our values and principles?

**Schaerer R.**

*Joseph Fourier, Medecine, La Tronche, France*

Comparing the current development of palliative care (PC) in Europe with our original values and principles, as inherited from C. Saunders and others, one can say that we – as the PC movement – have been widely faithful to our commitments and our dreams and, most likely, beyond. Total pain of terminally ill patients has been, and remains being, taken into account in its four dimensions by interdisciplinary teams. PC structures have dramatically increased and diversified in response to patient and family needs. Clinical research is a major branch of PC commitment. Education has been admitted as an academic discipline and evaluated, both at graduate and post-graduate levels. Three more unexpected developments are noteworthy: 1) the wide

adoption by European states of national PC policies; 2) the acknowledgement of PC as a medical specialty; 3) the extension of the field of PC to non-terminal patients, particularly to geriatric patients, and to conditions other than cancer. Among the questions that could be raised, three will be discussed: 1) Does the advent of PC as a specialty detract in some way the diffusion of PC as a common behaviour in every clinical practice? 2) Will the development of national PC policies and official PC organisations lead to a kind of neglect of dying people and of questions about death and dying in society? 3) Are we faithful to our humane condition when we admit, as a historical and social reality, that euthanasia is now an unavoidable fact that will exist beside PC? ■

PL 1.2

## Delirium at the end of life: developing the evidence base?

**Agar M.R.**<sup>1,2,3</sup><sup>1</sup>*Flinders University, Adelaide, Discipline of Palliative and Supportive Services, Sydney, Australia*<sup>2</sup>*HammondCare, Braeside Hospital, Palliative Care Service, Sydney, Australia*<sup>3</sup>*University of New South Wales, South West Sydney Clinical Schools, Sydney, Australia*

**Background:** Delirium in palliative care is prevalent and distressing. Understanding clinical decisions in palliative populations and delirium is crucial. The role of the anticholinergic system is considered important in the pathophysiology of delirium but has not been explored in the palliative population. Therapies need to be subject to robust trials to ensure net clinical benefit.

**Methods:** The talk will outline four studies and a clinical trial with results to date. The first two studies explored specialist and nurses' views on delirium management. Anticholinergic medication use as death approaches and the association with symptoms, quality of life, function and health service use was explored. In the third, serum anticholinergic activity and its association with delirium in advanced cancer was explored. A clinical trial of risperidone, haloperidol and placebo in delirium in palliative care illustrates robust designs to determine net clinical benefit of therapies for delirium.

**Results:** Significant variability in delirium care exists. Anticholinergic medication is associated with reduced function, dry mouth and difficulty concentrating, but not health service utilisation or survival. Delirium occurrence was not associated with anticholinergic medication or serum anticholinergic activity. Comorbid illness severity, benzodiazepine dose and the presence of cerebral metastases on admission predict delirium.

**Implications:** Some of the variability seen in clinical practice relates to an evidence practice gap with implications for translation of the delirium evidence base into practice; equally, there are some aspects of delirium care unique to the palliative population. Anticholinergic prescribing in palliative care has a potential impact on function, symptoms and quality of life, but not, however, on delirium occurrence. Well-designed and feasible randomised controlled trials can be conducted to evaluate delirium therapies, and this can also be achieved in the palliative population ■

PL 2.1

# Human rights and palliative care: the perspective of a public health physician

**Martin-Moreno J.M.**

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*& Hospital Clínico Universitario, Valencia, Spain*

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The notion of human rights implies that everyone deserves a basic set of universal and inalienable freedoms and entitlements to protect their dignity. European societies have long understood access to healthcare among these. Indeed, medicine and public health embody the best of humanity: intelligence, cooperation, solidarity and kindness. Doctors and healthcare professionals are with us in the most vulnerable moments of our lives – in birth and in sickness – and they also usher us to death. This transition is, perhaps, one of the greatest potential threats of all to human dignity. Terminal illness, if unattended, strips individuals of basic comfort, autonomy and personal freedom. Palliative care restores these dignities, offering pain relief, spiritual comfort and grief support. If healthcare is part of the foundation of human rights protection, then palliative care is a cornerstone, incarnating the principles that

underpin the concept of human rights. It enshrines the objectives that modern medicine strives to achieve in all fields: (i) patient-centred care rather than disease-centred cure; (ii) holistic attention to both physical and psychosocial aspects; (iii) interaction with the social and human environment; (iv) coordinated teamwork; (v) objectives based on the patients' best interests; (vi) humanisation of the relationship between patient and doctor; (vii) comprehensive bioethical perspective; (viii) dialogue-based practice; and ix) an intense vocational, philosophical and empathetic nature. With all of this in mind, and from a public health perspective, health systems are compelled to include palliative care services in their portfolio of basic health services. Death comes to us all, and all wish to meet it with dignity and peace. Universal, inalienable, egalitarian ... we all deserve the protection that this human right offers to our passing ■

PL 2.2

## EAPC News: the EAPC Atlas (new edition of the EAPC Atlas of Palliative Care in Europe)

### **Centeno C.**

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*ATLANTES Research Program, Pamplona, Spain*

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The second edition of the EAPC Atlas of Palliative Care in Europe is the result of three years of work of the EAPC Task Force on the Development of Palliative Care in Europe working in partnership with the ATLANTES Research Programme of the Institute for Culture and Society (ICS) of the University of Navarra.

Our surveys have collected data on the national development of palliative care (PC) in 53 European countries from a variety of sources: leaders of PC in each country, experts in national development of the discipline, bibliography and other sources. A peer review process has been implemented in order to improve the quality of the information provided. With a rate of answer of around 85% in the surveys, the Atlas will provide country reports, thematic maps, and more graphic information on a country-by-country basis. The diffusion of data related to the development of PC at a national level is the engine of that very development because it:

- a) allows society to estimate whether a country's citizens

receive adequate care when suffering from advanced and terminal illnesses and b) provides a comparison with other countries in that region, so that healthcare professionals, institutions and politicians can plan and make strategic decisions in terms of the nation's health.

The full second edition of the EAPC Atlas of PC in Europe will be available in PDF format due to its excessive size (approximately 500 pages in length). Consequently, we offer this time a smaller edition (EAPC Atlas of Europe Cartographic Version) in order to present the most important information in thematic maps and one-page graphic country reports. This information will be accessible in multiple formats; for example, via the internet and also in printed format to provide both visibility and credibility. The free availability of maps in diverse formats will enhance the use of the Atlas in professional public presentations and will also be effective in dissemination among politicians and planners ■

PL 2.3

# Dementia and palliative care

**Volicer L.***University of South Florida, School of Aging Studies, Land O'Lakes, FL, United States**Contact address: lvolicer@usf.edu*

Palliative care for persons with a diagnosis (PWDs) and their families should start at the time of the initial diagnosis, but that does not exclude continuing efforts for aggressive treatment of coexisting or intercurrent medical conditions. Both PWDs and their caregivers need support by explaining the diagnoses and their consequences, and for future planning. Strategies for decreasing the risk of dementia development should be explained, and both PWDs and the caregivers should be referred to support groups and activity programmes if these are available. If pharmacological management is indicated, it should be started as soon as possible. When the dementia progresses to moderate stage, the emphasis should be on management of behavioural symptoms of dementia, which may decrease significantly the quality of life of both PWDs and their caregivers. Environmental and physical causes should be excluded (especially the presence of pain), and a distinction between agitation and rejection of care made. Since both

of these syndromes are aggravated by depression, PWDs should be evaluated for the presence of depression and effectively treated. Agitation may be managed by appropriate levels of meaningful activities that are provided as a continuous activity programme. In the severe and terminal stages, the emphasis shifts to medical issues, although behavioural symptoms may continue. Medical interventions should correspond to the goals of care, and both the benefits and burdens of these interventions should be taken into account. Decisions have to be made about cardiopulmonary resuscitation, transfer to an acute care setting, use of antibiotics for treatment of generalised infections, and tube feeding. PWDs should be cared for in a comfortable environment, in the presence of others, and using loving touch for activities of daily living until death (for example, Namaste Care). There is a need for continuous support of professional caregivers and for bereavement support of families after PWDs' death ■



PL 3.1

## Team Work and Palliative Care

### Speck P.W.

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**Aim:** To explore the relevance of team work in palliative care and any evidence of effectiveness.

**Background:** For many years, it has been recognised that the changing needs of patients can best be met by a team approach, in which a variety of health professionals with different skill can collaborate to meet the range of needs presented by people being treated in the community or hospital. This is especially true within palliative care and is reflected in many of the guidance and strategic documents issued by governments, professional/international bodies, and charitable agencies. A review of the literature, however, indicates that the form and success of that collaboration between professions and disciplines varies and is reflected in the adjectives used to describe the team: multi-, inter-, trans- and so on. Team effectiveness is influenced by the relationships that exist, leadership style, trust and respect between members, and resources; a challenge reflected in the EAPC Mission Statement of the need to 'promote palliative care in

Europe through ... multi-professional collaboration'. A team is essentially a group of people brought together for a specific task and who work together interdependently, taking ownership for the outcome. Leadership and clarification of a task are key and will affect the skills mix of the team, and how well they work together and achieve satisfactory outcomes for any interventions made by the team. While the study of teamwork has developed in recent years, little has been done to examine the factors contributing to effectiveness.<sup>1</sup>

**Conclusion:** I wish to examine the key components of teamwork in palliative care – factors, which contribute to mentally healthy teams or to dysfunctional teams. I also wish to review some of the studies that seek to examine team effectiveness and offer suggestions for maintaining healthy teamwork within palliative care.<sup>2</sup>

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PL 3.2

## EAPC News: the Prague Charter

### **Schmidlin E.R.**

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The European Association for Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA), and Human Rights Watch (HRW) have joined together to formulate the Prague Charter to recognise access to palliative care as a human right. The Prague Charter urges federal governments of all developing and developed countries around the world to implement

healthcare and social policies that will ensure the relief of suffering through adequate access to patient-centred palliative care, wherever it is needed – whether in hospital, a hospice, home or any other place of care. This short presentation will examine the activities that have led to the creation and launching of the Prague Charter, and will highlight options for future advocacy work ■

PL 3.3

# Integrating palliative and oncology care in advanced lung cancer

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**Aim:** To improve care for patients with metastatic non-small cell lung cancer through the introduction of ambulatory palliative care at the time of diagnosis.

**Methods:** Patients were randomly assigned to receive either early palliative care integrated with standard oncological care or standard oncological care alone. Quality of life and mood were assessed with the use of the Functional Assessment of Cancer Therapy Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care and components of palliative care visits were collected from electronic medical records. Quantitative and qualitative methods were used to analyse the data.

**Results:** Patients assigned to early palliative care had improved quality of life compared with those patients assigned to standard oncological care alone (mean score on the FACT-L scale). In addition, fewer patients in the palliative care group than in the standard care group had

depressive symptoms. Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care, median survival was longer among patients receiving early palliative care.

Initial palliative care visits focused primarily on symptom management and building rapport. Few patients discussed advance directives at the first palliative care visit.

In addition to symptom management, palliative care visits focused on cultivation of prognostic awareness and promotion of positive coping strategies.

**Conclusions:** Patients with metastatic non-small cell lung cancer who received early palliative care had significant improvements in both quality of life and mood. As compared with patients receiving standard oncological care, patients receiving early palliative care experienced less aggressive care at the end of life and longer survival ■

PL 4.1

# What happens to the 'inbetweeners' – transition from children's to adult palliative care services

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With advances in medical sciences and practice, children with long-term, chronic conditions are often living past the legal limit of childhood, even into their 30s. The differences in service provision by children's and adult services are highlighted at this time, with many young persons uncomfortable in adult services that are predominantly geared towards older people with a limited life expectancy. Added to this, often difficult decisions regarding care, taken by parents and carers during childhood, legally become the responsibility of the young adult. Dreams of this age group, for loving relationships, studies and work may be unrealistic for many young people facing the challenges of increasing disability and dependence.

Some children's hospice services have dealt with this by extending their programmes to meet the needs of young adults, with programmes, facilities and resources geared towards improving their quality of life in a way that will be acceptable to them. Some innovative programmes have been developed by transition task forces or teams set up in the UK. Where resources are limited, care is community-based and one programme cares for every age group, the different psychosocial needs of the young adult may not even be considered. This presentation will discuss present trends, existing challenges, innovations in palliative care for young people and proposals for the future ■

PL 4.2

## EAPC News: EAPC and social media

### Jackson A.P.

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**Aims:** Social media help the EAPC's aim to develop and promote palliative care in Europe through information, education and research. Our blog ([www.eapcnet.wordpress.com](http://www.eapcnet.wordpress.com)) aims to connect people interested or involved in hospice and palliative care with short, timely bursts of information from practitioners, researchers and academics working in the field.

The blog drives traffic to the EAPC website by highlighting news of task forces, publications, recommendations, and so on. It strengthens communication with our membership; promotes research and other projects published in the EAPC's official journals; fosters debate, and highlights the global need for palliative care.

**Method:** In February 2012, we set up a social media team with representation from the Universities of Bonn and Lancaster, and the EAPC board, membership and head office. The blog is merged with the Central and Eastern Europe and Former Soviet Union newsletter, and we strive to achieve a balance of Eastern and Central European content. One person manages the blog, commissioning and editing articles, with the whole team advising, commenting and approving content before

publication. The blog is published on a WordPress site linked to the EAPC website, Facebook and Twitter.

**Results:** So far, 127 posts have been published from 30 countries, with 30,474 views: Europe 73%, Americas 14%, Asia 6%, Oceania 3%, Greater Middle East 2%, Africa 2%. The five most popular posts are:

- What do hospices do or not do?
- On opioids and wisdom
- Use of opioid analgesics in treatment of cancer pain
- Deathbed tweets
- Big Five revisited.

Snappy titles, good images and opioids seem to engage readers.

**Conclusion:** Excellent teamwork and the collaboration of our membership and others help us to reach a worldwide audience. There is substantial participation and goodwill from contributors, and an increasing number of unsolicited posts. Spontaneous debate is growing – a recent post elicited 31 comments from five continents. To encourage more contributions from Eastern and Central Europe we now have limited funds for translation ■

PL 4.3

## Spiritual care in palliative care: a comparative analysis in Europe

**Leget C.**

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Although palliative care is supposed to address the physical, psychosocial and spiritual dimension of the human person, many of those involved struggle with the last of these four. The spiritual dimension is hard to grasp due to a number of historical and cultural reasons. At the same time, however, we see an increasing interest in this 'fourth dimension' of palliative care. Both scientifically and culturally the number of studies and initiatives related to spiritual care are growing rapidly.

In this lecture we will give an overview of the current state of affairs of spiritual care in palliative care in Europe by making three comparisons. These comparisons will help to understand both the problems and possibilities of developing spiritual care in Europe.

1) The first comparison is between times in history.

Europe is a multi-cultural phenomenon in transition from modern to late- or postmodern culture. Many of the particularities of this transition directly affect the position of spiritual care in our days. Among these are the decline of traditional belief systems and (religious) communities, an increase in influences from other cultural traditions, the growing impact of the economy and the market on all sectors of society (including care and science) and paradoxes like a call for robust scientific research underpinning policy on the one hand, and deep respect for individual spiritual convictions on the other. In this new situation palliative care has a special privileged position for the development and study of spiritual care, being an interdisciplinary enterprise concerning existential issues in which different types of knowledge meet and often clash.

2) The second comparison is between these types of knowledge. One of the key elements of why spiritual care is so hard to develop in a scientific way is because

it is based on types of knowledge that differ radically from scientific knowledge. Historically the study of spirituality was part of theology, using the same methodology as the humanities. Working within one particular tradition it reflected on the lived experience of people belonging to the same belief system. With the development of social sciences in the second half of the 19th century, and the rise of comparative anthropological and religious studies the study of spirituality started to include qualitative research methods. In the context of healthcare, however, the study of spirituality had to adapt to the dominant medical ideal of knowledge which has a preference for quantitative methods. As a result of this there is a great disparity between the ones who are trained specialists in spiritual care but have no empirical research education on the one hand, and the ones who have a research education but are not trained specialists in spiritual care on the other. This results in many problems in terms of understanding each other.

3) The third comparison is between countries in Europe.

Spirituality is indissolubly connected with culture and Europe houses many different cultures. As a consequence, again there are great differences between European countries. Although the Catholic South faces different problems than the Protestant North, and although the place of religion in the Western part of Europe has developed differently from in Mid and Eastern Europe, the entire continent shares the same challenge: a reinvention of the way questions of purpose and meaning in life can be integrated in palliative care. Against the background of the work of the EAPC Taskforce on Spiritual Care – which is building a platform for research, education and implementation – some inspiring examples from specific countries will be given of how spiritual care can be developed further in palliative care.

PL 5.1

## Pain and symptom control in dying patients/final phase

**Nauck F.***University Medicine Göttingen, Department of Palliative Medicine, Göttingen, Germany*

Palliative care (PC) aims to improve quality of life by early identification, impeccable assessment and treatment of symptoms and other needs in patients with advanced and progressive disease. The dying phase has often been claimed to be 'underdiagnosed'. As a consequence, team conflicts, 'futile treatment' and insufficient symptom control were reported. Pain and symptom control in dying patients, particularly in the final phase, have been one of the main foci in PC over many years. Treatment options and standards were established. PC has had, over years, a focus on patients with far advanced cancer. Then the focus changed, on one hand, to an early integration of cancer and non-cancer patients. This comprises a broader spectrum of disease-specific and symptom-guided interventions, with emphasis on preparing patients and their relatives for foreseeable, distressing clinical problems. On the other hand, PC has focused on 'peaceful' dying for all patients. But what

does this mean? Burdens and suffering of patients and relatives should be minimised. This is what patients and relatives expect from us. Physical, psychosocial and spiritual symptoms should be treated. Up to today, the three-step analgesic ladder is seen as a guide for initiating analgesic drugs and dosages that correspond to the patient's reported level of pain. Various new opioids and formulations of opioids, and a greater variety of application modes have broadened the range of options. After years of undertreated symptoms, there is now a danger of unreflected application of high doses of strong opioids without a medical indication or the application of sedatives to cope with difficult symptoms at the end of life. Therapeutic decisions must reflect probably conflicting issues of medical indication, ethics and law. This is of particular relevance when treatment preferences of patients are not known or in contrast to those of the carers ■

PL 5.2

## EAPC News: the EAPC Research Network

**Kaasa S.**<sup>1,2</sup>

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<sup>2</sup>*St. Olavs Hospital, Trondheim University Hospital, Cancer Clinic, Trondheim, Norway*

The EAPC Research Network invites all healthcare professionals who see the potential in conducting European multicentre research.

The network can offer:

- An established structure for collaborative research
- An infrastructure to take care of the planning and

organisation of large prospective studies, as well as data handling and analysis

- A meeting point for discussion and exchange of knowledge.

Highlights from ongoing research activities will be presented ■



PL 5.3

# Culturally and economically appropriate palliative care

**Goh C.R.***National Cancer Centre Singapore, Palliative Medicine, Singapore, Singapore*

We are all bound by our background, upbringing, family traits, education, life experiences and the community we live in. Even in a relatively homogeneous society, in terms of ethnicity and religion, there are still social class norms and generational differences.

Greater challenges are met when working across different cultures, whether with ethnic minorities, or in a multi-ethnic, multilingual, multireligious society. We have to familiarise ourselves with different behavioural norms, gender issues in role and caregiving, the meaning of food in nurturing and as therapy, and different systems of understanding health and disease processes. We need some background knowledge of the beliefs and religious practices of the patients and families, if they are different from our own. While communicating well is already a skill that needs to be honed by all working in palliative care, doing this without a common language becomes a greater challenge. The ideal of using professional

interpreters is often a luxury reserved for well-resourced services working with ethnic minorities and not available to the vast majority of practitioners who are trying to cover a heterogeneous population in emerging palliative care services.

Healthcare provision is necessarily shaped by the resources available. Much of palliative care practice in resource-rich countries is inaccessible or irrelevant in resource-poor places, and adaptation and improvisation are necessary.

A multi-ethnic, multireligious, multilingual palliative care team is a great resource. Diversity becomes a real advantage. Openness and respect for one another, whether colleague or client, can create harmony, where differences are celebrated rather than feared. This is one of the aspects of palliative care where the learning is life-long, which continues to fascinate and is a real source of joy in the practice of medicine ■



# Parallel sessions

Pain Management in 2013  
Gastrointestinal Symptoms  
Spiritual Care  
Volunteers  
Leadership in Palliative Care: From Good to Great  
Paediatrics I  
Neuropsychiatric Symptoms  
Ethics and End-of-life Decisions  
Implementing Palliative Care in Nursing Homes  
Teaching Session: Planning and Conducting Clinical  
and Public Health Research in Palliative Care  
Innovations in Learning  
IMPACT  
Neurology  
Public Health Perspective  
Religious Aspects in Palliative Care  
Common Battlefields for Palliative Care and Oncology (ESMO Supported Session)  
Developing Collaboration for Palliative Care: Experience and Challenges  
Paediatrics II  
Dementia  
Outcome Assessment in Palliative Care  
Access Issues / Access to Care  
EAPC Atome Session Title: Regulatory Barriers in Palliative Care Opioid Treatment  
From Budapest to Prague - From Commitments to Rights  
Palliative Care - Part of the Main or Specialized Discipline?  
Nutrition in Palliative Care  
End of Life Preparation - Health Literacy in the Community  
Palliative Care as a Human Right  
EUROIMPACT: How to Be Successful as a Palliative Care  
Researcher within the European Research Area  
Dyspnoea

## Pain Management in 2013

**Abstract number:** PS 1.1  
**Abstract type:** Parallel Symposium

### Treatment of Pain, New Developments and Research Findings

*Kalso E.A.*  
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Non-steroidal anti-inflammatory drugs and opioids are the main pharmacological tools for nociceptive pain whereas tricyclic and dual-action antidepressants and Ca<sup>2+</sup>-channel modifiers (gabapentin and pregabalin) are the first line drugs for neuropathic pain. New data from systematic reviews and meta-analyses suggest that there is huge variability in the individual responses with some patients achieving much benefit whereas some stop the treatment due to lack of efficacy or intolerable adverse effects. New information regarding the mechanisms of opioid tolerance and immune effects will also be discussed. Opioids seem to activate glia via toll like receptor 4 (TLR4) which is important in the immune defence. Glial activation can be responsible for many adverse effects due to opioids. Blocking the specific TLR4-mediated activation of glia offers a new therapeutic approach to improving opioid efficacy.

New analgesic drug classes that are currently being investigated in pain management include e.g. cannabinoids, TRPV1 and TRPA1 antagonists which will also be introduced. TRPA1 antagonists are particularly interesting as they may also have disease modifying effects in certain neuropathic pain conditions such as diabetic or chemotherapy-induced polyneuropathies.

Members of the hyperpolarization-activated cyclic nucleotide-modulated (HCN) ion channel family play an important role in both inflammatory and neuropathic pain. The HCN2 channels are potentially very exciting new targets in pain relief. Interestingly, the HCN1 channel subunits are a molecular substrate for ketamine which is currently investigated not only as an analgesic but also as a potent antidepressant drug.

The efficacy of various analgesics can be significantly modulated by the context in which they are administered. The possibilities of enhancing analgesic efficacy through positive therapeutic interaction will be discussed.

**Abstract number:** PS 1.2  
**Abstract type:** Parallel Symposium

### Improving Access to Pain Medicines - the Example of Czech Republic

*Slama O.*  
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The opioid consumption has increased dramatically in Czech Republic during last 15 years, being actually slightly under the EU average consumption. The Czech legislation concerning controlled substances is relatively liberal. Every physician (disposing with special triple copy prescription form) can prescribe opioids; there is no „maximal” therapeutic dose or daily dose formally defined by law. The pharmacies are able to supply the opioid medication within short time span. The prices of most opioids are covered by health insurance are nearly free for the patient at the point of delivery in out-patients setting.

The most important factors which contributed to this evolution are:

- Impact of European legislation on Czech legislation within the process of becoming the member of European Union
- Making pain an issue of public debate
- Educational and marketing activities of pharmaceutical companies producing opioids
- Pre- and postgraduate educational activities of Czech Pain Society and Czech Society for Palliative Medicine
- Accreditation and quality improvement process in Czech hospitals making pain assessment an important indicator of good quality care
- Involvement of nurses in systematic pain assessment and delegation of more competencies in pain management from physicians to nurses

Despite all these positive changes, there are huge differences in availability and accessibility of opioids in different setting and parts of health care system

- The main barriers are
- Persisting misconceptions about opioids among physicians, especially among general practitioners (GPs)
- Persisting opioidophobia among general public
- Relatively high prices which make these drugs unaffordable in the setting with very limited budget as long term care hospítale or in-patient hospices.

**Abstract number:** PS 1.3  
**Abstract type:** Parallel Symposium

### Symptom-based Management of Neuropathic Cancer Pain

*Rolke R.*  
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A neuropathic pain component can be suggested, if cancer growth leads to compression or infiltration of nociceptive nerve fibres, or cancer treatment such as surgery, chemotherapy or radiation therapy induces damage to the somatosensory system with pain as a direct result of that lesion. Depending on the neurobiological pain mechanisms in action different sensory symptoms may occur. Peripheral sensitization of the nociceptive system, e.g. due to an inflammatory environment surrounding a tumour, will be indirectly reflected by localized hyperalgesia to heat and blunt pressure. In contrast, central sensitization leads to pinprick hyperalgesia and/or dynamic mechanical allodynia in the affected area. Deafferentation due to neuronal damage is reflected by a decreased sensitivity to all types of thermal or mechanical non-painful or painful stimuli.

Using quantitative sensory testing (QST) it is possible to assess the complete somatosensory phenotype of a cancer pain patient. Using the QST protocol of the German Research Network on Neuropathic Pain (DFNS) seven sensory tests are performed to assess thermal and mechanical detection and pain thresholds. Sensory profiling of symptom patterns in cancer patients is fostering better knowledge about possible neurobiological mechanisms underlying the pain problem. Based on the literature and recent QST studies about 40% of cancer patients present with a clinical or subclinical neuropathic pain component. The next step will be to compare a symptom-based treatment of neuropathic cancer pain in clinical trials.

**Abstract number:** PS 1.4  
**Abstract type:** Parallel Symposium

### Spirituality and Biographical Pain at the End of Life in Old Age

*Johnson M.*  
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It is well recognised that as individuals move into later life, they are less occupied by the demands of paid employment and consequently spend more time in reflection about the life lived. In part this is due to the onset of infirmities, as chronic diseases take their toll on mobility and autonomy. As they enter into the 4th age of dependency, characterised by conditions which deliver decrements of worsening health or what epidemiologists have termed 'long dwindling' there is often a reactive depression. Unchosen solitude and the frustration of a failing body, both prompt recollections of more engaged times and draw attention to the deficits of old age.

The evidence of my own biographical interviews indicates that the predominant self evaluation is of disappointment, unworthiness and having failed to 'come up to expectation'. When it is accompanied by profound guilt, anger at the dishonesty, misuse and abuse of others and shame, there is reason to be deeply concerned. I have termed this condition Biographical Pain. This paper explores the conditions in which biographical pain arises and how it might be addressed.

## Gastrointestinal Symptoms

**Abstract number:** PS 2.1  
**Abstract type:** Parallel Symposium

### Management of Constipation and Gastrointestinal Obstruction

*Becker G.*  
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**Background:** Constipation and bowel obstruction are common problems experienced by patients with end-stage cancer. The prevalence of constipation in cancer patients varies (according to the patient population assessed and the definition of constipation used) from 30 to over 80%. Malignant bowel obstruction (MBO) occurs in 3-6% of patients suffering from advanced cancer and is highest in patients with ovarian cancer (5-42%) and colorectal cancer (4-24%). Therefore, the evidence for clinically established pharmacological therapies for constipation and gastrointestinal obstruction in palliative care patients have to be evaluated.

**Materials and methods:** A systematic literature search in different databases (Cochrane Library, Embase, PubMed, Ovid Medline, Embase from 1966-2011) was conducted. **Results:** Only 10 controlled trials with palliative care patients suffering from constipation could be identified: three RCT with methylalntrexone and one with the combination of oxycodone and naloxone showed the efficacy and safety of opiate antagonists for patients who are not at risk for gastrointestinal perforation. There have been no studies testing methylalntrexone against the optimization of therapy with conventional laxatives. Six other controlled studies of limited quality in design and with only few participants tested naloxone, senna, lactulose, Co-danthramer, an Ayurvedic preparation (Misrakasneham), magnesium hydroxide, fluid paraffin, sodium picosulfate and docusate without finding statistically significant differences in efficacy or side effects.

In malignant bowel obstruction only few studies with only small sample sizes could be identified showing weak evidence for the use of somatostatin analogues and anticholinergics in treating MBO.

**Conclusion:** Evidence on medical treatment of constipation and bowel obstruction in palliative care is sparse and guidelines have to refer to evidence from outside the palliative care setting and expert opinions.

**Abstract number:** PS 2.2  
**Abstract type:** Parallel Symposium

### AIHPC Guidelines on the Management of Constipation in Palliative Care

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In Ireland, a national framework for clinical effectiveness has been in place since 2010, as a response to better patient safety and quality assurance measures. Part of this framework has been the establishment of a National Clinical Effectiveness Committee with a responsibility to oversee the development and implementation of evidence-based clinical guidelines to inform and guide best practice. In response to this, the Health Services Executive (HSE) National Clinical Programme for palliative care has sought to develop clinically focused guidelines relevant to the discipline. This presentation reports on the development of clinical guidelines in relation to the management of constipation in palliative care. Developed through a collaborative approach between the HSE National Clinical Programme for palliative care and the All Ireland Institute of Hospice and Palliative (AIHPC) two scholarships (one physician, one nurse) were awarded to undertake the complex process of guideline development using the ADAPTE methodology and AGREE tool. Scholars were guided by an international expert advisory group. The challenging process of guideline development will be discussed including the selection and grading of evidence, methods of process evaluation and agreement on core recommendations will be discussed. The potential for national clinical guidelines as a key driver in establishing quality and rigour in evidence-based practice for palliative care will also be presented.

**Abstract number:** PS 2.3  
**Abstract type:** Parallel Symposium

### Pharmacotherapy of Chronic Nausea and Vomiting

*Leppert W.*  
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Chronic nausea and vomiting are frequent symptoms in advanced cancer patients. The management should be directed at underlying causes, which may be multifactorial e.g. gastrointestinal tumours, oncology treatment (chemotherapy, radiotherapy, surgery), opioid-induced bowel dysfunction, metabolic disturbances. Still, the treatment is based on a meticulous assessment comprising detailed history taking and physical examination. Laboratory tests may be useful to diagnose hypercalcaemia, hepatic dysfunction, and renal impairment. Radiological investigations may be carefully considered in patients with symptoms of gastrointestinal obstruction. Although several antiemetic groups are available (prokinetics, antihistamines, anticholinergics, neuroleptics, 5-HT<sub>3</sub> and NK<sub>1</sub> receptor antagonists), controlled studies are lacking in chronic nausea and vomiting in advanced cancer patients.

Patients with bowel obstruction need special care due to poor prognosis and severity of symptoms that may devastate their quality of life. Each patient with symptoms of

bowel obstruction should be considered for a surgical intervention. However, only minority undergo surgery due to poor prognosis and general condition, dissemination of the tumour in the abdomen and co-morbidities. The conservative approach to patients with symptoms of mechanical bowel obstruction comprises antidiopaminergics along with hyoscine derivatives to reduce colicky pain and bowel secretion. An addition of octreotide and corticosteroids may increase the effectiveness of such regimen. In patients with functional or those with partial mechanical bowel obstruction without colicky pain prokinetics may be used. In case of the ineffectiveness of pharmacotherapy a nasogastric tube may be inserted for a short period of time. For patients in general stable condition parenteral nutrition may be carefully considered

## Spiritual Care

**Abstract number:** PS 3.1  
**Abstract type:** Parallel Symposium

### Research and Spiritual Care

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**Aims:** An update on the most recent developments on research and spiritual care  
**Methods:** A critical philosophical analysis of the different methodologies used by different disciplines in palliative care studying spiritual care  
**Results:** Although the field is developing rapidly using a great variety of methodological approaches, there is no agreement on fundamental conceptual and methodological issues. At this moment the research is scattered over many disciplines and journals. Theological and philosophical studies are hardly used by and are pushed to the side by approaches informed by the social and medical/nursing sciences.  
**Conclusion:** More communication and integration is needed. Chaplaincy should develop a research culture and cooperate with other disciplines in order to help developing research in spiritual care in a way that is congruent with the subject studied.

**Abstract number:** PS 3.2  
**Abstract type:** Parallel Symposium

### Interprofessional Spiritual Care: The Role of Spirituality in Palliative Care.

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The biopsychosocialspiritual model emphasizes the totality of a patient's experience in the context of their illness and/ or dying with spirituality being an essential component of care. Studies have demonstrated that spiritual care affects healthcare outcomes and that patients want their spirituality addressed by healthcare professionals. Spiritual care was cited as an essential domain of care by the 2004 National Consensus Project for Quality Palliative Care. Despite these guidelines, the implementation of spiritual care is not uniform in clinical settings. Reasons cited in the literature include confusion as to the definition of spirituality, lack of resources and implementation tools and, inadequate professional education. The variability in approaches to spirituality in palliative care underscored the need to articulate a definition of spirituality and to set common guidelines for spiritual care. In 2009, a national Consensus Conference developed recommendations for implementing the spiritual care domain of Palliative Care. Forty interdisciplinary leaders in Palliative Care and Spiritual Care were invited to develop specific and practical recommendations for the implementation of interdisciplinary spiritual care in palliative care, which was defined as starting from initial diagnosis of a serious or chronic illness. Specific recommendations as well as models for spiritual care implementation and interdisciplinary spiritual care education were developed. The resultant recommendations were then reviewed nationally, approved through a consensus process, and published for widespread dissemination as a consensus document titled "Improving the Quality of Spiritual Care as a Dimension of Palliative Care" (Puchalski, Ferrell, et al. JPM. 2009). This presentation will review these recommendations and describe a model for interprofessional spiritual care.

**Abstract number:** PS 3.3  
**Abstract type:** Parallel Symposium

### Spiritual Care - What Does This Mean in a Secular Society?

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The World Health Organization defines health as a state of spiritual well-being as well as physical, psychological and social well-being, and palliative care policy globally includes spiritual care as an intrinsic component. Evidence suggests many people with incurable, progressive illness have spiritual needs [1,2] and wish those needs to be considered in a healthcare context [3,4]. Yet patients' spiritual needs are often neglected [5], healthcare staff struggle with the provision of spiritual support and often confuse spirituality with religion [6], and the very appropriateness of a spiritual aspect of healthcare is debated [7].

Making use of sociological and philosophical perspectives as well as social science, in this paper I examine the extent to which European society truly is 'secular' and consider challenges to the provision of spiritual care in healthcare. I argue that spiritual care is a contentious and challenging domain of care for three main reasons:

1. Conceptual confusion regarding what spiritual care is and a consequent lack of clarity regarding its place in healthcare and whose responsibility it is in the multi-professional team;
2. The subversive nature of spiritual care, in which the personal, political and professional collide and we are challenged to bring who we are and what we believe into the clinical encounter; and
3. The limited body of robust evidence to inform the provision of spiritual care.

I also review the evidence regarding patient and carer preferences and the nature and effectiveness of spiritual care, highlighting directions for future research.

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## Volunteers

**Abstract number:** PS 4.1  
**Abstract type:** Parallel Symposium

### Volunteers: The Model of India

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I am a volunteer, a cancer survivor and the founder of CanSupport a non-profit that runs the largest home-based palliative care programme in Northern India, free of charge, for disadvantaged people with advanced cancers.

In India, traditionally, volunteerism beyond the home has confined itself to religious places and institutions. Volunteerism for a cause in the secular sphere is an idea borrowed from the West. That CanSupport was able to attract a sizable number of volunteers is because first, they were all touched by cancer and second, had time at hand as they were mostly educated, middle class home makers.

The challenge has been to get volunteers to understand that volunteerism requires following a strict discipline and observing organizational rules. Training volunteers so that they are more effective at what they do and helping instil in them respectful regard for those they interact with, regardless of religious background or socio-economic category, is also essential. To get office staff to work alongside volunteers in a spirit of cooperation requires the building of mutual understanding and respect.

Our first home care team was launched in 1997 in partnership with the Institute Rotary Cancer Hospital. It comprised a nurse and a counselor both of whom were volunteers. As time went by we began to develop a healthy mix of paid staff and volunteers that we feel is the sustainable model for India. It suits conditions where the majority of volunteers are women who are also primary caregivers for their families. Today, volunteers raise funds, organize training workshops and run a very successful day care programme, twice a week.

To conclude, CanSupport continues to depend on volunteers for many of its activities. Besides the fact that they represent a spirit of voluntary giving and sharing which is commendable and has a ripple affect on others, they also help free up limited resources that can be used elsewhere.

**Abstract number:** PS 4.2  
**Abstract type:** Parallel Symposium

### Ordinary or Peculiar Folk? On the Role of Volunteers in Palliative Care in Czech Republic

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The phenomenon, that people who do right things are peculiar within their society, is well known. Prophets of all ages were refused because they seemed weird. Yet thanks to them "illness" of their age could be diagnosed: they served as a mirror which reflected the world around them. Our ambivalent relationship to the prophets has much to do with what we expect to see in the mirror.

In the perspective of palliative care our age is the age of institutions. We believe that at the end of life institutions help us better than a person who has legs, hands, head and soul. In spite of that these beings with head and soul are helping us in their special way.

Volunteers in palliative care aren't prophets at all, but there is a similarity: they indicate something important about us and often we consider them to be peculiar. In the Czech Republic something else can even be traced down: after more than twenty years of freedom, some of our diseases from the period of totality survive. We were used to having the same salary; all hospitals had the same beds, all bakeries had the same shop signs. Whatever stood apart was suspicious.

Volunteers stand apart in many respects: the questions they are faced with from their close ones reveal something about our society today: We are harassed and sad - how is it that you are happy? We come home exhausted - how can you work more? We have little money - how is it that you are doing it for free? We only want to see the pretty things - why do you want to see people die? After all day at work we need to recover - how is it you don't need it?

Or, after all, do they receive anything? It seems they do, although it is often incomprehensible for many people. In my opinion, the volunteers are ordinary and rich people and our society is enriched by them. They are silent builders of inner freedom: we have already lived in the external freedom for two decades, but the questions volunteers are faced with show us that the inner freedom is still missing.

**Abstract number:** PS 4.3  
**Abstract type:** Parallel Symposium

### Management of Volunteers in UK Hospices: New Research Evidence

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**Aims:** Volunteers have always formed an integral part of the care offered in hospices across the UK. Without them, hospices could not have continued to do the work that they do. Hospice volunteers report having a deep sense of satisfaction in being there for someone during a difficult time of life. They feel like they are making a significant contribution to the community and providing a service they hope others would offer them, were they in need.

**Methods:** A mixed methods two phase study was conducted. Phase one involved a national survey of volunteer managers based in hospices in the UK. Phase two used organisational case study methodology to investigate how volunteers contributed to the delivery of direct patient and family care associated with adult hospices.

**Results:** In Phase 2, a total of 205 interviews with volunteers (n=96), managers and staff (n=72), patients (n=29) and families (n=14) were conducted between May - December 2012 at 11 purposively selected hospices in the North West and South East of England, with 14 - 24 interviews at each site. The majority were undertaken face-to-face, individually and in small groups, and a few were telephone interviews. All were recorded and transcribed and have been entered and coded in NVIVO, a software analysis package for qualitative data. The sample had an age range of 21-88, with an overall mean of 60 years. The mean age of staff was 50, that of volunteers and carers were 62 and 63 respectively, with patients' mean age was 67 years. The time that participants had been involved with the hospice ranged from two months to 23 years. Qualitative analysis has identified four overarching themes:

- Impact of volunteering
  - Management Practice
  - Relationship to the external context
  - Role of volunteering in the hospice
- These will be explained and illustrated by direct quotations.  
**Conclusions:** There remain challenges facing hospices in the recruitment and management of volunteers.

### Leadership in Palliative Care: From Good to Great

Abstract number: PS 5.1  
Abstract type: Parallel Symposium

#### The Leadership Development Initiative (LDI): My Experience

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As a medical doctor I had never been trained in leadership or management. Given the growth of our hospice program, I felt inadequate in addressing management problems and meeting people in high position. Therefore, I felt fortunate to be selected for the inaugural class of LDI. The program has equipped me with techniques and skills which help me lead and coordinate our team as we expand our services to provide care for increasingly more patients in need. Apart from the formal aspect of LDI, I met wonderful colleagues from all around the globe, who are facing very similar challenges. Their enthusiasm, dedication and honesty constantly recharge my batteries. Their personal experiences shared taught me important lessons. I am proud and deeply grateful to have been a part of the first cohort of LDI.

I have used my new skills and knowledge I'd been equipped with to advance palliative care through introducing new forms of care and academic programs. Still I am aware that Hungary is twenty years left behind compared to developed countries. I appreciate that change needs time and attitudes change slowly. However, programs like LDI with their expert support, clear vision, commitment and humility can give us inspiration to persevere. I see a very challenging twenty years ahead. But I also see a slowly-unfolding transformed cultural picture of death and dying in the minds and practice of Hungarians. Integration of palliative care services across the spectrum of healthcare will reduce suffering and ensure better quality end-of-life care in Hungary. Although, there is a long way to go, if we use every daily opportunity in our lives, we can make a difference.

Abstract number: PS 5.2  
Abstract type: Parallel Symposium

#### Mentorship in Palliative Care

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The Leadership Development Initiative (LDI) at San Diego Hospice and Institute for Palliative Medicine is a 2-year leadership programme, initiated in 2009. The participants in the program are young physicians in palliative medicine with a leading role in their region or country. The LDI include three residential weekly long courses in San Diego as well as continuous assignments, individual follow up between the courses and a mentor program. The mentors are invited senior palliative care physicians with extensive experience in both clinical palliative care/medicine and leadership. Challenges for the mentor relationships - as well as for the programme in general - include the global perspective, the many different cultural, social, economic and other differences between the participants and the mentors. The actual mentoring process follows a structure including a contract, set agendas, reports and evaluation, all based on a common shared value of mutual learning. Specific aspects to this mentor programme such as the assignment of mentors, mentoring at a distance and site visits by mentors will be contrasted to more regular mentoring conditions. Participant and mentor feedback and evaluations will be presented

Abstract number: PS 5.3  
Abstract type: Parallel Symposium

#### How to Lead to Improve Clinical Programs That Benefit Patient and Family Care

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Providing high quality, needs-based care for patients and families at the end of life is a crucial part of any health system whatever the background resourcing levels are. Such care needs to be within the overall context of health service provision. Within the context of health services as a whole, despite the level of training and dedication of staff, there is the need to ensure that hospice and palliative care services are delivering care as part of the health system. To do this in the most effective way, it is necessary to understand the pressures on the health system and to address

systematically these pressures as they intersect with hospice and palliative care. This requires an ongoing conversation with administrators, funders and policy makers. Within the community of hospice / palliative care service providers Delivering the highest quality care demands systematic performance measurement focused primarily on patient and family centred outcomes, both while the person is alive and in understanding the long-term outcomes for families and caregivers. Such systems require data collection at point-of-care and, ideally, in the longer term. Improved outcomes can only be achieved by measuring current performance and seeking to respond to areas of poor performance at an organisational level. It is far more likely that poor performance is caused by the way that a team or health system approaches issues rather than the performance of an individual practitioner. Defining and adopting best models of care, and identifying key success factors or barriers in other hospice / palliative care services can create a community of practice in hospice / palliative care that can deliver better care, sooner.

Abstract number: PS 5.4  
Abstract type: Parallel Symposium

#### Leadership in Clinical Research - Local, National and International Considerations

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Clinical research is complex. According to the latest WHO definition of palliative care both physical, psychological, social and existential issues are of clinical importance. It is probably impossible to be heavily involved in all of these areas, even for a large research group. Therefore one needs to prioritise through a democratic leadership process. Furthermore, the leader needs to:

- Have insight and skills in basic research methodologies and clinical practice
- Set up a team of researchers with complementary skills and knowledge
- Assure funding conducting the research programme through
  - High quality research applications
  - Local and national strategy for funding
- Recruit and motivate young researchers
- Assure that the research findings are implemented into clinical practice
- Have fun with the research team

### Paediatrics I

Abstract number: PS 6.1  
Abstract type: Parallel Symposium

#### The Importance of Respite in Children's Palliative Care in Ireland

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**Aims:** Respite in children's palliative care aims to provide a break from the routine of caring. Frequency, location and type of respite vary according to the child's age, diagnosis, geographical location and the family's capacity to meet the child's care needs. Despite being an integral part of children's palliative care there is a dearth of evidence identifying the respite requirements of parents.

**Methods:** Utilising multiple, longitudinal, qualitative case study design respite needs and experiences of parents caring for a child with a life-limiting condition were explored. Multiple, in-depth interviews were undertaken with parents identified by a palliative care team working in a children's hospital. In-depth interviews were also conducted with others identified by parents as having a role in the provision of respite. All data gathered were analysed using thematic analysis; Cross-case comparison was also conducted.

**Results:** Nine families were recruited and followed for two years. A total of thirty-eight in-depth interviews were conducted with parents caring for a child with a life-limiting condition in Ireland. Others identified as providing respite were also interviewed thus providing data relating to the same incidents from differing perspectives. Other sources of data were also included. Cross-case comparison revealed that for all parents utilising respite care, regardless of their child's age and condition home was the location of choice. Past experience of in-patient care of their child and trust and confidence carer's were key deciding factors. Concerns

about home care included the impact on family life, siblings and the concept of home. From a provider perspective home was seen as a challenging environment in which to provide care.

**Conclusion:** This study identifies the unique respite requirements of Irish parents caring for a child with a life-limiting condition and identifies the factors that enable responsive and family-focused respite

Abstract number: PS 6.2  
Abstract type: Parallel Symposium

#### Comprehensive Palliative Care for HIV Positive Children - the Role of Inter-Professional Teams

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HIV positive children have many and changing needs. This poses an excellent opportunity for health care workers to learn and practice inter-professional teamwork. Team members learn from each other, support each other and the success of one team member motivates the rest. The output is not equal to the sum of the input, it is much more!

The aim of this case presentation is to demonstrate how HIV can affect a child's life and the role comprehensive paediatric palliative care can play in the management of HIV.

Godfrey's mother died of HIV when he was 11 years old. As an orphan he was placed in a children's home where he developed shortness of breath. The diagnosis of HIV, pulmonary tuberculosis and cor pulmonale were made in hospital. Due to his HIV he had numerous symptoms that needed medical management. After discharge from hospital Godfrey was placed in Sunflower House, a paediatric palliative care inpatient unit.

At the first inter-professional meeting his main problem was that he wanted to stay with his grandmother in a town about 60 km from the hospice. The social worker investigated the situation and addressed it in the best possible way with his input. In Sunflower Godfrey identified different people that acted as his brother, father and grandfather. At different stages of his life different people played important roles e.g. the priest when his grandmother died, the physiotherapist helped with his lungs and the dietician established a special diet to address his HIV symptoms like chronic diarrhoea. Godfrey, as most HIV positive people, experienced multiple losses in his life. These multiple losses affected all levels of needs according to Maslow's needs pyramid. Time sharers (volunteers) took him out and exposed him to the life outside the hospice, while the occupational therapist arranged for him to attend school and his teacher and schoolmates supported him. Art played an important part in his life and he expressed his fears and joys in it.

Abstract number: PS 6.3  
Abstract type: Parallel Symposium

#### Decision Making for Children with Cancer When Standard Therapy Has Failed

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When cancer recurs parents are faced with a number of difficult decisions about further care and treatment. Options may include enrolling the child in Phase I/II trial, trying a second line chemotherapy or even more aggressive therapy, or shifting the focus entirely to symptom directed care. That few parents choose to shift entirely to symptom-directed care even within weeks and sometimes days of the child's death is of concern to some health care professionals. In this paper I present parents' approaches to care and treatment, consider explanations commonly offered and suggest an alternative approach to interpreting their behaviour; one routed in an analysis of the interactions among parents and clinicians over the course of the illness. Attention is given to implications for clinical practice particularly for developing solutions to what troubles us in practice.

This presentation draws on data collected as part of a comparative ethnographic prospective study of children with cancer when standard therapy had failed and cure was not likely conducted at two tertiary centres for children with cancer (Bluebond-Langner M, Belasco J, Goldman A) as well as on preparation and preliminary investigations for a prospective, longitudinal study of decision making for children with high risk brain tumours scheduled to start later this year (Bluebond-Langner M, Hargrave D, Kelly P, Gibson F, Bayliss J).

## Neuropsychiatric Symptoms

Abstract number: PS 7.1  
Abstract type: Parallel Symposium

### Delirium

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Up to 90% of palliative care patients develop delirium in the last days of life. Terminal delirium is one of the greatest stressors for patients, families and health care professionals alike. It is also the most frequent barrier impeding for death at home, and one of the most frequent reasons for palliative sedation. Despite this, it is underdiagnosed and undertreated in 22-50% of the cases. This is due in part to its heterogeneous clinical presentation: hyperactive delirium with agitation (2-21%), hypoactive delirium with apathy and withdrawal (29-43%), as well as mixed forms (43-54%). Pre-existing cognitive deficits or depression can also hamper diagnostic accuracy.

Palliative care patients often exhibit several risk factors for delirium, and 2-3 causes for the diagnosis can on average be identified. Among the most frequent causes are drugs, metabolic disturbances, infections, constipation, hyper- or hypoglycemia, insufficient pain therapy, as well as psychosocial or spiritual distress. The pathophysiological basis appears to reside in a neurotransmitter imbalance (reduced levels of acetylcholine and increases in dopamine and glutamate). Careful drug screening is required, since e.g. opioids, scopolamine, metoclopramide and antidepressants can cause or worsen a delirium.

Delirium carries a bad prognosis, but is reversible in 50% of palliative patients. Treatment includes non-pharmacological (calm environment, reorientation aids, information of the relatives, reduction of stressors) as well as pharmacological measures, such as neuroleptics. Haloperidol is the most widely used drug (beware of extrapyramidal side effects above 4.5 mg/d), atypical neuroleptics such as risperidone, olanzapine and quetiapine are also effective. Benzodiazepines should only be used in combination with neuroleptics. So far, insufficient data are available concerning the effectiveness of cholinesterase inhibitors and of psychostimulants such as ritaline for hypoactive delirium.

Abstract number: PS 7.2  
Abstract type: Parallel Symposium

### Terminal Restlessness

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In the last days of life, increasing restlessness and agitation may occur. This phenomenon is thought to be of multiple origins and does not need any treatment for mild stages. With decrease of organ functions such as liver or renal failure, many natural substances of human metabolism cannot be adequately washed out. Moreover, drugs that are usually used in that phase of life can accumulate, and restlessness, agitation and other disturbances of the central nervous system such as drowsiness, reduction of vigilance, respiratory depression may additionally evolve.

The management of terminal restlessness has to address a balance between side effects of the drugs in use and the continuously decreasing metabolic and excretory liver and renal functions. A frequent problem is the accumulation of morphine-6-glucuronide - the most important morphine metabolite, when morphine is given continuously via intravenous syringe drives in the presence of rapidly developing renal failure. Small pupils, muscular cramps, sedation, hallucinations, and terminal restlessness may develop. This problem can be aggravated in the presence of dyspnoea and hypoxemia due to lung failure or reduced ventilation at the end of life or as a side effect of the pharmacological treatment in use.

Terminal care then has to reduce or exchange drugs in use for symptom control to account for organ failures. If cognitive homeostasis cannot be established, palliative sedation using benzodiazepines rather than neuroleptics should be considered for refractory cases. Most important, communication with patients and their relatives helps to understand that restlessness is not only a symptom to be treated, but also reflects the last movements or steps of a person that has to make one's way.

Abstract number: PS 7.3  
Abstract type: Parallel Symposium

### Anxiety in Individuals with and without Cognitive Impairments

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Anxiety is one of the most common psychiatric disorders. In European countries among inhabitant age 18 or older, 13.6% had lifetime history of any anxiety disorder and more than 6% reported any anxiety disorder in the last year. Specific phobias were the most common and women were twice as likely to suffer anxiety disorders as men. Anxiety is also a symptom present in many other diseases, e.g., schizophrenia, HIV, cardiac disease, Parkinson disease, cancer and in persons with pain. However, the most frequent combination of anxiety is with depression, and combination of these diseases have more severe consequences than each of the diseases alone. The most common psychotherapy strategy for anxiety is Cognitive Behavioral Therapy but other strategies are also used for specific anxiety disorders. First-line medications for generalized anxiety disorder (GAD) are antidepressants such as selective serotonin reuptake inhibitors (SSRIs) and selective serotonin and noradrenalin reuptake inhibitors (SNRIs). Pregabalin and quetiapine are the two most promising non-antidepressant treatments for GAD if antidepressants are not effective. Beta blockers may be useful for social phobias. There is a large overlap of symptoms of anxiety, depression and dementia. Anxiety is present already in 38% of persons with mild cognitive impairment and is equally common in AD and vascular dementia. Anxiety increases the rate of progression of dementia and is present in many AD caregivers. Anxiety in persons with advanced dementia may be treated by Peaceful Mind program or Namaste Care. Medications used in dementia include benzodiazepines, buspirone and SSRIs. Benzodiazepines should be used with caution because they may cause fatigue, drowsiness, motor dysfunction with risk for falls, and cognitive impairment. There is also some evidence that anxiety could be diminished by administration of cholinesterase inhibitors, drugs used to decrease progression of Alzheimer's disease.

## Ethics and End-of-life Decisions

Abstract number: PS 8.1  
Abstract type: Parallel Symposium

### Euthanasia and Palliative Care: Belgium and the Case for Collaboration

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When euthanasia was depenalised in 2002, a substantial part of the Belgian palliative care community was very reticent to become involved, judging that good palliative care could eliminate the need for it. Ten years later, the caring practice of E. is a part of the daily work of palliative care teams and caregivers, with deep respect for differences in the caregivers personal participation. The mental shift was induced by the experiences of patients receiving E. under poor circumstances of care, and by the inverse: E. can be part of genuinely good care. This led to the growing involvement of palliative experts and teams: in the name of continuity of care, we do not abandon our patients, referring them to E.-practitioners outside the familiar care environment. Moreover, as key reasons for E. turned out to be the desire for control, fear of dependency and existential despair, E. requests no longer appear to be a failure of P.C. nor antagonistic to it. On the contrary: palliative teams are multidisciplinary and have the best palliative skills, including communication, and thus are well qualified to practice end-of-life care incl. support for E.: both in a careful (regard. the law) and caring way. They work in an emancipatory way, so that the familiar caregivers are supported, strengthened and cared for, also for future care. The structural antagonism is no longer that of 'for E.' or 'for P.C.', but rather that between the described model and a separate circuit of special E. doctors, teams and clinics for palliative patients requesting E. Thus palliative care in Flanders (1) resolutely chooses to take care of patients with E. requests; (2) remains open to reconsidering former choices whenever new social or ethical challenges arise; (3) avoids having the public and patients become victims of internal discussions about other models; but (4) insist on being involved regarding the long-term effects of E. (e.g. pressure) and the tendency to broaden E. to other target groups.

Abstract number: PS 8.2  
Abstract type: Parallel Symposium

### Euthanasia and Palliative Care: Incompatible

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The discussion on potential relationships between euthanasia (EU), hastened death (HD) and palliative care (PC) has been going on since the beginning of modern PC 40 years ago. The position that PC is the antidote to the wish for HD has been refuted by proponents of the legalisation of EU in the Netherlands and Belgium, who have held against it that these countries have put considerable resources in the development of PC. But to complement the term palliative care with the adjective "integral" must attract considerable attention. The European Association for Palliative Care (EAPC) has defined its position in 2003 by saying that the provision of EU and physician-assisted suicide (PAS) should not be part of the responsibility of palliative care. The EAPC paper did acknowledge that the issues around EU and PC are receiving increasing attention in different European countries, and that active debate surrounding these issues is to be encouraged. However, understanding and respect for alternative viewpoints is not the same as the ethical acceptance of either EU or PAS. Even if in some countries/or by some people EU and PC are accepted as compatible, this does not mean that the normative statements of the European Association for Palliative Care need to be revised. Ethics is not about an 'objective' truth but making a choice about a moral concept. The EAPC's ethical position does not include the viewpoint that EU classifies as a therapeutic intervention in the framework of symptom control, and EU or PAS conflict with its ethical concept of autonomy.

Studies showed that training in PC reduces the incidence of HD and that patients' wishes for HD are fluctuant or based on the fear to be a burden for others. These are empirical findings. Empirical findings cannot serve as a basis for a moral standpoint, but they strengthen our attitude that EU and PAS should not become integral parts of PC.

Abstract number: PS 8.3  
Abstract type: Parallel Symposium

### Palliative Sedation and Patient Preferences

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**Background:** While symptom control is a key element in understandings of the 'good death', extensive debate surrounds the practice of sedation for symptom palliation. **Aim:** To report aspects of the UNBIASED study (UK Netherlands Belgium International Sedation Study), examining how clinicians recall the role of patients' preferences in decision-making about sedation in end of life care.

**Methods:** Qualitative case studies in hospitals, hospices and home care, comprising interviews with nurses and physicians involved with the care of cancer patients who received continuous sedation until death.

**Results:** We studied 84 cases (22 UK; 35 NL; 27 BE) involving 57 physicians (17 UK; 18 NL; 22 BE) and 73 nurses (25 UK; 28 NL; 20 BE). UK clinicians perceived the movement towards continuous sedation until death unfolded gradually with no 'moment of decision' except in rare cases. In these rare cases, the patient's request for sedation was not always seen as sufficient to inform decision-making. Dilemmas were perceived to be posed by patients who requested assisted dying or who wanted sedation for existential reasons. Belgian clinicians placed primary emphasis on the importance of establishing patients' preferences for either sedation or euthanasia and honouring patients' requests to be 'taken out of suffering' or to be 'put to sleep'. Dutch clinicians placed primary emphasis on the importance of making a 'formal' medical decision to initiate sedation informed by the patient's wish. Where patients could not express preferences clinicians from all three countries sought to make decisions based on consultation with colleagues and the patient's relatives.

**Conclusion:** Clinicians in the UK, Belgium and the Netherlands all place high value on patients' preferences for sedation, but emphasize patients' choices differently when making decisions to implement continuous sedation in end of life care. These differences may be related to different histories and contexts of practice.

### Implementing Palliative Care in Nursing Homes

Abstract number: PS 9.1  
Abstract type: Parallel Symposium

#### The EAPC Taskforce on Palliative Care in Long-Term Care Settings for Older People

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**Background and Aim:** Many older people living and dying in long term care facilities (LTCFs) are in need of palliative care during their residency there. A number of ways have been developed to promote palliative care provision for older people living in LTCFs. The EAPC Taskforce on Palliative Care in Long-Term Care Settings for Older aimed to identify and map different approaches to the development of palliative care provision.

**Methods:** Country informants from 13 European countries (Austria, Belgium, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, UK) were identified as sources of data within their countries. Two phases of work were undertaken: Phase 1: information about the context of long term care provision in each country was collected considering the types of LTC settings, the status of LTC providers, funding and regulation. Phase 2: examples of initiatives to develop palliative care provision were collected.

**Results:** The context for LTC provision across Europe is variable. All countries offer care that meets low and high levels of dependency. Providers of care are located in the public, private, and not for profit sectors. Funding is complex and sources draw on state and personal funds. Regulation is national or state led. A typology of interventions has been identified that categorises the initiatives identified. This addresses a number of levels: Individual (staff, family, resident), Team, Organization, Regional /Networks and National. Examples of initiatives at all levels can be seen across Europe. A compendium of current practice interventions has been compiled. Issues of sustainability for these developments and the important role of LTCF organisations as mediators of change were identified.

**Conclusion:** A range of initiatives are being undertaken to develop palliative care provision in LTCFs across Europe. Organisational change is key to ensuring the successful implementation of new developments.

Abstract number: PS 9.2  
Abstract type: Parallel Symposium

#### The Gender Issue

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**Aims:** Questions of integrating palliative care in long term care settings are concerned with initiatives and effects on different levels: individual, team, organisation and systems environment. Organisational cultures that create space, time and communication about living, dying and bereavement are needed. Gender issues as integrated social category have to be considered. The aim of the contribution is to show in which ways gender is important for palliative care in nursing homes.

**Methods:** A meta-analysis of two projects on gender in nursing homes is presented. Working within a qualitative paradigm of organisational research, in one of the studies a single case study was conducted. Multiperspective interviews, group discussions and feedback arrangements were part of the case study. The other study encompassed a literature review, a transdisciplinary workshop, a book publication and expert interviews.

**Results:** Nursing homes can be characterised as "female lifeworlds". Traditional gender roles and gender relations dominate the lifeworlds in nursing homes. Women living there have to be acknowledged in their life long balancing act of bringing „doing family“, housework and occupational work together. Men living there have to be acknowledged for their mainly job-focussed biographies. Historically relevant knowledge of gender relations play a central role in palliative and end-of-life care.

**Conclusion:** The traditional gender culture has to be reflected critically to overcome gender stereotypes in the work of palliative care. Professionals and management working within nursing homes are requested to ask themselves in what way gender sensitivity can be integrated into daily work routines. Structural gender inequalities within our societies have to be recognised. Gender sensitivity in palliative care in nursing homes is a multidimensional process that always has to do with the interplay of attentiveness, interaction, reflection and structures.

### Teaching Session: Planning and Conducting Clinical and Public Health Research in Palliative Care

Abstract number: PS 10.1  
Abstract type: Parallel Symposium

#### How to Get Started - and How Can the EAPC Research Network Contribute?

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In order to optimise palliative care, we need high level scientific evidence implemented into international and national treatment guidelines. The content of these guidelines must be implemented into clinical practice. One mechanism is to develop standardised patient trajectories, assure the implication of these into the health care system and to quality assure the level of effect on each individual patient.

Some key elements need to be considered before clinical research projects are initiated:

- The aim / research questions must be relevant and have a potential to improve patient care
- The method/design of the study needs to be sound and contribute to valid answers to the research questions
- Intervention studies are needed since these types of studies have a good potential to improve clinical practice
- The studies need to be planned and conducted according to international standards and to be sufficiently sized
- Multicentre studies will often be needed

Abstract number: PS 10.2  
Abstract type: Parallel Symposium

#### Planning, Conducting and Avoiding Pitfalls in Public Health Research

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Planning public health research in palliative care involves a large amount of money and one or more grant preparations and applications. The process of building a consortium or research team, designing grant application(s) and negotiating contracts will take at least a year. When you have mobilised enough resources, researchers have to be recruited and selected, a full protocol written, and all procedures for data collection have to be developed and tested. Finally in the preparatory phase, you have to prepare and get approval from ethics committees and sometimes from other data protection agencies. At that stage, you have still not collected any data for your study, and a second year may have passed. If it is your aim within your study to conduct a full PhD trajectory, this will require three to five more years in general. Hence, planning of public health research in palliative care requires time and patience.

Successfully conducting public health research in palliative care is difficult and requires good organisational conditions and personal research knowledge and skills (e.g. creativity, questionnaire development, sampling techniques, statistics, data analyses, scientific writing, multidisciplinary collaboration and team work). An embedment in an academic multidisciplinary research environment is helpful, and implies supporting services (statistics, IT support, research methods trainings, PhD training etc). Furthermore, researchers need a positive attitude towards research in general, but also towards guidance from their supervisors. Above all, they will need perseverance.

In this presentation, a number of issues will be highlighted and discussed: What do we have to know before planning a study? How can we optimise the team and research environment? How do we draft a good research protocol? What kind of specific problems and pitfalls are related to public health research in palliative care, and how can we best deal with these?

Abstract number: PS 10.4  
Abstract type: Parallel Symposium

#### How to Enhance Quality in Collaborative Multinational Studies

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In the last decades research networks have been established in various health care disciplines with the aim to share resources, infrastructures and to exchange specialized research skills.

Multicentre study designs have then become more common since they offer the possibility to achieve quick patient enrolment within a practical time frame and because of the increased external validity of the results, mainly when centers from different countries participate in the network.

Conversely, data quality can be a critical issue because of potentially different standards in assessment/data collection skills and in research infrastructure availability among different centers.

Data quality is a central requirement of scientific research and one of the tasks of the coordinating centre is to assure it through multiple interventions both when planning the study and during its course.

Possible strategies to enhance study quality are: precision in writing protocols; standardization of recruitment and data collection procedures; training and supervision of the research teams; limitation of the burden of data collection for all study participants; implementation of pilot study in each centre; definition of minimum standards of data quality; regular assessment of data quality indicators and feedback to each investigator and study coordinator; involvement and motivation of investigators.

### Innovations in Learning

Abstract number: PS 11.1  
Abstract type: Parallel Symposium

#### How to Teach Attitudes

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The importance of the 'right' attitudes towards patients, colleagues and even ourselves, should not be underestimated. Can we define, teach and assess them? What do they look or feel like? Might it depend on who you are, the field you work in, or the country you live in? Are they fixed or flexible? How might societal and technological changes affect what attitudes are required of healthcare professionals (HCPs)? Attitudinal competence is recognized as vital for doctors. Professionalism, encompassing values, beliefs and attitudes that underpin the trust that patients have, is high on the agenda. Undergraduate medical educators have recognized the importance of developing positive attitudes in their students, with many innovative approaches in the literature. How do doctors and HCPs develop their attitudes, and what role can we play as palliative care clinicians? Might this extend to fostering positive attitudes in our patients and their carers? How might our own attitudes affect our ability and willingness to engage in any of these activities? Apprenticeship is key to how medical students learn, and role-modelling is integral. Aside from learning experiences that might be anticipated, organizational structure and culture also inform learning, 'the hidden curriculum'. Importantly this reminds us that attitudes may be taught/learned inadvertently. It is not possible, nor desirable, to control clinical educational environments so that learners see only glowing examples of the 'right' attitudes in their seniors and peers. Instead, developing a culture of self-awareness and reflectiveness where attitudes and their impact are recognized is key. Palliative care can learn from other specialties where such practice is embedded. Fostering resilience in students, colleagues, patients and carers allows them to recognize, deal with and speak up about negative attitudes encountered, allowing development of positive attitudes and behaviours in a conscious and constructive way.



**Abstract number:** PS 11.2  
**Abstract type:** Parallel Symposium

### Education Needs in Central and Eastern European Countries

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Eastern European countries are in different stages of developing palliative care services. Education is one of the three main pillars in the WHO public health approach model in order to develop palliative care services. The presentation will focus on examples of approaching different educational needs by countries in the region as follows

- Developing of education centers (Poland, Hungary)
- Palliative care subspecialty training for doctors (Romania, Czech Republic)
- Preparing future leaders for palliative care services (European Academy for Palliative Care)
- On-line training for palliative care approach (Romania).

**Abstract number:** PS 11.3  
**Abstract type:** Parallel Symposium

### Experiences with an Online Master's Program

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In light of the growing need for palliative care, in 2009 the Ministry of Science, Research and Arts of the federal state of Baden-Württemberg, Germany backed the establishment of a part-time, postgraduate, multiprofessional Master's program, "Master Online - Palliative Care". The program resides in the Medical Faculty of the University of Freiburg. Upon completion of the four-semester program, students obtain an internationally recognized Master's degree. This interdisciplinary, practice-oriented and research-based degree qualifies students take on various positions in both inpatient and outpatient palliative care settings, ranging from management to work with patients. One particularly innovative element of this Master's program is its use of blended learning, which allows students to continue their career alongside their studies. Blended learning combines traditional face-to-face classroom methods with e-learning, utilizing the strengths of both methods to communicate knowledge and skills. In the winter semester 2010/2011, the Master's program admitted its first students and succeeded in bringing together students from various professional backgrounds. Two-thirds of the presently enrolled 36 students are physicians, while the other third consists of nurses, theologians and social workers. Among the current students, 19 work in Germany and 17 are employed in Switzerland. In the fall of 2012, the first students successfully completed the Master of Science in Palliative Care. To foster the continued improvement of the program, regular evaluations are conducted. Due to the small sample size, the data provided in this report cannot be generalized and only provides overall tendencies regarding students' responses to the program offerings. Nevertheless, the data presented here along with the feedback of students show that there is a very positive response to the courses currently offered within the program because of the practice-oriented material presented.

## IMPACT

**Abstract number:** PS 12.1  
**Abstract type:** Parallel Symposium

### Changing Palliative Care: Measuring and Improving the Organization of Palliative Dementia and Cancer Care

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New knowledge is not necessarily readily applied in palliative care, even when there is evidence of its effectiveness in helping to solve problems. Systematic implementation is needed to translate scientific evidence or consensus into everyday clinical routines. Implementation is 'a planned process or systematic introduction of innovations and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functioning of organizations or in the health care structure' (Grol et al 2005).

An increasing number of older people with progressive, incurable, life-limiting chronic diseases like dementia or cancer need palliative care. Altering well-established

patterns of care or organization is difficult. Changing the organisation of palliative care is a major challenge, since this requires collaboration between a range of different professionals and healthcare organizations. For those reasons the aim of this project is to implement quality indicators (QIs) and improvement projects in settings that provide palliative care to patients with dementia or patients with cancer.

QIs can be used to measure the organization of palliative care. Within our EU FP7 IMPACT project with partners from 10 European countries, we developed such a set of QIs, that will be used to measure the organization of palliative care in general practices, nursing homes, hospices and hospitals in NL, D, UK, It, and No. With the help of tools and guidance of a consultant, teams within the settings will use the feedback on the QIs to improve their organization of care. After 9 months, the QIs will be used again to measure the effect of the intervention. Throughout the development phase, the intervention period, and the process analysis, barriers and incentives for improving the organization will be taken into account.

At the end of the IMPACT project (2011-2015) the set of QIs, as well as the tools will be available for broader implementation in Europe.

**Abstract number:** PS 12.2  
**Abstract type:** Parallel Symposium

### Models for the Organization of Palliative Care in Patients with Cancer and Patients with Dementia

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**Aim:** To develop a model of palliative care for people with dementia that captures commonalities and differences across Europe.

**Background:** Palliative care for people with dementia is often sub-optimal. This is partly because of the challenging nature of dementia itself, and partly because of system failings that are particularly salient in primary care and community services. There is a need to systematize palliative care for people with dementia, to clarify where changes in practice could be made.

**Methods:** A technology development approach was adopted, using mixed methods including 1) critical synthesis of the research literature and policy documents, 2) interviews with national experts in policy, service organisation, service delivery, patient and carer interests, and research in palliative care, and 3) nominal groups of researchers tasked with synthesising data and modelling palliative care.

**Findings & Outputs:** A generic model of palliative care, into which quality indicators can be embedded, was developed. The proposed model includes features deemed important for the systematisation of palliative care for people with dementia. These are: the division of labour amongst practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between active treatment and palliative care and between palliative and end-of-life care; and the process of bereavement.

**Conclusion:** The co-design approach to developing a generic model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines. This model will be described in this presentation, and its future evaluation discussed.

**Abstract number:** PS 12.3  
**Abstract type:** Parallel Symposium

### Barriers and Facilitators to Implementing Quality Improvements in the Organization of Palliative Care

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**Background:** Implementation of change is a challenge in health care settings in general, also in palliative care (PC) settings. In order to plan and conduct a quality improvement project, it is essential to take barriers and facilitators for success into account. The EU-funded IMPACT project aims to increase the knowledge-base in this area.

**Aim of the presentation:** One objective of the IMPACT project is to identify factors that may act as barriers or facilitators to the implementation of improvement strategies in the organization of PC for cancer and dementia patients. This presentation will highlight factors identified so

far, and describe the data collection tools used within the IMPACT project to identify additional factors.

**Method:** So far we have conducted a literature review and interviews / focus groups with health care professionals who have experience from improvement projects in PC. The IMPACT project partners are currently conducting a pretest-intervention-posttest study in 40 home care services, nursing homes, hospitals and hospices in Europe in order to shed further light on this issue.

**Lessons learned so far:** The findings from the literature review, interviews and focus groups are being used to tailor interventions to improve the organization of PC in the 40 services participating in the study. For example, motivation and involvement of the staff and management are crucial for the interventions to succeed. Therefore, each of the services may choose their own objectives for improvement, and influence the plans for how to reach their goals.

**Next step:** We are currently collecting data in order to conduct a process evaluation that will describe the intervention in each service, the actual exposure to the intervention, and the experience of those being exposed. Data from questionnaires, activity reports and interviews will be used to make an inventory - for each type of setting - of barriers and facilitating factors influencing implementation.

## Neurology

**Abstract number:** PS 13.1  
**Abstract type:** Parallel Symposium

### Palliative Care for ALS Patients

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Amotrophic lateral sclerosis (ALS) is the most common degenerative motor neuron disease in adults. The clinical picture consists of generalized fasciculations, progressive atrophy and weakness of the skeletal muscles, spasticity and pyramidal tract signs, dysarthria, dysphagia and dyspnea. Pathologic laughing and crying is common, as are cognitive deficits of the fronto-temporal type. Disease-specific treatment options are still unsatisfactory. However, therapeutic nihilism is not justified as a large array of palliative measures is available to enhance the quality of life of patients and their families. Because of its clinical characteristics, ALS represents a paradigm for palliative care in neurological diseases. Numerous projects are being undertaken worldwide in order to enlarge the evidence base for palliative interventions in ALS. Palliative care in ALS is a multidisciplinary effort requiring careful coordination of care. An open and empathic disclosure of the diagnosis is essential. Nutritional deficiency due to dysphagia can be relieved by a percutaneous endoscopic gastrostomy. Symptoms of respiratory insufficiency can be effectively treated by non-invasive home mechanical ventilation. The terminal phase of the disease should be discussed at the latest when symptoms of dyspnea appear, in order to prevent unwarranted fears of "choking to death". Psychosocial and spiritual care of patients and families are of paramount importance. Collaboration with hospice institutions and completion of advance directives can be of invaluable help in the terminal phase. Remarkably, ALS patients can maintain a high quality of life and satisfaction with their subjectively perceived meaning in life throughout the course of the illness, despite progressive loss of physical functions.

**Abstract number:** PS 13.2  
**Abstract type:** Parallel Symposium

### The EAPC Neurology Guidelines

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**Aims:** A European Association for Palliative Care Taskforce, in collaboration with the European Federation of Neurological Societies, has produced guidelines on the palliative care of neurological disease.

**Methods:** The guidelines have been developed from a literature search of relevant articles and using a group of experienced clinicians and researchers in both palliative care and neurology.

**Results:** The following areas of recommendations were made and would be presented, with supporting evidence:

- Palliative care should be considered early in the disease trajectory
- Assessment of care should be by a multidisciplinary team
- Patients should have access to a palliative care assessment
- Communication with patients and families should be open, including setting of goals and therapy options

## Parallel sessions

- Early advance care planning is recommended
- Recognition of deterioration over the last weeks and months is relevant for appropriate management
- Proactive assessment of physical and psycho-social issues reduces the need for crisis intervention
- The principles of symptom management should be applied to neurology
- Diagnosis of the dying phase allows appropriate management and standardised tools, such as the Liverpool Care of The Dying Patient Pathway, may be helpful
- Carers needs should be assessed regularly and support provided - before and after death
- Professionals should receive support and supervision
- Palliative care principles should be provided in the training and education of neurologists
- The understanding and management of neurological symptoms should be provided for specialist palliative care professionals

**Conclusion:** The development of the guidelines has allowed recommendations on practice for the care of people with neurological disease. The aim is for these to be disseminated to both neurology and palliative care clinicians with the aim of improving the care and quality of life of these patients and their families.

**Abstract number:** PS 13.3

**Abstract type:** Parallel Symposium

### Neuromuscular Electrical Stimulation for Muscle Weakness in Adults with Advanced Disease: A Cochrane Systematic Review

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**Background:** Patients with advanced disease often experience muscle weakness which impacts adversely on independence and quality of life. In patients unable or unwilling to undertake existing forms of exercise, neuromuscular electrical stimulation (NMES) may provide an alternative means of enhancing leg muscle strength. Programmes appear well tolerated and have led to improvements in physical function and quality of life. Our primary objective was to determine the effect of NMES on quadriceps strength in adults with advanced disease. Secondary objectives were to determine effects on maximal and sub-maximal exercise capacity.

**Methods:** Randomised controlled trials in adults with advanced COPD, chronic heart failure or cancer comparing a NMES programme to a no treatment, placebo or active control were identified from the Cochrane Library, databases and conference proceedings. Two authors independently extracted data on study design, participants, interventions and outcomes. Mean differences or standardised mean differences (SMD) between NMES and control groups were calculated.

**Results:** Eleven studies involving 218 participants across COPD, chronic heart failure and thoracic cancer met the inclusion criteria. NMES significantly improved quadriceps strength by a SMD of 0.9 [95% CI 0.33 to 1.46], equating to approximately 25 Nm [95% CI 9 to 41]. Mean differences across various walking tests, all favouring NMES, were 40m [95% CI -4 to 84] for the six-minute walk test, 69m [95% CI 19 to 119] for the incremental shuttle walk test and 160m [95% CI 34 to 287] for the endurance shuttle walk test.

**Conclusion:** NMES appears an effective means of improving muscle weakness in adults with advanced COPD, chronic heart failure and cancer. Further research should clarify its place in clinical practice by determining optimal programme parameters, patients most likely to benefit, and impact on morbidity and service use.

**Abstract number:** PS 13.4

**Abstract type:** Parallel Symposium

### Palliative Care for Stroke Patients - Experience from the Regional Organization of Care

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Every year 105 000 people die in the CR: 25% of malignant tumours, 50 % of circulatory system diseases (cardiovascular and cerebrovascular diseases), the remaining 25 percent being pulmonary, liver and kidney diseases, poisoning and accidents [1]. Most of these people (70-80%) need specialized palliative care not only in last weeks, but many months of their end-of-life. Patients with the post-stroke syndromes are in some situations (frailty, coma, multiorgan failure, co-morbidities, large strokes, difficult traumatic reasons etc.) the typical examples of "the needness for early

indication" to specialized palliative care.

The Health Care System in Czech Republic stands generally in front of a great challenge - how to cope the system and behaviour or thinking of HC professionals to the century of neurodegenerative diseases, to the aging population and above all to the living (and treating... searching the "well being") in the long life with disease. Unfortunately the primary care, long term care and also only few developed specialized palliative care are not able to manage the multidisciplinary care, long time (many months or some years), support sufficiently family care and bring the value of QoL to patients and family lives. I can see more the "service departments for cars" than the "well being institutions".

There are several institutions, and also acute care settings, where the professional teams try to change the habits like I mentioned. Mostly the problematic is about "how make the categorisation of patients in acute, long term care, what are the indicators as for the prognosis and how set the range of palliative care out of the palliative specialized care settings". The presentation will describe our 10 years experience, the tools of co-operation with other medical institutions in region, and a description of our daily care for patients and families in the field of specialized palliative care for patients with post-stroke syndromes.

## Public Health Perspective

**Abstract number:** PS 14.1

**Abstract type:** Parallel Symposium

### Silver Tsunami: The Future Challenge of Palliative Care

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World-wide population are ageing. In developed nations, the majority of deaths occur in elderly patients suffering from multiple coexisting and progressive chronic illnesses, such as congestive heart failure, chronic obstructive pulmonary disease, stroke, dementia and renal failure; these patients, in the end stage of their disease, need palliative care. The needs of patients with progressive non-malignant disease are similar to those of patients with advanced cancer. Literature has found that patients dying from non-malignant disease were just as likely to experience distressing symptoms as cancer patients, but were less likely to have these symptoms relieved. Furthermore, only a small minority of non-cancer patients access specialist palliative care services. Meeting the palliative care needs of non-cancer patients presents a number of difficult and unresolved challenges, that include difficulties caused by prognostic uncertainties and the lack of evidence in the needs of non-cancer patients, on the best ways of meeting these needs and on the effectiveness of services.

Several recent studies emphasized the unmet needs of patients with advanced disease with conditions other than cancer. Data on treatment of pain in old age suggests that elderly patients also receive less pain medication than younger persons for chronic and acute pain. Furthermore, pain is often under-treated in end stage dementia. Palliative care for the elderly needs to focus on therapeutic interventions that can preserve function and help patients maintain quality of life; discussion on the course of illness so that patients can plan for the future; recognition and management of caregiver stress; and management of physical and psychological symptoms of chronic illnesses. Physicians should discuss goals of care with their patients, considering that goals may change as disease progresses. A multidisciplinary team is critical to caring for patients at the end stage of chronic illness.

**Abstract number:** PS 14.2

**Abstract type:** Parallel Symposium

### The Right to Palliative Care from the Public Health Perspective

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Availability of and access to pain management and palliative care are problematic in many countries around the world. Seya *et al.* were able to quantify the approximate number of people that live in countries where access is low. Based on this research project (figures for 2006), the World Health Organization (WHO) estimates that 5.5 billion people (83% of the world's population) live in countries with low to non-existent access to controlled medicines and have inadequate access to treatment for moderate to severe pain. Figures for 2010 will be presented in this presentation. Lynch

*et al.* mapped availability of palliative care at the country level and distinguished 6 levels from "No known hospice-palliative care activity" to "At a stage of advanced integration into mainstream service provision" Only 19% of the countries is in the highest two groups (2011).

The WHO policy guidelines *Ensuring Balance in National Policies on controlled substances: guidance for availability and accessibility of controlled medicines* (2011) distinguish four imperatives to make pain management (and palliative care) available to those in need: the legal, the political, the moral imperative and finally the public health imperative. The latter is in the service of the other three imperatives: to attain an optimal access to palliative care services, integrated services are indispensable and a public health approach is necessary to realize this.

This presentation will focus on the public health imperative. From the perspective of access to opioid analgesics it means that there is an obligation of governments to establish a system of drug control that ensures the adequate availability of controlled substances for medical and scientific purposes, while simultaneously preventing abuse, diversion and trafficking. From the palliative care perspective, it means that a number of changes are necessary. These will be elaborated on.

**Abstract number:** PS 14.3

**Abstract type:** Parallel Symposium

### Public Health Research in Palliative Care and the Possibilities of Death Certificate Studies

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Public health is a domain that has enjoyed strong support from governments and international organisations ever since the World Health Organisation (WHO) launched the WHO Health for All Strategy back in the 1970s. This can be considered as a health care revolution and introduced the concept of the power and responsibilities of people and governments for health and sickness. But a comprehensive public health approach is also less expensive than acute and chronic forms of care, because its emphasis is on prevention and health promotion. A holistic policy aimed at service provision for all in the last year of life and at promoting palliative care to all in need can prevent expensive overtreatment of patients with cancer and other chronic diseases. If we want more policy-makers and practitioners to embrace the aims and ideals of palliative care, a public health approach is essential.

The results of public health studies can guide policy-makers and practitioners in defining and allocating the resources needed to establish palliative care services for those patients in need. Public health can also improve awareness among the public of the values underlying palliative care and the possibilities it offers for improving the quality of life of both the patient and the family involved. In this presentation we will explore the following topics:

1) What are the challenges of public health research at the end of life (e.g. population-based monitoring of the end of life, the value of retrospective designs versus prospective designs, etc)? 2) In Europe each death is attested by a physician in the form of a signed death certificate. Have death certificate data added value to a public health approach in palliative care? 3) As well as generating mortality statistics, death certificates can also be used for additional studies (e.g. place of death studies, mortality follow-back surveys, etc) 4) What would a research agenda for public health and palliative care research look like?

## Religious Aspects in Palliative Care

**Abstract number:** PS 15.1

**Abstract type:** Parallel Symposium

### Palliative Care in Muslim-majority Countries: A Situation Analysis

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There are currently over 1.6 billion Muslims living in all parts of the world and representing nearly one-quarter of the world's population ([www.pewforum.org](http://www.pewforum.org)). About three-quarters of the world's Muslims live in the 49 Muslim-majority countries (MMC's), and about one-quarter live in Muslim-minority countries of the developing world. In

analyzing data re. morphine consumption, it became apparent that the higher-GDP MMC's of the Arab Gulf (Bahrain, Oman, Qatar, Kuwait, Saudi Arabia & the United Arab Emirates) are among those using very low amounts of opioid analgesics despite their relative abundance of resources for health generally speaking. The objective of this study was to assess palliative care in MMC's by compiling and analyzing published data relative to palliative care. Available published data on services and on consumption of opioid analgesics including recent data comparing consumption to need were compiled for the 49 MMC's. More research is needed to understand the barriers to the use of opioid analgesics in MMC's, and it is essential that this research be local since diversity is likely within the MMC's. A clear barrier to the integration of palliative care into healthcare is the shortage of physicians and nurses with specialized or advanced training in palliative care delivery. Ideally, palliative care would be a part of multidisciplinary case management from the date of diagnosis and not merely appended at the end of life. To achieve this goal, training and capacity building in palliative care should be a high priority of the governments of the MMC's as well as the international community as a whole. It is clear that modules related to cultural and religious distinctives should be added to palliative care training courses and training programs. Such modules would benefit not only those healthcare workers who practice in MMC's but also those working in settings where Muslims are a growing minority (e.g., the U.S. and Europe).

**Abstract number:** PS 15.2  
**Abstract type:** Parallel Symposium

### Islam and Palliative Care - Practical Implications in Turkey

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Turkey lies at the crossroads between Eastern and Western civilizations. Turkey has a history which contains the diverse cultural and religious traditions of both the East and the West. Social life contains a large number of different beliefs, customs, traditions, rites and ceremonies, stereotype attitudes, etc. in many fields.

Turkey has a unique place among modern Muslim nation states. Turkey is a secular country, trying to find a balance between religion and secularism by constantly improving its democratic culture. Today, Turkey emerges a country that supports a moderate, tolerant and inclusive perception of Islam. The widespread perception of Islam in Turkey is not radical, fundamentalist or exclusive.

The majority of the Muslim population belongs to the loosely defined Sunni interpretation of Islam. The current perception and practice of Islam varies from mystical and folk Islam to conservative and more moderate understanding of Islam. Several non-Muslim religious groups also exist in Turkey.

In this paper, the current perception and practice of Islam in Turkey will be discussed in the focus of palliative care. The meaning of life and death, perception and social aspects of illness, taking care of the ill, grief and mourning, disclosure of diagnosis and prognosis, etc will be argued.

Palliative care is an emerging topic in Turkey within recent years. One of the main headings of Turkish Cancer Control Program 2009-2015 is palliative care and a serial palliative care unit implementation with continuous training programs. The current palliative care situation in Turkey and Pallia-Turk Project will be also briefly summarized.

**Abstract number:** PS 15.3  
**Abstract type:** Parallel Symposium

### Issues of Guilt and Shame in Life Threatening Illness and Death: A Challenge for Christian Pastoral Care?

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**Aim:** To explore Christian pastoral responses to the presence of guilt or shame for people who are dying

**Background and method:** From a very early age we can experience guilt or shame and, while these feelings may overlap, they can also be distinguished. Guilt is concerned with the consequence of committing actions which are believed to be wrong or harmful. Shame links more closely to embarrassment or humiliation and feelings of low esteem - often for not having met the expectations of others. In the context of illness and terminal care both these experiences can result from the way the individual tries to find a cause for the illness or responds to the reactions (or expected reactions) of others to news of the diagnosis and prognosis.

This is often expressed in terms of questions such as: "Why me?", "What have I done to deserve this?" etc. In this presentation I shall look at some of the ways in which guilt and shame can shape responses to diagnosis and treatment, assess the contribution they can make to spiritual and psychological distress, and suggest pastoral responses from within the Christian tradition.

**Conclusion:** Sensitive pastoral exploration can help to re-frame some experiences of guilt and shame. When appropriate religious liturgy / ritual can also assist transformation of the experience and help the dying person achieve a greater sense of inner peace.

### Common Battlefields for Palliative Care and Oncology (ESMO Supported Session)

**Abstract number:** PS 16.1  
**Abstract type:** Parallel Symposium

#### The International Collaborative Project to Evaluate the Availability and Accessibility of Opioids for the Management of Cancer Pain: Final Survey Result

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**Introduction:** The International Collaborative Project to Evaluate the Availability and Accessibility of Opioids for the Management of Cancer Pain has been coordinated by ESMO, EAPC, UICC, PPSG + WHO with collaboration from international PC and oncology societies.

**Aim:** To develop a comprehensive database on the availability and accessibility of opioid medication for the management of cancer pain in: Africa, Asia, Latin America and the Caribbean and Middle East. The adequacy of formulary availability is evaluated relative to the International Association of Hospice and Palliative Care list of Essential Medicines for Palliative Care. Overregulation is evaluated according to descriptors identified by the World Health Organization and the International Narcotics Control Board.

**Results:** Between 12/2010-7/2012, 156 reports were submitted from identified reporters in 76 countries and 19 Indian states (58% countries, 83% population). Very few countries provide all 7 opioids on the essential drug list of the IAHPC (Codeine, immediate and slow release oral morphine, oral IR oxycodone and transdermal fentanyl) and in many countries less than 3/7 drugs are available. Furthermore, in most of the countries opioids are either not or are weakly subsidised by gov. and availability is often limited. Many countries have highly restrictive regulations that limit entitlement of cancer patients to receive prescriptions, limit prescriber privileges, impose restrictive limits on duration of prescription, restrict dispensing, and increase bureaucratic burden of the prescribing and dispensing process.

**Conclusions:** In many places across Africa, Asia, ME and L+C America governments are failing cancer patients in delivery of adequate pain relief. There is a need for increased availability of affordable opioids for the management of cancer pain. A priority action is examination of drug control policies and repeal of excessive restrictions which impede this most fundamental aspect of cancer care.

**Abstract number:** PS 16.2  
**Abstract type:** Parallel Symposium

#### Integration of Palliative Care into Oncology

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Cancer care has become more complicated due to the developments of diagnosis, treatment and follow-up of patients. More patients are living longer because of better life-prolonging treatment. However, the benefit for the patients on symptom control, function and quality-of-life is varying, and there is a need for quantifying the effect. One needs to focus just as much on quality as on quantity of life.

The competence of palliative care is needed at various stages of cancer care: Curative, life-prolonging, palliative care and end-of-life care.

The patients are in need of symptom management, psychological and social and existential care independent of treatment intention. Therefore, the traditional organisational structure as a division between mainstream oncology and palliative care does not seem to be the optimal structure.

Some aspects needed to achieve such an integration are:

- All participants need to have a common understanding and acceptance of this organisational structure
- The organisational structure needs to be incorporated and resource-set at each institution
- All health care providers in the teams (oncology and palliative care teams) need to have competence at level three
- Communication and structure needs to be established, understood and followed
- The patients must be in the centre.

**Abstract number:** PS 16.3  
**Abstract type:** Parallel Symposium

#### Treatment of Toxicity of New Targeted Therapies

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The new types of toxicity of targeted anticancer agents are skin, vascular/cardiac, gastrointestinal and endocrine effects. Dermal toxicity is usually mild-to-moderate, reversible and dose-dependent. Rash, dry skin and itching are the most common skin effects (< 75%). Preemptive manners are limited exposure to sun, avoidance of products that dry skin like soap and moisturizing. In localized eruption topical antibiotics (clindamycin or metronidazole) and corticosteroids, and antiseptic creams appear to relieve the symptoms. In extensive lesions systemic therapy with tetracyclines (doxycycline 100-200 mg/d for 4-8 weeks) is needed. Paronychia (inflammation around the nail) affects especially large toes. The treatment is topical corticosteroids and antiseptic creams, and oral tetracyclines with more severe cases. For prevention and treatment of Hand-Foot-Skin-Reaction (HFSR) mechanical or chemical keratolytic measures (urea or salicylic acid containing creams or ointments) of hyperkeratotic areas, footbath and emollients are recommended. Alopecia, facial hypertrichosis, elongation of the eyelashes and hair pigmentation are reversible self-limiting side-effects. For more severe or prolonged dermal toxicity dose reduction, treatment interruption or discontinuation is needed. Vascular/cardiac toxicity includes hypertension (15-60%), arterial and venous thromboembolic complications, wound healing problems, hemorrhage, gastrointestinal perforations, heart failure and coronary symptoms. Blood pressure should be regularly monitoring and when necessary, treated with antihypertensive agents. Other toxicities include diarrhea, mucositis, hypothyroidism, hepatotoxicity and pancreatitis (ibilimumab), proteinuria (bevasizumab) and pneumonitis (mTOR inhibitors). In summary, proactive and supportive managements of adverse effects are often effective and allow for uninterrupted minimally altered-dose therapy.

### Developing Collaboration for Palliative Care: Experience and Challenges

**Abstract number:** PS 17.1  
**Abstract type:** Parallel Symposium

#### Developing Collaboration for Palliative Care: Experience and Challenges

*McIlfratrick S.J.<sup>1,2</sup>, Larkin P.<sup>1</sup>, Payne S.<sup>3</sup>, Gamondi C.<sup>4</sup>, Connolly M.<sup>1</sup>, Murphy L.<sup>5</sup>*

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The concept of collaboration features prominently in palliative care. The purpose of this symposium is to share the experiences and challenges of developing a model of collaboration used by the All-Ireland Institute of Hospice and Palliative Care (AIHPC), which is a large 5 year collaborative initiated in 2011 to improve palliative care on the Island of Ireland. There have been a number of challenges as a result of seeking to create an initiative that brings together three Work Packages of Education, Research and Policy and Practice into a single entity, allowing the activities and outcomes of each to add value to the others. The papers included in this symposium will present work streams that are aimed at developing collaboration for palliative care in line with the international agenda. Paper 1 will provide the strategic context within Ireland that has supported the development of the All-Ireland Institute of

## Parallel sessions

Hospice and Palliative Care. Paper 2 will describe the activities undertaken in developing a research collaborative community, emphasising the importance of the spectrum of activity that can contribute to research and knowledge generation. Paper 3 presents models of mentorship and educational networks drawn from the literature and from discussions with recognised leaders in palliative care. The final paper, paper 4, will draw together the key issues and challenges, by reflecting on the quality of palliative care research nationally and internationally, highlighting issues for the development of future collaborations.

**Abstract number:** PS 17.2  
**Abstract type:** Parallel Symposium

### Developing a Research Collaborative Community

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**Aims:** This presentation draws upon evidence of international and national research collaboratives and initiatives to identify barriers and opportunities for promoting and facilitating them.  
**Methods:** Using experience from two different types of research collaboratives, I will describe the strengths and limitations. One type of research collaborative has a specific goal which is to design, implement and deliver a specific piece of research such as those funded by the European Commission. The second type of research collaborative has a wider remit which might include research capacity building and service user involvement, in addition to high quality research outputs.

**Results:** The presentation will draw upon lessons learnt via these two types of research collaboratives. Specific focus will be directed to the United Kingdom's National Cancer Research Institute funded Cancer Experiences Collaborative project which was a five year initiative designed to increase the quality and quantity of supportive and palliative care research, and to increase the capacity of researchers.

This will be contrasted with the European Commission funded ATOME (Access to Opioid Medication in Europe) project which is designed to support 12 countries in Central and Eastern Europe to have better balance in medication policy and access. Analysis of the resources, structures, processes and outcomes of these projects will be discussed. There have been some key challenges in developing research collaboratives such as: sustainable capacity building, leadership, engagement of service users, track record of key players and mentorship.

**Conclusions:** This presentation will outline the processes used within the development of research collaboratives and provide evidence of the factors that determine sustainability, and provide further debate on considerations of key criteria that predict positive outcomes.

**Abstract number:** PS 17.3  
**Abstract type:** Parallel Symposium

### Models of Mentorship and Educational Networks for Palliative Care

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Modern society is changing in terms of social, cultural and economic features. Europe is developing novel forms of political and health care systems. Palliative care is a relatively young health specialty, in rapid growth, with a solid and well established philosophy at its roots, and with new landscapes to explore. Future palliative care leaders need to be prepared to face the challenges of this new liquid modernity. An important question concerns the role of educators and education in this capacity development. Careful succession planning is a critical step, which includes the identification of priorities, visioning and transparency as key elements. For education mentorship to be effective and tailored it needs international networking and peer support. As such it is advisable that a formal academic setting should be paired with informal settings where students can meet and share experiences. Central to this is the development of a close collaboration between universities, research institutes and management schools, in order to provide the skills and competencies needed to accomplish future leadership roles. Learning methods, such as e-learning and new technologies, should be used to enable blended learning together with traditional techniques. The need for exposure to interprofessional learning has been highlighted as something that can enhance both learning and mutual recognition of roles within the multi-disciplinary team. In conclusion stakeholders should recognize, prioritize and respond to emerging educational needs. Educational

networks should provide leaders with the competencies which enable them to bring palliative care of excellent quality, and which is visible and accessible within the complex European panorama.

**Abstract number:** PS 17.4  
**Abstract type:** Parallel Symposium

### Developing Collaboration for Palliative Care: Experience and Challenges

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## Paediatrics II

**Abstract number:** PS 18.1  
**Abstract type:** Parallel Symposium

### EAPC Taskforces in Paediatric Palliative care and European Steering Committee for Palliative Care in Children

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In 2006, an international group of 18 paediatric palliative care experts and representatives from the Maruzza Lefebvre D'Ovidio Foundation (Maruzza Foundation), the Livia Benini Foundation and the 'No Pain for Children' Association, met in Trento, Italy to examine strategies and best practices for the care of children with incurable conditions. The outcome of the Trento meeting was the publication of a united document; the "IMPACT Charter", which defines and identifies standards of care for children with life-limiting and terminal illness. The initiative was acknowledged by the EAPC and, consequently, the EAPC Taskforce - Palliative Care in Children was established.

The second publication resulting from the work of this Task Force; "Palliative Care for Infants, Children and Young People: The Facts", translated into several different languages, has become a reference document for professionals working for the improvement and reorganization of palliative care practices for children in many parts of the world.

Subsequently, in 2010, the Task Force was broadened to encompass members from a wider geographical, professional and operational scope. The European Steering Committee for Palliative Care in Children was created and two key areas of Interest were identified for the formation of two new EAPC Task Forces;

- The EAPC Task Force for the mapping of palliative care services for children and adolescents in Europe, in collaboration with the International Observatory on End of Life Care, is gathering information regarding the provision of Palliative Care for Children and Young People throughout Europe.
- The EAPC Task Force for the formulation of standardized

curricula for medical staff working in Paediatric Palliative Care is working to define core curricula for healthcare professionals working in paediatric palliative care.

The Maruzza Foundation provides essential funding and logistic coordination for the Steering Committee and Task Forces' activities.

**Abstract number:** PS 18.2  
**Abstract type:** Parallel Symposium

### An Educational Programme for Paediatric Palliative Care

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Education is an essential component of the development of children's palliative care, and it is important that education programmes which are 'fit for purpose' are available and accessible for all those who need it. This session will discuss the development of a strategy for education for children's palliative care, identifying first the training needs for children's palliative care in order to help shape future training programmes on children's palliative care, and an outline of the some of the training programmes available across Europe and a comparison with need. The WHO 2-stage approach for providing education programmes will be discussed and the challenges that exist in providing children's palliative care training.

There are a variety of types of training programmes available on children's palliative care, some more accessible than others, and some which impact not just knowledge but also the skills and attitudes necessary for children's palliative care. Examples will be discussed utilizing work from the EAPC children's palliative care task force along with the programmes developed through the International Children's Palliative Care Network. Key components of an education programme/ strategy for children's palliative care will be identified and discussed and the implications of this for us in practice.

In order to improve the quality of palliative care provision for children, it is important that there are educational initiatives that are both available and accessible to those who need it, as well as fit for practice, addressing both skills and attitudes as well as knowledge. A comprehensive education programme needs to address education for different cadres working at the different levels of service delivery such that children in need can access palliative care in the place that they need it.

**Abstract number:** PS 18.3  
**Abstract type:** Parallel Symposium

### Managing Differences - the Influence of Culture in Palliative Care for Children

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The holistic nature of palliative care for children and families involves accepting the family as part of their own culture, and the cultural environment in which they are cared for. With the changing nature of society, the team around the child may consist of many different cultures and cultural beliefs, some of which may conflict with the families own norms and beliefs. Respect for the differences includes knowledge of the different cultures, differences in understanding and differences in approach. Communication can be complex when members of the family and team do not speak the same language as their first language. Within the cultural complexities, the child may have his or her own "culture", language and beliefs. These differences can be seen as a difficulty, a challenge or an opportunity for shared growth and understanding. The role of anthropologists and sociologists is seldom recognised in most countries. However, there is within paediatric palliative care, an understanding of the important role these professionals can play as part of the multi-disciplinary team.

## Dementia

**Abstract number:** PS 19.1

**Abstract type:** Parallel Symposium

### White Paper on Palliative Care in Dementia

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Dementia is an incurable, life-limiting disease. Patients and families may have specific palliative care needs. The European Association for Palliative Care (EAPC) presents a white paper that defines optimal palliative care in dementia.

Using a five-round Delphi study (2011-2012), first, a core group of twelve experts from six countries drafted a set of eleven core domains with 57 salient recommendations for each domain, based upon literature and clinical experience. Sixty-four experts (72% response rate) from 23 countries evaluated these in a two-round online survey with feedback. The fourth round involved decisions by the core team, and the fifth, input from the EAPC. According to pre-defined, stringent criteria, there was immediate and full consensus on the following eight domains including the recommendations: Person-centred care, communication, and shared decision making; Optimal treatment of symptoms and providing comfort (these two identified as central to care and research); Setting care goals and advance planning; Continuity of care; Psychosocial and spiritual support; Family care and involvement; Education of the health care team; and Societal and ethical issues. After revision, full consensus was additionally reached for Prognostication and timely recognition of dying. Recommendations on nutrition and dehydration (Avoiding overly aggressive, burdensome, or futile treatment) and on dementia stages in relation to care goals (Applicability of palliative care) achieved moderate consensus.

The EAPC provides the first comprehensive definition of palliative care in dementia based on evidence and consensus, which may provide guidance for clinical practice, policy and research.

**Abstract number:** PS 19.2

**Abstract type:** Parallel Symposium

### Pain, Stress, Anticipation, and Immobilization in Patients with a Cognitive Impairment

*Scherder E.J.*

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Although there is ample evidence for a close relationship between stress and pain, this relationship has received relatively little attention in patients suffering from a neurodegenerative disease. Most literature concerns stress in caregivers of dementia patients which in itself is undoubtedly most important. The finding that the relationship between stress and pain in patients with a neurodegenerative disease has much less been addressed, is the more remarkable for several reasons. In the first place, patient's awareness of a progressive decline in cognitive functions may be most stressful. In the second place, neuropathology characteristic for the various subtypes of dementia may affect brain areas/neuronal circuits that play a crucial role in stress regulation. Thirdly, the same or related neuropathology may alter the processing of the various aspects of pain such as the motivational/affective aspects of pain, memory for pain, autonomic responses to pain, and the sensory-discriminative aspects of pain. In the fourth place, being able to anticipate upcoming pain may reduce stress; unfortunately, brain regions that are involved in pain anticipation may be damaged in specific subtypes of dementia. Finally, inactivation/immobilization as a reaction to agitation/ restlessness may increase already existing pain/discomfort, further increasing agitated behavior, thus creating a vicious circle.

**Abstract number:** PS 19.3

**Abstract type:** Parallel Symposium

### Communication in Dementia

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The population of people with dementia (PWD) is rising throughout the world and providing them the opportunity to live with quality in their lives during the duration of their disease is a challenge for family caregivers and healthcare professionals. In each stage of a demencing illness positive communication is paramount to the PWD's quality of life.

Therefore, we must understand how to successfully communicate using appropriate verbal and non-verbal techniques. This includes an awareness of how the environment may hinder communication if there are too many distractions that disrupt the ability to pay attention. The care partner's must insure they have the PWD's attention before they begin to communicate with them and make sure their words match their non-verbal communication. In the early stage, people with mild memory loss may still be able to understand simple commands both verbal and written. In the moderate stage, PWD may be living in a different reality and the person communicating with them needs to "join their journey" rather than try to use a reality based approach. When the person with dementia enters the severe stage of a demencing illness, touch is the most effective way of communication. Not only is it important for care partners to successfully communicate to a person with dementia; they must also be able to receive communication from them. This lecture will explore how to learn the "language" of dementia. Assessment of pain and discomfort is vital to helping people with dementia live a comfortable existence. Many scales have been developed for people in the early stages of dementia and the PAINAD Scale is successful in assessing pain and discomfort in people with severe dementia. Although we do not have a cure for dementia and no way to successfully slow down its progression, we do know how communicate with PWD's and help them have moments of joy.

## Outcome Assessment in Palliative Care

**Abstract number:** PS 20.1

**Abstract type:** Parallel Symposium

### Electronic Assessment: Pros and Cons

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Reports have emphasized the benefits of replacing the traditional paper and pencil based questionnaires or registration forms with electronic assessment tools in clinical work and research. This presentation focuses on three aspects in relation to palliative care cancer patients; 1) electronic self-report tools for symptom assessment by patients; types and content, 2) applicable user-friendly platforms for patient self-report, and 3) how the outcomes can be implemented in clinics.

1) Many symptom assessment tools have been adapted for electronic use, e.g. EORTC QLQ-C30, ESAS and different versions of pain body maps. Rapid presentation of results may improve the doctor-patient communication, facilitate symptom assessment in patients not in physical proximity of the care team, and reduce respondent burden by skipping irrelevant questions. 2) Several common devices can be used with a high degree of user-friendliness; computers, cell phones, and tablets. This enables self-report at or between clinical visits by phone or web, saving time and efforts. 3) Immediate presentation of results in the medical chart may enhance clinical care by flagging high symptom scores. Medical decision support systems and treatment guidelines may be automatically incorporated, based on pre-programmed algorithms for scores and clinical signs.

The enthusiasm for rapid results must be viewed against the fact that introducing new technology implies costs; money, training time, and education and relies on the buy-in from stakeholders. Palliative care patients also have specific needs regarding usability, and must be engaged in the development process. Poor compatibility and ethical restraints may hinder direct transfer to patient records, and may limit the usefulness in clinical settings, less so in research. Also, the content of an electronic tool is never better than the input, it should facilitate, not replace the clinical consultation and should always be part of a dynamic development process.

**Abstract number:** PS 20.2

**Abstract type:** Parallel Symposium

### Assessing the Quality of Palliative Care Using a Quality Indicator Set

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**Aims:** Evaluation of quality of palliative care is an important condition to optimize and improve care. Following a scientifically rigorous method we developed a comprehensive quality indicator set and tested the face-validity, feasibility, and usefulness of the set across different

palliative care (PC) services.

**Methods:** The set was developed in 4 phases, including an extensive literature review, two rounds of scoring to develop the indicator set, and a phase in which the set was tested and evaluated in palliative practice for face-validity, feasibility, and usefulness. Within 9 specialist PC services in Belgium, living patients under care and deceased patients (1.5-6 months ago) were cross-sectionally selected. Questionnaires were distributed to all living patients and their most involved palliative caregiver, and to a close family member and the treating physician of the deceased patients.

All quality indicators were calculated and fed back to the participating services after which interviews were held to evaluate face-validity, feasibility, and usefulness.

**Results:** We received a total of 414 questionnaires. Response rates ranged from 53% for patients to 91% for palliative caregivers.

We could successfully measure several process indicators (eg assessment of anxiety [82%]; care planning meeting with family [92%]) and outcome measures (eg improvement of pain after treatment [78%], family received bereavement support [51%]).

Face-validity and usefulness of most indicators was high. Some indicators had an extremely skewed distribution or a high percentage of missing values resulting in an advice to modify the indicator. The procedure was evaluated as feasible.

**Conclusion:** Our 4 phased indicator development resulted in a set applicable to all patients in all PC services, including patient and next-of-kin perspectives, and covering outcome, process, and structure indicators. Our study indicated that using such a quality indicator set in palliative care is feasible and accepted.

**Abstract number:** PS 20.3

**Abstract type:** Parallel Symposium

### The EAPC White Paper on Outcome Measurement

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The EAPC Taskforce on Outcome Measurement in Palliative Care is working on a White Paper to provide guidance on outcome measurement in clinical practice and research in order to attain excellent quality of care for patients and their caregivers and to advance palliative care. It is written for healthcare professionals, managers, professional bodies, researchers, educators and opinion leaders in Europe. The paper offers guidance to all services regardless of the setting it is being provided in (e.g., community, hospice, hospital), the country in which it is being delivered and regardless of the model of care being used. The paper consists of ten recommendations and concludes with guidance on establishing national outcome measurement programmes to aid benchmarking of services and special considerations regarding outcome measurement in low-to-middle income countries.

Recommendations cover the use of locally validated and multi-dimensional patient-reported outcome measures (PROMs) that capture the holistic nature of palliative care and those that allow for proxy reports; the use of measures that cover the needs of family carers alongside the needs of patients; the use of measures with sound psychometric properties with culturally sensitive and validated translations that allow for comparisons across care settings and throughout Europe; the use of measures that are suited to the clinical task and suited to clinical work; the use of change management principles, facilitation and communication to help embed outcome measurement into routine clinical practice; to establish and use quality improvement systems to help sustain routine outcome measurement; to relate outcome measurement to quality indicators and to advance the field of palliative and end of life care through establishing national and international collaborations including benchmarking.

## Access Issues / Access to Care

**Abstract number:** PS 21.1

**Abstract type:** Parallel Symposium

### Disadvantaged Groups in the Access to Palliative Care

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Equity of access means that people of equal need should have the same access to care. The level of care should depend only on patients' level of need and not on factors

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irrelevant to that need. This presentation will in particular focus on patients with non-cancer diagnoses, older patients, patients with lower socioeconomic status and ethnic minorities who appear to be disadvantaged in their access to palliative care. It will present evidence that differential access is unlikely to be due to differences in need and consider alternative factors that may help explain patterns. These include difficulty in establishing prognosis, differences in care giving context, communication with professionals and acknowledgement of dying, existing resources, knowledge of services and expectations. Finally, potential solutions to inequity in access will be considered.

**Abstract number:** PS 21.2  
**Abstract type:** Parallel Symposium

### Rural Perspectives in Palliative Care - How Do We Deliver Care in Sparsely Populated Areas?

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Countries that were under Communism previous to 1989, located in Eastern Europe (EE), have social systems that are considered rudimentary, with economical backgrounds mainly based on agriculture. This rural perspective creates a need to find ways of delivering good Palliative Care (PC) to the underserved population and overcome challenges like: poverty, migration of young generations to urban areas or abroad, low availability of trained medical staff willing to serve these communities, difficult access to medical facilities and drugs, underdeveloped infrastructure, etc. The focus of this presentation is on the existing situation in 4 different EE countries, where there are PC initiatives to serve few rural regions: **Moldova** - 58% rural population, Hospice "Carolina de Nord" inpatient unit and home care team in Zubresti, Strasenii county; **Romania** - 45,8% rural population, Hospice "Casa Sperantei" home care teams in Zarnesti and Fagaras, Brasov county; **Armenia** - 36,1% rural population, investment on training of physicians and nurses on prescribing and administering Methadone in Ararat and Vanadzor; **Ukraine** - 32% rural population, initiative on developing the nurse's role, by empowering them to implement autonomous interventions in end-of-life situations. As the lecturer had the chance and privilege to witness and support, throughout education (both theoretical and clinical), the way care is delivered in the Region the personal input and experience gives the presentation a particular testimonial flavor, in support of the efforts that local services and teams are making.

**Abstract number:** PS 21.3  
**Abstract type:** Parallel Symposium

### Social Diversity in Palliative Care: Ways Forward for a Rising Challenge

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It has only been recently that palliative care has given attention to the importance of caring for increasingly diverse societies. Many are already multicultural and this is amplified by growing migration. Moreover, social disparities are increasing; the number of smaller families, women in full-employment out of home and older people living alone is rising. This socio-demographic shift widens the diversity of circumstances in the population including people in need of palliative care. This means that although general patterns, preferences, priorities for palliative care persist, there is greater heterogeneity and minority groups with different needs/experiences/preferences. Professionals are required to ensure both equity and quality care for all. There is therefore a major need for evidence on social diversity in palliative care and ways of addressing this in the future.

This presentation examines different facets of the issue, drawing on a growing body of evidence in Europe and beyond to: 1) discuss variations in access and outcomes of palliative care likely to reflect inequity, 2) identify key social factors posing challenges while caring for patients with advanced illness and families, 3) learn from recent initiatives and care models tailored to respect diversity and address needs/preferences of people living in harder social conditions. Clinical, policy and research actions needed to more closely reflect the increasing diversity in social circumstances of patients and families in need of palliative care will be discussed.

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## EAPC Atome Session Title: Regulatory Barriers in Palliative Care Opioid Treatment

**Abstract number:** PS 22.1  
**Abstract type:** Parallel Symposium

### The ATOME Project: Improving Access to Opioid Medication in Central and Eastern Europe

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The Access to Opioid Medication in Europe (ATOME) project commenced in December 2009, funded by the European Commission's 7th Framework Programme over five years. The objective is to improve access to opioids in 12 European countries (atome-project.eu/) in order to ensure accessibility, availability, and affordability for all patients requiring treatment with opioid medicines. To accomplish its objectives, the ATOME project follows two tracks of activities in parallel.

One track is related to the analysis of national policies and circumstances that affect the accessibility and availability of opioids, such as a lack of education for health-care professionals, as well as myths and misconceptions about opioids among policy makers, health-care professionals and in the general public. The goals are both to make recommendations to the government and to make health-care professionals aware of problems arising from their professional practice related to the use of opioids.

The other track aims at optimising the relevant legislation in order to acknowledge both the prevention of abuse and dependence and the medical need for these medicines. The goal is to identify legal provisions that may impede access to controlled medicines and make recommendations for improvement in consultation with the national counterparts.

To raise awareness on a larger scale and increase the likelihood of change, the outcomes of the national policy and legislation analysis are disseminated to a wider audience of relevant policy makers, stakeholders, and health-care professionals during national one-day conferences in each of the 12 countries.

Close collaboration with country teams in the European countries shall ensure that recommendations for legislative and policy changes made within the ATOME project will be validated and their applicability to the country-specific situation will be verified. The final recommendations will be handed over to the Ministries of Health of the 12 countries in 2014.

**Abstract number:** PS 22.2  
**Abstract type:** Parallel Symposium

### Regulatory Barriers in Practice

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**Background:** Many factors contribute to limited access to opioid medicines for medical purposes, including legislation and policies. The 'Access To Opioid Medicines in Europe (ATOME)' is undertaking a situational analysis in European countries. Legislation regulating opioid medicines is reviewed to identify potential barriers to access and make recommendations for improvement.

**Aims:** To identify potential legal barriers that may impede access to opioid medication in practice in 11 Southern and Eastern European countries.

**Methods:** A template was developed as the 'ATOME legislation review method' focusing on 9 different categories of barriers. Relevant national legislation was collected in consultation with national counterparts in the target countries. Selected provisions were independently reviewed by three reviewers. Different views were discussed until consensus was reached.

**Results:** All countries showed potential barriers in their legislation that pertained to prescribing, dispensing and language (most frequent barriers). In addition, all 11 countries showed potential barriers in several other categories (manufacturing, usage, trade and distribution, affordability, penalties and other). Examples of potential barriers are overly strict administrative requirements (prescribing and dispensing), limited validity of prescriptions (prescribing), restrictions regarding the maximum daily dosage or the duration of the treatment period (prescribing), and the use of stigmatizing terminology, unclear language or the incorrect use of definitions (language).

**Conclusion:** Potential legal barriers can be identified using the 'ATOME legislation review method'. Commonalities in the eleven countries include the areas of prescribing, dispensing

and language as main potential barriers. Although the identified potential barriers could lead to limited access, additional research is needed to assess the actual impact of these potential barriers on accessing opioid medicines in practice.

**Abstract number:** PS 22.3  
**Abstract type:** Parallel Symposium

### Differences between Countries and Cultures

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**Aims:** The object of this session is to address gaps in knowledge about the nature of palliative care services provided to adults by hospices, specialist palliative care services and other health care organisations in Europe. Specifically, the aims include a critical analysis of how health care differences are described in international comparative analyses and the extent to which cultures of care and social norms are assessed and recognised.

**Method:** Drawing upon data from 'Country Reports' prepared by the International Observatory on End of Life Care and experiences gained during the ATOME project. The ATOME project involves senior people working together in 'Country teams' which are based in 12 Central and Eastern European countries with the aim of addressing barriers to opioid medication access in their countries. Data were collected using: documentary analysis, questionnaires, national and international participative workshops.

**Results:** The majority of respondents were from nine countries. They attributed differences to a number of causes: the legacy of European history, especially communism, the availability of resources, especially recent economic pressures on the euro and recession, the acceptance of dying and open disclosure of cancer, concerns about opioid medication use, especially addiction and tolerance in the public and professionals.

**Conclusions:** Many of these countries appear to share common features which act as barriers to access to pain medication and the development of palliative care. Moreover, there is a tension between aspirations to promote 'excellence' in palliative care based on models developed in Western European countries, and the need for sustainable, affordable and culturally appropriate care which values cultural aspects inherent in each country.

## From Budapest to Prague - From Commitments to Rights

**Abstract number:** PS 23.1  
**Abstract type:** Parallel Symposium

### Charter for the Care of the Critically Ill and the Dying in Germany

Link J.

German Association for Palliative Medicine (DGP), German Hospice and Palliative Care Association (DHPV), German Medical Association (BÄK), Berlin, Germany

In September 2010, the Charter for the Care of the Critically Ill and the Dying in Germany was officially launched in Berlin.

This national project is Germany's contribution to the Budapest Commitments, an international framework for palliative care development.

Since its launch, more than 600 organisations and 1800 individuals have signed up to the charter. Furthermore, in over 40 so-called "Charter projects", the charter principles are being implemented. Furthermore, a national strategy based on the charter will be developed.

The responsible bodies are the German Association for Palliative Medicine (DGP), the German Hospice and Palliative Care Association (DHPV) and the German Medical Association (BÄK).

The charter comprises the following five key principles:

#### 1 Socio-political challenges

##### • Ethics, the law and public debate

Every human being has a right to a dignified death. It must be ensured that they will be respected in the last phase of life with regard to their preferences, wishes and values.

#### 2 Needs of patients and families / organisation of care

All critically ill and dying people have a right to comprehensive medical, nursing, psychosocial and spiritual care that takes into account their individual situation and palliative/hospice care needs.

#### 3 Training and education requirements of professionals

All critically ill and dying people have a right to appropriate, qualified and, if required, multi-professional care.

#### 4 Future development and research

All critically ill and dying people have a right to care based

on best practice. To ensure this, new knowledge derived from research and practice must be shared and integrated into clinical routine, provided ethical and legal regulations are respected.

#### 5 European and international dimension

All critically ill and dying people have a right to benefit from care that takes into account internationally recognised and adopted recommendations and standards regarding the delivery of palliative care.

Abstract number: PS 23.2

Abstract type: Parallel Symposium

#### Rolling out a Palliative Care Program in Spain

*Gomez-Batiste X.*

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The developments of palliative care in Spain will be described, with a qualitative and quantitative analysis, and describing the new challenges and Programs currently developed: the NECPAL Program, the Chair of Palliative Care, Regional perspectives, etc.

Abstract number: PS 23.3

Abstract type: Parallel Symposium

#### National Standards for Palliative Care in Croatia

*Mardetko R.*

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Croatia is a country without an organised palliative care service at the national level.

The health system is under increasing pressure and patients and their families do not receive the help and support they need. As a result the end of life care is less than satisfactory for the whole population.

Although the need for palliative care has been supported by several legal documents the government has not significantly contributed to the service developments over the past. However, care has been provided by many enthusiastic individuals across Croatia.

In the last few years more interest among general public and local government has induced progress in institutional form of care.

The City of Zagreb has formed a Centre for Coordination of Palliative Care in Zagreb which coordinates professionals and volunteers that provide palliative care and collaborates with local health, social and spiritual service providers.

In Zagreb there have been developments in palliative care education through national programs within CEPAMET, a centre for education in palliative care at The University of Medicine in Zagreb. The University has held palliative care modules for English medical students for the last ten years.

Other areas have developed localised palliative care services such as a multidisciplinary mobile team in Istria, a day centre and a clinic within the hospital in Koprivnica, charities in Čakovec and Osijek and institutions for palliative care established by Catholic Church in Strmac and Rijeka.

All this initiatives have contributed to the National Strategy that has been in the process of developing by The Ministry of Health. The aim of the strategy is to create a framework of standards in palliative care, provide a guideline for service development and encourage collaboration between different services and levels of care. In this way palliative care in Croatia could be based on a national policy, but developed within each local community according to their own particular needs.

Abstract number: PS 23.4

Abstract type: Parallel Symposium

#### From the Budapest Commitments to the Prague Charter

*Schmidlin E.R.*

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This brief presentation will cover the world wide campaign, the "Budapest Commitments," which were launched at the EAPC Budapest Congress in June 2007 as a collaboration between the EAPC, the International Association for Hospice and Palliative Care (IAHPC) and the World Palliative Care Alliance (WPCA). The Budapest commitments provide a framework of effective strategies for individuals and national palliative care organizations to develop specific areas of palliative care within their countries. In the past six years, this structure has been used to develop many interesting projects within the realms of policy, education, quality improvement, and research. The Budapest commitments

provide useful methods for planning and initiating change, and can serve as an inspiration for organizations around the globe for the development of palliative care. The framework will continue to be valuable for the newly launched "Prague Charter," an initiative that aims to raise awareness of palliative care as a human right. At the end of the presentation, there will be time for discussion.

## Palliative Care - Part of the Main or Specialized Discipline?

Abstract number: PS 24.2

Abstract type: Parallel Symposium

### Pro General Approach: Palliative Care for All Means by All

*Murray S.A.*

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Around 80% of people die after a progressive illness and thus can benefit from palliative care. However most people in Europe fail to access such care from palliative care specialists as there are not enough of such specialist doctors and nurses to see all the patients in need. The most important challenge facing palliative care in the next decade is to make it equitably available to all according to need, and there is only one practical way of delivering this. The only way for palliative care to reach the vast majority of people in need is for it to be delivered by generalist nurses and doctors working in all settings: hospitals, general practice, nursing homes. These generalists are in a position to identify people for early palliative care, and then provide generic palliative care. In other words, they can assess physical, social, psychological and existential dimensions of need, and then provide pro-active care to the patient and carer. Where they need assistance or in complex cases patients can then be referred to specialist palliative care. In summary, if palliative care is integrated into mainstream medicine, especially into care of people with long-term conditions, it can:

- Reach patients with all life-threatening illnesses
  - Start early in the course of life-threatening disease
  - Meet all dimensions of need: physical, social, psychological and spiritual
  - Provide care in clinics, care homes and at home thus preventing unnecessary hospital admissions
  - Support family carers and provide bereavement care
- In the case that I will put forward I will indicate how this approach is actually carried out in some countries, and how it can be progressed throughout Europe and internationally.

Abstract number: PS 24.3

Abstract type: Parallel Symposium

### The Specialist or Generalist - Data from the EAPC Taskforce on Development

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Integrative Palliative Care (PC) is a new paradigm for all professionals working in palliative services around Europe. Today, best practices, new consolidated experiences and new evidence support a new model where palliative medicine specialists has to play in key role that demand communication skills and the decision of work in a bigger team with other specialist and primary care professionals.

The EAPC Task Force on the development has explored the situation of the official certification in 53 countries and have collected the most updated information regarding pathways of specialization in Europe. A questionnaire was designed to explore the situation in each country including official certification name or title, year of approval, process of certification, number of physicians certified to date, etc. Qualitative analysis of answers was undertaken with categorization in three groups. The questionnaire was part of the EAPC Facts Questionnaire (FQ) which was completed by a 'key person' in 47/53 European countries; the information from the FQ is incorporated within the Second Edition of the EAPC Atlas of PC in Europe.

Our results show that there are several countries where PM is officially certified: UK, Ireland, Poland, Romania, Germany, Malta, Latvia, Czech Republic, Norway, France, Finland; in Italy a "Master Universitario" as official certification is legally regulated. 8 countries with certification 'in process' also were identified: Austria ("Diploma in Special PM"), Denmark ("Field of competence"), Spain ("Specific Capacitation Area"), and Hungary, Iceland, Slovenia, Sweden and Switzerland (sub-specialization).

Further comparative analysis is required to examine the process of PC accreditation and the meaning attributed to such 'specialization' within professional practice. We

continuing working in the field through a dedicated Task Force with a membership of a physician per country where is already certificated PC.

## Nutrition in Palliative Care

Abstract number: PS 25.1

Abstract type: Parallel Symposium

### EN and PN: Practical Recommendations in Advanced Cancer

*Arends J.*

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In addition to supplying energy and nutrients, eating and drinking may alleviate hunger and thirst; they may be associated with joy and pleasure or with nausea and pain. Food intake has emotional and social impact and affects the awareness of self-control. These aspects need to be considered when dealing with nutritional problems in cancer patients. Enabling normal food intake should receive high priority.

If nutritional intake in a patient is insufficient it needs to be considered whether this impacts on his/her quality of life and/or on the course of the disease and possibly the expected overall survival. This impact will be small or irrelevant if nutritional intake is close to normal and if the patient's expected survival is severely limited; the impact will be large if energy intake is close to zero and the expected disease-associated survival is long.

The following problems need to be discussed and assessed with the patients and their families: the effects of not using artificial nutrition; the potential benefits of providing artificial nutrition; the burden of undergoing artificial nutrition; the importance of including physical activity in the treatment plan; the importance of considering and if necessary modulating metabolic derangements which interfere with nutritional benefits.

Abstract number: PS 25.2

Abstract type: Parallel Symposium

### Complex Interventions to Prevent or Treat Cancer Cachexia

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Cancer cachexia is a multifactorial syndrome characterized by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support, and leads to progressive functional impairment. The condition is accompanied by increased mortality and morbidity. The clinical consequences of cachexia are now well established, but there has been little progress in treatment strategies. Several different agents with different acting points have been tested in different trials, all with minor results. The last years there have been several calls for the need of multimodal strategies in cancer cachexia. Multimodal treatment strategies have proven necessary in several diseases. As an example was the treatment of heart failure only symptomatic with no possibility of improving the meager mortality rates until the late 80's. During the last thirty years there have been major improvements partly due to increased knowledge on heart failure pathophysiology and accompanying strategies in order to tackle the diverse nature of this. Morbidity and mortality has plunged as the accumulative effect of the different agents has become evident.

The treatment of cancer cachexia is only in its infancy with merely are a very few symptomatic treatment alternatives are available such as corticosteroids and megestrol acetate. Unfortunately are these drugs accompanied by serious adverse events, which make them unsuitable for long term use. The pathophysiology of cachexia is now gradually unraveled and thus the possibilities of developing more targeted treatment strategies.

There is a need for randomized controlled trials that fully incorporate a structured exercise program, nutrition, good symptom treatment as well as drug treatment to counteract the effects of altered metabolism. In cachexia it seems likely that the full advantage of any drug intervention only will be reached if it is integrated it into multimodal treatment.

**Abstract number:** PS 25.3  
**Abstract type:** Parallel Symposium

## Social and Cultural Dimension of Food and Eating

*Schmidlin E.R.*  
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The meaning and importance of flavourful food and a shared meal cannot be underestimated. Through the course of an incurable illness, the fulfilment of these fundamental needs is challenged, profoundly affecting both the person and the carers. Research has shown that appetite and the ability to eat are both very important physical aspects in a patient's quality of life. But eating - or the inability to do so - is loaded with social and existential meaning.

Eating signifies being alive and living on. Not being able to eat or refusing to eat due to an advanced illness can be seen as giving up the fight, abandonment and failure. Such feelings may lead to existential distress for the person concerned and - often even more so - for their carers. Not uncommonly, it can also lead to inappropriate and futile interventions.

In this presentation, the social and cultural dimensions of food and eating will be explored. Film sequences and patient stories will highlight the complexity of this topic and point to a variety of holistic interventions which may help the patient and their loved ones to cope with cachexia-related suffering.

## End of Life Preparation - Health Literacy in the Community

**Abstract number:** PS 26.1  
**Abstract type:** Parallel Symposium

### End of Life Preparation - A Genuine Task for the Community

*Eychmüller S.*  
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During the last two decades considerable progress has been made in communities in the field of professional palliative care in various countries. However, such development has rarely been based on proper general needs assessment of the broad public. Needs of communities may reflect the population's perspective of end-of life problems and challenges, and may differ from a professional view.

There has been recent effort to reconnect to the community as a nucleus providing framework and concrete support for those who will die within the next months. Models from India and Australia highlight underused resources - structural, intellectual, emotional and even financial - we can find within communities. Findings from these models provide encouraging guidance how to create attention and concrete structure for community based palliative care and end of life preparation.

Experience from various industrialized countries, however, shows several challenges while setting up community end of life preparation and volunteer services: uneasiness of political community leaders to engage in this topic, hesitation of school directors to integrate dying and death into curricula, inability to find sustainable financing for ongoing information and volunteer support, and reluctance of concerned families to finally accept help and support.

Political and societal framework, educational strategies and concrete steps how to enable communities to become supporter for end of life preparation will be discussed.

**Abstract number:** PS 26.2  
**Abstract type:** Parallel Symposium

### The Hospice Movement as Catalyst for Developing End-Of-Life Literacy - Results from an Oral History Project

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While the development of the hospice idea can be traced back to one person, namely Cicely Saunders in the UK, the German history of hospice and palliative care shows multiple roots. The first initiatives date back to the 1980's and it was not until the late 1990's that hospice and palliative care started to spread out nationwide. How can this delay in time be explained?

An oral history project was done to better understand the specific development of hospice and palliative care in

Germany (IFF, University of Klagenfurt). The sample consisted of 73 oral history interviews with pioneers of the hospice movement, representing broad variety of initiatives and movements in various countries and regions.

Results show that in Germany the hospice movement can be characterized mainly as a "social movement". People engaged themselves because they were fascinated by the idea of dealing with the dying in a human way, giving a voice to the dying and their families following a holistic approach. Christian foundations did play a role for many people, though first initiatives were strongly opposed by the official church. Voluntary hospice services, free standing hospices or various courses for health professionals and lay persons were developed within these grass-root initiatives. These had a major impact on the society as a whole: The hospice movement raised the issue of dying, death and bereavement in Germany and offered a language to verbalize feelings after years of silence as an aftermath of the 2<sup>nd</sup> world war and the crimes of the Nazis.

The global concept of palliative care as it has developed in Germany under the term "palliative medicine" shows many commonalities with the hospice movement, indeed. In case of Germany a distinction between palliative care and the hospice movement is necessary to preserve the unique achievements of this civil movement for future development.

**Abstract number:** PS 26.3  
**Abstract type:** Parallel Symposium

### Parallel Symposium End of Life Preparation - Health Literacy in the Community

*Gomez-Batiste X.*  
*Catalan Institute of Oncology, Barcelona, Spain*

Identifying and improving the palliative care approach for persons with advanced chronic conditions and limited life prognosis in health at social services with a duration of 28 minutes including time for questions.

Describes the experience of the NECPAL Program, of implementation of a methodology to identify patients with advanced chronic conditions in the general population, including:

- Creation of a tool based in the GSF
- Determination of the prevalence in districts and settings
- Implementation of a comprehensive program of improving the quality of care for those patients in the region and in Spain
- Research and ethical debates associated to this project.

## Palliative Care as a Human Right

**Abstract number:** PS 27.1  
**Abstract type:** Parallel Symposium

### The Right to Palliative Care as a Human Right

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This presentation will describe the legal, ethical and moral basis for the recognition of palliative care as a human right; the advocacy initiatives by several organizations, the role of UN bodies and member states, and some of the strategies to continue advancing this effort.

The concept of the right to palliative care gained momentum in the late 1990's as a result of 4 factors: the interaction of 3 disciplines (palliative care, public health and human rights); the recognition of palliative care as clinical and academic discipline which coincided with the development of a public health approach to global and community health; the recognition of the care of the dying as a public health issue; and the accumulation of evidence which indicates that patients are not adequately treated.

Several palliative care and human rights organizations developed campaigns to remind member states of their obligations to ensure access to palliative care and to generate awareness among the civil society of the patients' rights to care, including the Joint Statement of Commitment for the Recognition of Palliative Care and Pain Treatment as Human Rights, and more recently, the Prague Charter.

The role of the World Health Organization, the International Narcotics Control Board, and the Human Rights Council as how they relate to this right will be discussed, particularly with respect to access to opioids for pain treatment.

Strategies for improvement include promoting palliative care as a fundamental human and legal right, framing palliative care as an ethical issue; providing constitutional guarantees and statutory regulations that span negligence law, criminal law, and elder abuse; categorizing failure to provide palliative care as professional misconduct, and issuing guidelines and standards of practice by professional

bodies. Failure to treat suffering should be viewed worldwide as poor health care, unethical medical practice, and a denial of a fundamental human right.

**Abstract number:** PS 27.2  
**Abstract type:** Parallel Symposium

### Palliative Care Policies in the National Governments and the European Institutions

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**Aims:** Approximately 5 million Europeans need palliative care (PC) every year. The objective of this presentation is to review the initiatives of European governments and institutions addressing this need.

**Methods:** Using primary data on 46 countries from the EAPC Atlas (2<sup>nd</sup> ed., 2012), the presentation will consist of an analysis of governmental barriers impeding the development of PC; a review of the main legislative initiatives adopted since 2006; and an examination of which countries currently have a national PC plan. We will also provide a qualitative analysis of the most important political and legal changes affecting PC development, according to professional leaders in each country. Finally, a systematic review of available information, including from scientific literature and EU and WHO websites, will be presented.

**Results and discussion:** Specific laws on PC exist in at least Belgium, France and Germany. Many other countries include the right to PC in their general health legislation (e.g., Spain, the Netherlands, Poland and the UK). In addition, 23 out of 46 countries have developed a national PC plan. Obstacles include problems related to national health policy; poor distribution of the health system budget, insufficient services, problems with organization and coordination affecting PC provision, geographical inequity in the distribution of services, limited access to existing services for patients, and lack of coverage by insurance companies. In November 2012, and within the framework of noncommunicable disease control, WHO approved as an indicator of access to PC the consumption of strong opioids (in equivalent dosage of morphine) for cancer deaths. **Conclusion:** The rising need for PC requires clear action from EU Member States and European institutions. The study of PC policies should be promoted in order to ensure accountability in an area which constitutes an ethical responsibility as well as a matter of health system efficacy and efficiency.

**Abstract number:** PS 27.3  
**Abstract type:** Parallel Symposium

### Changing the Legislation: An Example from Russia

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Palliative care in Russia had its origins in late 1980's with the emergence of the first pain clinics in Moscow, Saint-Petersburg and Rostov and the hospice movement led by Andrey Gnezdilov and later Vera Millionschikova. During all these years palliative care developed sporadically and mainly by the initiative of enthusiasts. In November 2011 Russia's president has ratified the New Health Bill "On the Basis of Health Care Provision in the Russian Federation". As well as making fundamental changes to the country's health care system in general, the bill in fact opens a new era for palliative care progress. For the first time in the national Health Care history it provides a definition of palliative care, it says "palliative care is a set of interventions aimed to relieve pain and other severe manifestations of the disease in order to improve the quality of life of incurable people" (Article 36). Palliative care in accordance with the law for the first time has been included in the list of medical care forms guaranteed by the government for the citizens (Article 32). The law says that palliative care "... can be provided by health professionals who have been trained to provide such care" (Article 36). Palliative care will be funded through the Program of the state guarantees of rendering free medical care to the citizens of the Russian Federation... (Article 80). Palliative care issues have been included in the Health Care Strategy of the Russian Federation to 2020. Recently the National Guidelines for palliative medical care delivering for adults in the Russian Federation has been approved. According to the Guidelines palliative medical care should be provided in both inpatient and outpatient units, and in specialized medical institutions, such as hospices, palliative care departments and clinics. Specialist palliative care centers will be established and physicians will have the opportunity to study specialist palliative care on a regular basis.



## EUROIMPACT: How to Be Successful as a Palliative Care Researcher within the European Research Area

Abstract number: PS 28.1  
Abstract type: Parallel Symposium

### Introductory Lecture on EUROIMPACT

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The European Intersectoral and Multi-disciplinary Palliative Care Research Training network -EUROIMPACT - is an EU funded Marie Curie Initial Training Network funded under the 7<sup>th</sup> Framework Programme (2010-2014) (FP7/2007-2013, under grant agreement nr [264697] [www.euro-impact.eu](http://www.euro-impact.eu)) coordinated by the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Belgium, in partnership with 5 other universities/research institutes from the Netherlands, the United Kingdom, Norway and Italy and several European umbrella organisations, all at the forefront of palliative research training and representing a wide spectrum of disciplines.

EUROIMPACT aims to develop a multi-disciplinary, multi-professional and intersectoral educational research framework in Europe aimed at monitoring and improving palliative care. The network currently trains 12 junior and 4 postdoctoral researchers from all over the world in becoming excellent palliative care researchers.

After a general introduction on EUROIMPACT by prof. Van den Block (coordinator of EUROIMPACT), prof. Payne (UK partner of EUROIMPACT) will discuss the importance of training and of developing research and complementary skills when mastering your PhD in palliative care. Prof. Deliëns (Scientific Director of EUROIMPACT) explains how to successfully build value on your resume as a postdoctoral researcher highlighting the importance of mobility in career development. Mrs. Jaspers from Yellow Research (company providing training and consultancy in the field of EU Framework Programmes) shares her insights in how to write competitive EU research proposals and Mrs Linden from Springer Media (publishing company) (partner of EUROIMPACT) focuses on publishing and dissemination as important features of becoming a successful palliative care researcher within the European research area.

Abstract number: PS 28.2  
Abstract type: Parallel Symposium

### Mastering Your Phd in Palliative Care: Research and Training Skills

Payne S.A.  
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**Aims:** This session examines the process of writing a research thesis and/or publications and getting a PhD. It is based on my experience of being a PhD supervisor to over 30 PhD candidates, both successful and unsuccessful at completing their research. PhDs are increasingly required to progress a career in academic education, senior leadership and in research. They are the foundation for a career and provide palliative care with essential evidence to build practice, policy and service development.

**Methods:** There are two main types of PhD; those that are produced as a monograph and those that are presented in the format of a number of journal publications. Both styles of PhD require a number of essential characteristics namely: originality, intellectual ownership, coherence and theoretical development. I will draw upon the experience of the EURO IMPACT project which aims to provide 12 early career research an opportunity to complete a PhD in the context of an international network.

**Results:** The process of undertaking the research that underpins a PhD will be examined, highlighting different routes that may be taken. I will offer suggestions on how to maximise the likelihood of your PhD application being successful at the outset. There will be a discussion about how to prepare a research proposal. The session will end with a reflection on the reality of seeking research funding and suggestions about coping with the trajectory of a PhD, and the high and lows of the journey. Attention will be given on how to select and 'manage' your supervisors (promoters). There will be discussion about the types of research training that should be considered to be an integral part of the PhD experience including, writing and presentation skills, data collection and analysis skills, networking, project and time management.

**Conclusions:** A PhD is an individual process of learning to

become a competent researcher and is facilitated by a network of supervision and support.

Abstract number: PS 28.3  
Abstract type: Parallel Symposium

### How to Successfully Build Value on Your Resume as a Postdoctoral Researcher (Incl the Importance of Mobility)

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As a PhD student in palliative care research, your training is focused on the skills needed to become an "independent" researcher. This implies that you have the skills to choose an appropriate research problem, develop it into good research questions, choose a suitable research design, draft an adequate protocol, obtain all required approvals, conduct the study, and report at good conferences and in good scientific journals. These skills should enable you to develop your own research in an independent way. However, if you want to become a senior researcher and leader in palliative care research, you need additional research training and managerial and dissemination skills. Having a PhD does not imply that you will not need supervision and guidance in your research, but that you have the skills to manage all you need to initiate new research and to know how to create the optimal environment for performing quality research. Successfully graduating and obtaining your PhD will open additional possibilities for developing your career in palliative care research, and further improving your research skills. Therefore, an advanced development and training plan is preferred. In this presentation we will address the question "How to successfully build value on your résumé as a postdoctoral researcher". Part of the answer is international mobility. In order to obtain a post doc position (e.g. at the Fund for Scientific Research in Flanders), as well as an excellent research plan, an excellent scientific CV and accompanying publications, you will need international mobility. Having experienced different research teams is prerequisite to becoming a qualified senior researcher. In this presentation we will also address the important performance indicators that are needed to establish a successful career as a postdoctoral researcher.

Abstract number: PS 28.4  
Abstract type: Parallel Symposium

### Horizon 2020 - Writing Competitive Proposals under a New Framework

Jaspers L.  
Yellow Research, Amsterdam, Netherlands

The new programme structure as proposed under Horizon 2020 deserves further exploration on how this impacts on the research field of palliative care. An important aspect is the influencing of the rolling agenda's through 3-year Strategic Programmes and 2-year Work Programmes in order to ensure calls for research topics at the core of the palliative care field. During the talk, an overview of the new framework structure will be provided with a strategy on how to become actively involved in influencing the agenda of the strategic agenda's as well as an overview on the main evaluation criteria for project selection.

Abstract number: PS 28.5  
Abstract type: Parallel Symposium

### Future Developments in Electronic Publishing

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The dissemination of scientific research is an integral component of the research process. Publishing and, as a consequence, dissemination of scientific results is changing rapidly.

#### Aims:

- Gaining insight in future developments in publishing and electronic publishing
- Gaining insight in the editorial process
- Dissemination of scientific results through the internet: what to expect?
- This presentation will contribute to a better understanding of the dos and the don'ts in publishing scientific research.

## Dyspnoea

Abstract number: PS 29.1  
Abstract type: Parallel Symposium

### Can Topical Opioids Improve Breathlessness and Cough in Patients with Chronic Lung Disease?

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Although morphine is frequently used for the treatment of cough and breathlessness, an unanswered question remains as to whether opioids act locally in the respiratory tract. This question is especially relevant in case of the patients with chronic lung pathology, like lung cancer, COPD or cystic fibrosis.

Recently the immunohistochemical visualisation of endogenous opioid network in the human respiratory tract revealed its presence in tracheal and bronchial epithelium, including pulmonary neuroendocrine cells (PNECs) and unmyelinated sensory nerves containing peptides. The cellular location of the opioid systems indicates their role in the neurohormonal regulation of local response of the bronchi and blood vessels, as well as the perception of "urge-to-cough" and dyspnoea. How to reach these opioid receptors to achieve the therapeutic effect? It can be hypothesized that, at least in case of hydrophilic opioids, these peripheral mechanisms are important to some extent after systemic administration. Intrabronchial opioid application should be more effective in utilization of peripheral opioid receptors in lung as a target for therapeutic effort. Only a few clinical trials have supported the role of nebulized opioids in cough and breathlessness. However, until now the target of the treatment has been unknown and in many cases the methods of drug administration not well chosen. It is likely that morphine delivery in breathlessness and cough should be rather directed to the tracheobronchial area, in the vicinity of its receptors located in PNECs and sensory C-fibres of the bronchial epithelium. What is more, morphine used in the specially designed pneumodosimetric method (BCTS-S) allowing its precise deposition in the bronchial tree, showed a unique pharmacokinetic profile suggesting local metabolism with preferential formation of morphine-6-glucuronide.

In this presentation where, how and why topical opioids should be used in dyspnoea and cough will be discussed.

Abstract number: PS 29.2  
Abstract type: Parallel Symposium

### Breathlessness, Outreach Services

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**Aims:** to introduce participants to different sorts of service models for breathless patients that reach out to patients in community or into institutions to help patients being treated as in-patients.

**Methods:** participants will be reminded of the practical difficulties in reaching patients with breathlessness and giving them optimum treatment as it is currently understood. The epidemiology of breathlessness will be outlined. The evidence base for outreach services will be reviewed and ways in which patients with breathlessness and advanced disease can be identified.

**Results:** possible structures and working models for outreach services will be suggested and the evidence base for them will be reviewed. Current best practice, the complex intervention of a combination of pharmacological and non-pharmacological interventions will be outlined. Assessing the outcome of outreach services will be examined.

**Conclusions:** There is now evidence that outreach services for breathless patients with cancer are evidence-based but need to fit the environment in which they are going to operate.

**Abstract number:** PS 29.3

**Abstract type:** Parallel Symposium

### **Treatment of Dyspnoea: What is the Evidence?**

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Breathlessness is a common and distressing symptom in advanced malignant and non-malignant disease, which is still challenging to manage. Reversible treatment options should be considered. For symptomatic management, non-pharmacological and pharmacological treatment options are available which should best be combined. To influence the perception of breathlessness and reduce anxiety, breathing therapy, self management, relaxation and pacing of daily life can be offered. There is evidence for the beneficial effect of rollators, hand held fans, and neuromuscular electrical stimulation.

Good evidence exists for oral and parenteral opioids.

Titrated against breathlessness, they are safe to use.

Average doses are normally lower than for pain

management but it is not clear whether any opioid is better

than the others. The evidence for benzodiazepines is less

clear and they only should be used as second line or in

combination with opioids. In non-hypoxic patients, oxygen

is not better than room air and the air draft can be produced by easier means such as a hand-held fan.

# Meet the expert sessions

Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us ... or Do they Need to Be Improved

Resilience in Palliative Care

How to Prevent and Treat Cancer Cachexia

The Development of Paediatric Palliative Care Services

The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe

How to Be a Better Reviewer

Spiritual Care

Palliative Care Support for Young People and their Families Provided through Schools and Colleges

Doing Palliative Care Research in Primary Care: Challenges and Opportunities

Action Research

Gender Issues in Palliative Care

Physiotherapy and Palliative Care

### Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us ... or Do they Need to Be Improved?

Abstract number: ME 1.1  
Abstract type: Meet the Expert

#### Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us or Do They Need to Be Improved?

*Sjogren P.*  
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Decades ago WHO outlined the use of a stepwise approach or "analgesic ladder" in order to manage cancer pain. The main tenet is to initiate treatment with less potent analgesics and to advance to more potent analgesics with concomitant use of adjuvant drugs and invasive procedures as pain intensifies. The EAPC guidelines and recommendations were published following up the WHO guidelines in addressing the need for an international consensus. The EAPC recommendations published in 1996 and 2001 have been widely cited and used in clinical practice around the world. These recommendations have been criticised for the non-systematic approach in their development and incomplete review of the available evidences. In order to respond to this criticism the EAPC consortium of research in collaboration with the EAPC Research Network undertook the first effort in Europe to develop a novel set of opioid guidelines for the treatment of cancer pain based on a rigorous evidence based methodology. A comprehensive list of relevant topics on opioid use for cancer pain was derived from a comparison of the previous EAPC recommendations with other currently available guidelines on cancer pain relief. This list was submitted to an expert consensus process that led to 30 practical clinical questions summarised in 22 topics. The subsequent guidelines development process for each of the 22 topics followed the GRADE system. The EAPC Opioid guidelines has been a major step forward in treating cancer pain; however, initiatives have recently been taken in order to address other cancer pain management modalities by a systematic approach in order to include them in more comprehensive guidelines.

### Resilience in Palliative Care

Abstract number: ME 2.1  
Abstract type: Meet the Expert

#### Resilience in Palliative Care

*Oliviere D.J.<sup>1</sup>, Monroe B.<sup>2</sup>*  
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Resilience is a concept that is attracting growing interest (Bluglass, 2003; Huppert, Baylis and Keverne, 2005; Newman, 2005). Vanistendael, (2003) has defined it as 'the capacity to do well when faced with difficult circumstances' and the International Resilience Project which collected data from thirty countries described resilience as a 'universal capacity which allows a person, group or community to prevent, minimise or overcome damaging effects with adversity' (Newman and Blackburn, 2002). The concept has considerable relevance to palliative care.

The session aims to offer a focus on resilience that can assist practitioners to hold on to the increasingly important balance between a medical model that assesses for risk of health problems within individuals and the founding ethos of the hospice and palliative care movement in empowering individuals and promoting their strengths and resources and those of their families, communities and teams (Monroe and Oliviere, 2005). This presentation offers an introduction to a resilience-promoting approach to patients, families, communities, organisations and team; overviews methods of working with patients' strengths; and contextualises the strengths-based approach when there is a need for re-orientating service provision in hospice and palliative care. Resilience is particularly important to enhance cost-effective ways of working with recession and increasingly multiple chronic health and social care needs, when the holistic model and traditional ways of working are under challenge. Core to its methodology is partnership and empowerment. There are direct implications for workforce, environmental and change management; for service sustainability; and community engagement. An improved focus that emphasises 'resilience' rather than 'risk' or 'vulnerability' in

service planning and provision as well as in therapeutic interventions in the social, spiritual and psychological dimensions of care, is a major theme.

### How to Prevent and Treat Cancer Cachexia

Abstract number: ME 3.1  
Abstract type: Meet the Expert

#### How to Prevent and Treat Cancer Cachexia

*Arends J.*  
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Prevention and treatment of cachexia require both understanding of the responsible causes and the availability of effective interventions. Unfortunately, both problems have not yet been solved adequately. But while knowledge about the pathophysiological features of cachexia is advancing rapidly, we are still very much in need of more and better treatment options.

Cachexia is a syndrome of muscle loss complicated by the metabolic derangements associated with chronic systemic inflammation. In cancer patients, inflammation may be tumor-associated or caused by infections or treatment effects. Weight loss and muscle loss are promoted by anorexia, gastrointestinal disturbances, fatigue-associated inactivity and inflammatory proteolysis.

Prevention of cachexia would require the removal of all cachexia-inducing factors, i.e. optimally by curing the cancer. In all other cases prevention should be understood to be the treatment of early stages of cachexia. Treatment of cachexia should include supplying the required individual energy need, interventions to increase muscle mass and treatments to antagonize inflammation.

### The Development of Paediatric Palliative Care Services

Abstract number: ME 6.1  
Abstract type: Meet the Expert

#### Developing Palliative Care Services for Children - Global Trends

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Palliative care services for children began in 1982 with the opening of Helen House in Oxford, UK. The early children's hospices, both in the UK and countries such as Germany, Canada and Australia followed this model of predominantly respite care within a beautiful children's hospice unit. As the concept of hospice palliative care for children spread to other countries, some of them with very few resources, new and innovative models developed, most of them providing palliative care for children at community level. Very few free-standing children's hospice units exist outside of more developed countries.

With the development of palliative care for children, the need for education and integration became more apparent. Whilst few countries provide formal qualifications in this field, there exist a few Academic Chairs and specialist qualifications, and there are now a growing number of training courses, including e-learning courses. This presentation will look at the important trends in the development of palliative care for children, with some predictions for future development.

### The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe

Abstract number: ME 7.1  
Abstract type: Meet the Expert

#### The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe

*Eva G.<sup>1</sup>, Wee B.<sup>2</sup>*  
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Occupational therapy has the potential to provide a valuable service to people with palliative care needs: it supports patients to manage the disabling consequences of life-threatening illness, and it maximises patients' and their carers' ability to carry out practical, purposeful and meaningful activities. These include essential day to day tasks - such as dressing, cooking, going shopping - as well as those occupations that make us who we are - jobs, interests, hobbies and relationships.

Anecdotal evidence has suggested that the availability and scope of occupational therapy in palliative care varies widely between European countries. In order to investigate this, and to establish connections between occupational therapists working in palliative care, an EAPC Occupational Therapy Taskforce was set up at the end of 2010.

The main taskforce activity has been to undertake a survey to find out more about the role of occupational therapists working in palliative care in Europe. The survey aimed to identify:

1. The types of activities undertaken by occupational therapists.
2. The variation in activities between European countries.
3. Areas where there are gaps in service provision.

In this session, we will present the results of the survey as a basis for debate and discussion on the actual and potential contribution of occupational therapy to the care of palliative patients in Europe, both from a medical and a rehabilitation perspective. We will identify and seek to address some of the challenges that are encountered.

### How to Be a Better Reviewer

Abstract number: ME 8.1  
Abstract type: Meet the Expert

#### Meet the Expert - How to Be a Better Reviewer

*Walshe C.*  
The University of Manchester, The School of Nursing, Midwifery and Social Work, Manchester, United Kingdom

Peer review is an essential process for most journals in ensuring the integrity and quality of published research. Peer reviewers are a valued part of the team, and their comments and views important in assisting journal editors to make publication decisions, and in guiding authors to improve their papers.

However, the process of peer review does not always run smoothly for authors, editors or reviewers. Few peer reviewers have received any training in this role, and can be anxious about their role, responsibilities and contributions.

The aim of this session is to explore the practicalities of peer review primarily from the perspective of the reviewer and editor. The session will be based on the Peer Review Guidelines from the Committee for Publication Ethics and will cover the areas of accepting the invitation to review, conducting the review, preparing a review report, and post review expectations. This session will be led by Dr Catherine Walshe, Editor in Chief of Palliative Medicine, and will draw from the experience of the journal editors in working with peer reviewers.

### Spiritual Care

Abstract number: ME 10.1  
Abstract type: Meet the Expert

#### Spiritual Care: Recent Developments in Europe

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In this session we will discuss the latest developments in Europe in the field of Spiritual Care in Palliative Care. The session is hosted by members of the EAPC Taskforce on spiritual care that come from various European countries and different professional backgrounds. Spiritual Care is a rapidly developing field in palliative care and an important goal of this meet-the-expert session is to share experiences as regards research, education and implementation of spiritual care.

## Palliative Care Support for Young People and their Families Provided through Schools and Colleges

Abstract number: ME 11.1  
Abstract type: Meet the Expert

### Palliative Care Support for Young People and their Families Provided through Schools and Colleges

*Craig E.<sup>1</sup>, Samuel J.<sup>2</sup>, Boden C.<sup>3</sup>*  
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Educational accomplishment should not be considered the only primary purpose of school or college attendance for a young person with palliative care needs. Where we view it as such, we risk isolating the young person and their family from a support system that may supersede that which can be provided by health and social care services.

This workshop will explore several key issues:

1. The importance of maintaining school or college attendance
2. Working with young people, families and education services to facilitate access
3. Helping the school or college to develop the skills and knowledge to support the young person with palliative care needs, as well as their family (including siblings) and other students
4. Facilitating continued inclusion and involvement in the school or college community during periods of absence
5. Supporting the school or college to prepare for a death and to support the family, students and staff after a death

Through the development of our program for supporting schools and colleges, young people receiving palliative care can continue to access the social and emotional support of their peers and the adult professionals who work with them. It enables them to maintain a sense of value, purpose and belonging, with opportunities for personal growth and development. Sibling support can also be facilitated, with schools and colleges perhaps better placed to provide this than any other professional group, given that they will often be a constant presence in the young persons life for several years.

The failure of health professionals to recognise schools and colleges as key partners in palliative care provision must be viewed as a critical omission. With appropriate support, school and college staff, and other students, can make a meaningful contribution to the health and emotional care of a young person and their family, and can have a valued role in providing support before, during and after death. Much can be done to facilitate this.

## Doing Palliative Care Research in Primary Care: Challenges and Opportunities

Abstract number: ME 12.1  
Abstract type: Meet the Expert

### Doing Palliative Care Research in Primary Care: Challenges and Opportunities

*Mitchell G.K.<sup>1</sup>, Murray S.A.<sup>2</sup>*  
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Primary care is where most of the care of people in the final phase of life will take place. Research in and about end of life care in this space is essential to learning how best to do it, and what people coming to the end of their life experience this and the care they receive. There are well known challenges to conducting research in palliative care settings, and these are magnified in the primary care setting. Palliative care research struggles to compete in a very crowded market, because only about one per cent of patients die in a typical general practice per year. Recruitment of both patients and health professionals can thus be very difficult. However, this session will present examples of different types of research in primary palliative care, and how successful primary care research has been achieved in this setting.

## Action Research

Abstract number: ME 13.1  
Abstract type: Meet the Expert

### Action Research and Palliative Care: Principles and Challenges

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Action research and palliative care, as research and practice disciplines, are both relatively young and increasing in prominence. These approaches have arisen as a response to identified shortcomings and critique of the more dominant approaches to research and care provision for dying people. Both approaches pay attention to holism either through research that considers the whole person in their whole context or care that addresses all of an individual's needs in their wider social network of family and friends. An introduction to the principles of action research will be presented and the key features of the participatory research process explained. Drawing upon two recent examples of participatory research in palliative care from Austria and the UK, the current challenges of undertaking action research in palliative will be considered.

## Gender Issues in Palliative Care

Abstract number: ME 14.1  
Abstract type: Meet the Expert

### Gender Issues in Palliative Care: Tishelman and Twigg

*Twigg J.<sup>1</sup>, Tishelman C.<sup>2</sup>*  
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Carol Tishelman is Professor of Nursing at Karolinska Institute, Department of Learning, Informatics, Management and Ethics/Medical Management Center. She is also affiliated with the Research and Development Unit at Stockholm's Sjukhem Foundation—one of Sweden's major palliative care facilities, and both LaTrobe University and University of Manchester. After initial studies in Women's Health and a later BSN in Nursing from the US, Carol received a PhD from Karolinska Institute and has conducted research in cancer and palliative care for over 20 years in Sweden.

Julia Twigg is Professor of Social Policy and Sociology at the University of Kent, UK. She has written widely on the support of older people, focussing on the front line of care and significance of embodiment for this. In particular she has explored how care work needs to be understood as a species of bodywork. The provision of care, whether by family or workers, is shaped by gendered expectations, both with regard to who does this work and for whom, and how it is understood and valued. In 2012 she was co-editor of *Bodywork in Health and Social Care: Critical Themes, New Agendas*, Oxford: Wiley-Blackwell.

In this session, Julia and Carol will briefly present their perspectives on gender issues in palliative care, ranging from implications for patients and families, to staff and researchers, before chairing an open discussion.

## Physiotherapy and Palliative Care

Abstract number: ME 15.1  
Abstract type: Meet the Expert

### When to Involve Physiotherapy in Palliative Care?

*Maddocks M.<sup>1</sup>, Müllauer E.<sup>2</sup>*  
<sup>1</sup>King's College London, Cicely Saunders Institute, London, United Kingdom, <sup>2</sup>KH Hietzing, Pneumologische Rehabilitation, Wien, Austria

An increasing emphasis is placed on proactive intervention to reduce or delay the effects of disease and its treatment on physical function, independence and quality of life. In this session we wish to consider the most appropriate starting point for physiotherapy intervention in patients receiving palliative care using examples from thoracic cancer and

chronic respiratory disease. Attendees will be asked to discuss the role of physiotherapy at the point of diagnosis, around medical treatments and as physical dependence increases with progressive disease.



# Free communication sessions

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Organisation of Services  
End of Life  
Psychology and Communication  
Policy  
Family and Care Givers  
Non-Cancer  
Education  
Ethics  
Palliative Care in the Elderly  
Assessment  
Place of Death  
Children and Young People/ Spirituality  
Pain and other Symptoms

## Organisation of Services

Abstract number: FC 1.1

Abstract type: Oral

### Research into Practice within Resources: Development of an Integrated Palliative Care Service for People Chronic Obstructive Pulmonary Disease

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**Background:** Chronic obstructive pulmonary disease (COPD) is a common life-limiting illness that can result in significant burden for patient and carer. Despite this, access to supportive and specialist palliative care is inconsistent, resulting in unmet needs.

**Aims:** To establish a multidisciplinary team (MDT) meeting for patients with very severe COPD; improve patient identification and symptom management; increase advance care planning and the numbers of patients dying in their preferred place; increase patient and carer support and satisfaction.

**Methods:** A four step approach of plan, act, observe and reflect was used. A working group was formed and baseline data collected to identify the needs of people with very severe COPD. A MDT meeting was piloted and evaluated by community matron feedback, patient case studies and an after death analysis (ADA). This service development pilot was conducted across primary and secondary care.

Community matrons acted as the keyworker with regard to identification of people with severe COPD and complex needs for review at the MDT.

**Results:** The community matron feedback, ADA and patient case studies indicated a high level of satisfaction, with improvements in advance care planning, co-ordination of management and support for patients' preferred place of care at the end of life.

**Conclusion:** This is the first reported very severe COPD service development established in this way and within current resources. Preliminary data indicates the development of the MDT meeting has been positive, with regard to community matron feedback, ADA and patient case studies. The appointment of a coordinator will aid this development. Further evaluations particularly seeking patient views and estimations of cost savings will be performed. This service model could readily be implemented into other clinical services wanting to expand into COPD, without the need for extra resources.

Abstract number: FC 1.2

Abstract type: Oral

### Reducing Hospital Resource Utilisation in Patients with Advanced Life-limiting Illness with Community-based Case Conferencing

McCaffrey N.<sup>1,2</sup>, Currow D.<sup>1</sup>, Abernethy A.P.<sup>1,3,4</sup>

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The aim of this study was to evaluate the incremental resource use, cost and consequences of adding case conferences to specialised, community-based palliative care for improving the performance status of patients with a life-limiting illness.

Mean costs and effectiveness were calculated using patient-level data (n=273) from the published cluster-randomised Palliative Care Trial, including: survival time; performance status; quality of life; specialist palliative care service utilisation; acute hospital and palliative care unit inpatient stays; outpatient visits; medication usage; general practitioner and other non-hospital services. Participants were adults newly referred to a regional community-based palliative care program, experiencing pain, and expected to live >48 hours.

There was a significant reduction in the number of hospitalisations in participants who had a case conference versus those that received usual care only (case conference least square means, 1.26 hospitalisations per patient [standard error (SE) 0.10] vs usual care 1.70 [SE 0.13]; p=0.0069). Further analysis of outpatient services, medication usage and out of hospital resource utilisation

will be conducted to evaluate whether reduced hospitalisations offset other cost consequences of case conferences. Participants who had a case conference better maintained performance status (p=0.0368). The mean incremental cost/performance-adjusted life year will be calculated and 95% CI estimated using bootstrap analysis to evaluate the cost-effectiveness of case conferences in this context.

The findings suggest case conferences reduce hospital resource utilisation, whilst better maintaining performance status. Further incremental analysis will be presented, defining the net benefit of case conferences from a health system perspective.

Funding: Australian Government, Ian Potter Foundation, Cancer Council SA, Doris Duke Foundation, RGH, ACH Group Inc & Southern Division of General Practice.

Abstract number: FC 1.3

Abstract type: Oral

### Coordinate My Care (CMC) - An Electronic Palliative Care Coordination Service for London

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**Background:** CMC is a clinical service underpinned by an electronic solution. Clinicians are trained in identifying patients in the last year of life, consenting and having difficult conversations. It encourages a change in practice to facilitate coordination of care across multiple healthcare settings. The web based solution can be accessed by any legitimate care provider such as London Ambulance Service, 111 unscheduled telephone service, GPs, community nurses, hospital and hospice staff and social services. All patients prospectively consent to having a CMC record; this can be created in best interest where patients lack capacity. Following a pilot study, we hypothesised that CMC results in fewer hospital deaths and more patients dying in their preferred place (PPD). Pan-London roll out (7.7 million population) will be complete by April 2013 with evaluation the outcomes.

**Design and methods:**

- Stakeholder engagement, agreement of template
- Design of web based, secure, encrypted, scalable electronic solution
- Development of training module including how to: identify & consent patients, have sensitive conversations, create care plans, DNAR and use of IT software
- Liaise and contract to become interoperable with other services: 111, London Ambulance service, GPs, out of hours GPs, hospices and hospitals
- CMC rolled out Pan-London (population 7.7 million)

**Results:** Data censored on 24.10.2012. 2,827 CMC records created.

**Diagnosis:** Cancer 45%, non-cancer 55% (15% Dementia). Deaths: 673 (82% in PPD). Recorded PPD: home 29%, care home 22%, hospice 12%, hospital 19%, not recorded 18%. Professionals creating records: GP 7%, community nurses 43%, hospital 17%, hospice 33%.

**Conclusions:** To date, 70% of CMC deaths occur OUTSIDE hospital (65% deaths IN hospital 2010, ONS data). 82% die in their PPD. CMC represents a 'paradigm shift' in palliative care service delivery that is appropriate internationally given decreasing availability of funds and an ageing worldwide population.

Abstract number: FC 1.4

Abstract type: Oral

### The Development and Evaluation of an Inpatient Palliative Care Admission Triage Tool

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In Australia, there has been a steady increase in demand for palliative care services due, in part, to an aging population, increasingly geographically distant families and an enhanced role for palliative care in non-malignant illness.

This has led many specialist palliative care services to create waiting lists, in particular, for admission to inpatient palliative care units or hospices (PCUs).

**Aim:** The aim of this study was to explore the development, implementation, and outcomes following the introduction of an inpatient palliative care admission triage tool.

**Method:** The study proceeded in 2 phases:

- (1) Developmental phase, whereby semi-structured focus group discussions were held with a purposive sample of palliative care providers to determine the clinical and

administrative criteria relevant to considering the priority assigned for potential admitted patients, and

- (2) Implementation and Evaluation phase. Phase 2 involved a 3-month trial of the tool at two inpatient PCUs (encompassing 3 separate campuses), and subsequent evaluation using the quantitative and qualitative data recorded throughout the process of patient admission. A further focus group discussion was held with providers to seek feedback on the tool.

**Results:** Components of the final tool included: site of current care, adequacy of current care setting, reason for admission, prognosis, level of symptoms, psychosocial distress, time spent on waiting list and phase of disease. Of the 234 patients, those with less urgent needs, as indicated by a low admission score, spent longer on the waiting list. Clinicians reported wide acceptance of the tool, and stated it supported the current decision-making processes, and was a useful education aid.

**Conclusion:** This study represents the first reported attempt to define the priorities for a waiting list for admission to PCUs, and demonstrates its utility in providing a transparent process for PCUs to manage the competing needs of patients referred for care.

Abstract number: FC 1.5

Abstract type: Oral

### Palliative Care Models for Mental Illness - A Challenge

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**Aims:** Mental illnesses remain a huge burden in many parts of the world and services to support those with chronic illness living in the community are scarce in many low and middle income countries. MEHAC Foundation has adapted the principles of palliative care specific to mental health care with community participation.

**Design:** Models of service delivery were developed in districts in Kerala according to the local needs and in close collaboration with government and other partners. These incorporated outpatient, short admissions and most specifically home care. Holistic care included rehabilitation.

**Results:** 3 distinct models of collaboration across 12 services have emerged involving local governing bodies, non governmental bodies, institution/nursing homes. Key outcomes: establishing links with local community organisations, directly offered supervised care in addition to training, and advisory roles; modeling high quality service including rehabilitation and follow up; developing local ownership and empowerment with communities taking direct responsibility for long term support; integration in service delivery and training; changes in policy for community mental health provision.

**Conclusion:** Community based services are essential in the long term care of chronic mental illness. In many low and middle income countries models of integrated care are still to develop. There are often sporadic services that are institutional based and do not empower whole communities in the holistic approach to chronic mental health. Building on community palliative care initiatives in Kerala chronic mental health has been seen as part of the palliative care disease spectrum. This approach can be used to develop specific services for those living with chronic mental illness which has resonance for wider settings. The WHO in 2012 announced that mental disorders is included among the non-communicable diseases which is a significant step in terms of policy and implementation.

Abstract number: FC 1.6

Abstract type: Oral

### Similarities and Differences between Social Work and Spiritual Care Service for Terminally Ill Patients and their Loved Ones in a Hospice

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**Purpose of the research:** To describe differences and similarities in conversation topics between the social worker (SW) and the spiritual counselor (SC) in their conversations with the terminally ill patients and their loved ones in a high care hospice.

**Method:** A checklist consisting of 22 items was used extracted from the "Distress Thermometer" [1], recommended in the guideline "Detecting need Psychosocial Care" as measurement instrument to signal distress in oncological patients. With this checklist, possible conversation topics were registered and categorized into four categories: practical issues, social factors, mental



condition and spiritual matters. The number of conversations and the subjects were registered for each patient and their loved ones each week for the duration of 21 months.

**Results:** 158 conversations with patients and their loved ones were registered. The SW had 91 conversations with 28 patients and 127 with 61 loved ones. The SC had 253 conversations with 75 patients and 16 with 13 loved ones. The most prominent differences between SW and SC were found in the percentage of talks with the patient directed to practical issues (resp. 20% vs 9%), and spiritual matters (resp. 5% vs 22%). Percentages of conversation topics with the loved ones were higher for SC for talks related to social factors (64%), mental condition (46%) and spiritual matters (30%), compared to the SW (resp. 27%, 32%, 10%), albeit based on a small sample. Practical issues were more often discussed with the loved ones by the SW (20% vs. 8%).

**Conclusion:** The figures seem to indicate most overlap between professions in two categories: social factors and mental condition. The focus of the SW tends to be directed more towards practical issues, whereas spiritual matters tend to be predominantly the domain of the SC. These results indicate a degree of complementarity and added value of both disciplines in the palliative care of terminally ill patients.

[1] *Cancer* 2008; 113: 870-8

## End of Life

**Abstract number:** FC.2.1

**Abstract type:** Oral

### Dying with Dementia: Symptoms, Treatment and Quality of Life in the Last Week of Life

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**Aims:** Burdensome symptoms are frequently present in patients with dementia at the end of life, but little is known about symptom control, such as type and dosages of medication. This study therefore investigated the prevalence of symptoms, prescribed treatment, and explored associations with quality of life in the last week of life and symptom prevalence by causes of death of nursing home residents with dementia.

**Methods:** Within two weeks after death, physicians completed questionnaires about symptoms and their treatment in the last week of life of 330 nursing home residents with dementia in the Netherlands between 2007 and 2010. Quality of life was assessed with the Quality of Life in Late-Stage Dementia scale and the physicians abstracted (direct) causes of death from the death certificate. We used independent t-tests and chi-square tests to compare subgroups, and linear regression to assess associations with quality of life.

**Results:** Pain was the most common symptom (52%), followed by agitation (34%), and shortness of breath (34%). Opioids were the most commonly provided treatment for residents in pain (70%) and residents with shortness of breath (69%). Agitation was mainly treated with anxiolytics (53%). At the moment of dying, 76% of all residents received opioids with a median of 90 oral morphine equivalents and 20% received palliative sedation. Pain and agitation were associated with a diminished quality of life. Death from respiratory infection was associated with the largest symptom burden.

**Conclusion:** Burdensome symptoms are common and some were associated with a diminished quality of life at the end of life, despite the large majority of residents receiving opioids. Dosages may be suboptimal with regard to weighing of effects and side effects. Future observational research which employs observation on a day-to-day basis is recommend, to better address effectiveness of symptom control and possible side effects.

**Abstract number:** FC.2.2

**Abstract type:** Oral

### A Qualitative Study of Health Professionals' Views of Scope and Feasibility of Transferring Patients from Critical Care Home to Die in the UK

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**Background:** Increased choice and the concept of preferred place of care is key in current UK Health policy. Research

undertaken indicates that the majority of people express a preference to die at home. Whilst progress has been made toward this policy imperative there is limited evidence how might be applied in the context of those dying in critical care. The aim of this qualitative study was to determine the scope, experience and feasibility of transferring critical care patients home to die [TCCPHD] from UK critical care units.

**Methods:** Data collection involved six focus group discussions with Health Care Professionals (HCPs) from critical care units (n=4), primary care (n=1) and patient representatives (n=1). Focus group questions were informed by the results of a scoping review and clinical experience. Questions explored: participants' views toward TCCPHD, participants' experience of TCCPHD, factors that would influence decision-making regarding this initiative, and factors needed to facilitate this initiative.

**Results:** Data analysis generated five overarching themes; views, barriers/facilitators, experience, patient characteristics and guidelines, providing insight into the decision-making and action-orientated processes that inform practice regarding TCCPHD. While transfer home was positively regarded, identified barriers included: community care, home environment, time and logistics. In addition, concerns (under theme 'views') included: relatives' ability to care for the patient at home, the ethics of prolonging life to facilitate the transfer and the complexities of the decision-making process. **Discussion:** This study has highlighted the complexities of transferring patients home to die from critical care in identifying barriers to transfer and HCPs concern for stress on relatives when caring for a dying person at home. The decision-making process is dependent on a multitude of factors and timing making this negotiated process a complex one.

**Abstract number:** FC.2.3

**Abstract type:** Oral

### Emergency Readmission Rates in Patients Whose Recovery Is Uncertain: The Impact of the AMBER Care Bundle

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**Aim:** To evaluate the impact on 30 day emergency readmission rate of a novel care bundle. The bundle is aimed at acutely ill hospital patients with limited clinical reversibility judged to be at risk of dying in the next 1-2 months (uncertain recovery). Around 58% of deaths in England occur in hospital, contrary to surveyed preferences. The National End of Life Care Intelligence Network states that 89% of those who die in hospital do so following an emergency admission. In people in the last year of life with conditions with potential palliative care need, analysis shows that 32.6% of hospital admissions occur in the 30 days before death. There is evidence of delayed recognition of patients who, despite ongoing active medical care, are at risk of dying from their underlying illness.

**Methodology:** The AMBER care bundle was developed to improve treatment planning, escalation decisions and communication with patients, carers and the team, prioritising support of patient preferences. In our acute hospital where the bundle is used on seventeen wards, 55% of patients supported with the AMBER care bundle are discharged with an individualised package of care. Patients discharged from 01/10/10 to 30/09/11, who died within 100 days of discharge, were followed up to identify any emergency readmissions. We compared this group with patients discharged from the same wards and who also went on to die within 100 days but had not been supported by the care bundle.

**Results:** Patients receiving standard care were three times more likely to have an emergency readmission (36%) than those receiving AMBER care bundle support (12%) - a difference of 24% (95% CI 18%-29%).

**Conclusions:** Early findings demonstrate a significant difference in 30 day emergency readmission rate for this vulnerable group of patients. It is possible to implement a care bundle in this complex clinical area which supports discussion of patient preferences, more robust discharge arrangements and contingency planning.

**Abstract number:** FC.2.4

**Abstract type:** Oral

### Are Relatives' Preferences Aligned with the Patients' and Do They Change their Minds?

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**Aim:** To determine the congruence between patients and relatives preferences for place of death and verify how often relatives change their minds (and in which direction).

**Methods:** A population-based mortality followback survey with 596 relatives of cancer patients (from a sample of 1516) identified from death registrations in London (UK) in 2009/10. We report patients and relatives preferences for place of death and the percentage of agreement. We use kappa statistics to assess congruence between their preferences and the McNemar test to compare preferences for home death from patients and relatives. We report the proportion of relatives who changed their preferences and the direction of change; this was independently coded by two researchers with disagreements solved by consensus.

**Results:** As reported by relatives, patients most often chose home (69%) as the place to die (17% hospice, 5% hospital, 2% care home, 2% >1 setting and 5% had no preference). About half (48%) of relatives chose home, 24% hospice, 9% hospital, 4% care home, 2% >1 setting, 1% elsewhere and 13% had no preference. A preference for home death (vs. others) was less common amongst relatives than amongst patients ( $p < 0.001$ ), although paired patients and relatives achieved 80% agreement (kappa 0.634). A fifth (119) of relatives changed their preferences. In half of these cases (51%) the preference moved from home to another setting: 28 away from home (to a setting not specified), 23 home to hospice, 9 home to hospital and 1 home to care home.

**Discussion:** Our findings clarify a conflicting body of evidence showing that relatives choose home less often than patients. However, home remains the most commonly chosen place. It is crucial to understand better the reasons underlying relatives' preferences and why they change their minds. This will help to provide adequate support to patients and relatives and allow more people to die at home when this is their wish.

**Funding:** Cicely Saunders International

**Abstract number:** FC.2.5

**Abstract type:** Oral

### Elderly Patients with Advanced Frailty in the Community: A Qualitative Study on their Needs and Experiences

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**Aims:** Frail elderly patients are a major target group in general practice but little is known about the needs of these patients towards the end of life. This study\* aims to explore the needs and experiences of patients with advanced frailty in the community.

**Methods:** Qualitative study with patients interviews at home. Patients were purposively recruited in general practices to reflect a range of sex, social background and presence of an informal carer. Main inclusion criteria were moderate/severe frailty, age  $\geq 70$  years, and the ability to give informed consent. Interviews took place in the patients' homes addressing their experiences of being frail, support, concerns and expectations. Interviews were tape-recorded and transcribed verbatim. Narrative and thematic analysis was conducted within and across cases. To identify codes and develop (sub-)categories constant comparative analysis was used.

**Results:** The sample consists of 26 patients (15 female, 11 male; mean age 83 years, range 71-95 years). The patients' view of "being frail" affects almost all aspects of life: The exhaustion of capabilities due to the loss of physical and cognitive strength, increased vulnerable health and symptom burden, and social losses often interfere with the patients' striving for sustaining their self/identity, autonomy and participation. In the interviews, the importance of sustainable (in-)formal support and in particular of a "knowing" and "caring" family doctor was stressed.

**Conclusion:** Further integrating the palliative care approach into general practice seems necessary to meet the needs of frail elderly patients in the community. The study will be continued with three follow-up interviews every six months to gain a deeper understanding of the dynamic experience of advanced frailty, and how patients' needs vary over time if frailty progresses.

\* The study is funded by the German Federal Ministry of Education and Research (01GY1120), study duration: 02/2012-01/2015

Abstract number: FC 2.6  
Abstract type: Oral

## Maximizing Corporate Support: Useful Strategies to Develop Effective Partnerships

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In an era when many palliative care organizations are facing financial constraints and with the limited number of palliative care funders in existence, it is important for organizations to review their revenue generating models and aim to diversify resources. Philanthropy or corporate social responsibility is funding stream that can bring new dollars to the palliative care agenda and yet these streams remain largely untapped. Understanding the basic key steps in developing relationships with corporates is vital. The bottom line is that most, if not all palliative care organizations are doing spectacular work and changing the lives of many vulnerable people with great success. Unfortunately, there are many other spectacular organizations globally doing similar work with the same if not more level of success. They too are also looking for potential partners. In view of this, to access corporate partners, it is critical that we have done our homework and we can prove to a prospect corporate partner that we are the best non-profit partner for their support. 'Standing out' from the crowd of qualified organizations in order to attract corporate funders is a task that most nonprofits face time and time again. The presentation will offer useful insights to help organizations gain a better understanding of what they should do, and look for, when preparing to engage in a successful philanthropic partnership. It will discuss five key steps on 'how to make your case', by looking at; doing the research; developing relationships and ownership; being responsive and communicative; determining the resources that you can offer and finally, making tangible results that support your organization. In addition to the information above, useful contacts will be shared with participants giving them an opportunity to explore the contacts in order to develop their own organizational partnerships and funding.

## Psychology and Communication

Abstract number: FC 3.1  
Abstract type: Oral

### Negotiating Choices to Provide Psychosocial Support: A Mixed Methods Study in a Hospice Ward

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**Aims:** This study was the first to aim to examine the preconditions necessary for the provision of psychosocial support. It reports hospice nurses' responses to patients' psychosocial needs. The paper explores the realities of psychosocial support by focussing on one psychosocial need: patients' rights to make choices.

**Methods:** In a mixed methods study, participant observation of nurse-patient interactions was supported by data from interviews, nursing documentation, clinical meetings, workload distribution and participant demographics. A maximum variation sampling strategy was used, ensuring observations occurred at different times of the day, involving nurses with different roles and patients with different characteristics.

**Results:** The sample included 38 nurses and 47 patients, across 39 episodes of observation. Preliminary analysis of the observation data identified prospective independent variables which might be associated with the provision of psychosocial support; subsequent analysis tested these variables against the nurses' response to patients' expressed needs. The data showed that nurses responded to psychosocial needs in four ways: dealing, deferring, diverting and ducking. The process of making choices was observed in all observed episodes of care; however, patients were not consistently afforded the right to make their own choices. Nurses used varying levels of negotiation to influence patients' acceptance of professional decisions. Comparison of the amount of negotiation within choices to the nurses' "dealing" response showed that nurses could still provide psychosocial support despite denying choice to the patient. **Conclusion:** The findings of this study demonstrate that, by communicating openly with patients, practitioners can overcome the complexities of psychosocial care regardless of changes in patients' conditions or the constraints of healthcare. Funding was provided by the participating hospice and the authors' employing University.

Abstract number: FC 3.2  
Abstract type: Oral

### Advance Care Planning and Physician Orders in Nursing Home Residents with Dementia: A Nationwide Retrospective Study among Professional Caregivers and Relatives

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**Background/objective:** Advance care planning (ACP) is key to good palliative care for nursing home residents with dementia. We examined the extent to which family physicians (FP's), nurses and the relative most involved in the resident's care are informed about ACP, written advance directives (AD) and family physician treatment orders (FP-orders) of nursing home residents dying with dementia. We also examined the congruence between the FP, nurse and relative about the existence and content of ACP.

**Design/setting/participants:** Representative nationwide post-mortem study (2010) using random cluster-sampling, Flanders Belgium. In selected nursing homes, all deaths of residents with dementia in a three month period were reported. A structured questionnaire was completed by the nurse, the FP and the relative.

**Measurements:** ACP communication (verbally/writing) and FP-orders.

**Results:** We identified 205 deceased residents with dementia in 69 nursing homes. Residents expressed their wishes regarding care in the last phase of life in 11.8% according to the FP and in 8.2% according to the nurse. The FP and nurse spoke with the resident in 22.0% and 9.7% respectively and with the relative in 70.6% and 59.5%. An AD was present in 9.0% according to the FP, in 13.6% according to the nurse and in 18.4% according to the relative. FP-orders were present in 77.3% according to the FP, discussed with the resident in 13.0% and with the relative in 79.3%. Congruence was fair (nurse-FP) on the documentation of FP-orders, ( $k=0.26$ ), poor to slight on the presence of an AD (FP-relative  $k=0.03$ , nurse-relative  $k=0.05$ , FP-nurse  $k=0.12$ ).

**Conclusion:** Communication regarding care is rarely patient-driven and more often professional caregiver- or family-driven. The level of congruence found between professional caregivers and relatives is low.

**Funding source:** This study is supported by a major grant from Vrije Universiteit Brussel (GOA HW, VUB) and is part of the "Dying Well with Dementia" study.

Abstract number: FC 3.3  
Abstract type: Oral

### Development of an Intervention to Improve Physician-patient Communication in Patients with Advanced Cancer. A Focus Group Study

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**Research aims:** Many patients with recently diagnosed advanced lung cancer who wanted to be informed about prognosis, palliative care and end-of-life decisions (ELDs), were not. Patients who wanted to share medical decisions with their physician often did not achieve this involvement. The aim was

- 1) to discuss these problems with oncologists/pulmonologists and list their suggestions for improvement and
- 2) to develop recommendations and a model of intervention to improve communication, and present these to oncologists/pulmonologists for evaluation.

**Study design and methods:** Focus group sessions were transcribed and analysed through systematic coding and comparing and contrasting themes. To allow evaluation of recommendations and intervention, a questionnaire was developed.

**Results:** Three focus group discussions with 8 oncologists and 5 pulmonologists took place. Identified barriers to the

provision of information about prognosis, palliative care and ELDs were fear of destroying hope in the patient, uncertainty of the disease trajectory and propensity of physicians to cure rather than to offer palliative care options. Barriers for shared decision-making were the physician's belief that shared decision-making is not possible, and the perceived inability of the patient to have contributive input. On the basis of the received suggestions for improvement, we proposed

- 1) an up-front negotiable offer of information and deliberation by the physician and
- 2) 8 recommendations and an intervention to promote patient-physician communication.

The proposed intervention consists of a communication skills training program with role play for physicians and a question prompt list for patients. Recommendations and intervention were evaluated as useful and feasible.

**Conclusion:** In future research, recommendations and intervention have to be compared with existing ones, confronted with patient's view, and tested with regard to effect on patient outcomes.

Abstract number: FC 3.4  
Abstract type: Oral

### A Literature Review of Patient Recorded Outcome Measures (PROM's) Used to Measure the Quality of Doctor-patient Communication in Randomised Control Trials (RCT's)

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**Background:** Patients prioritise good communication skills in Doctors. Evidence that Communication Skills Training (CST) for Doctors can enhance a consultation, ensuring more patient concerns are elicited, is mostly through expert behavioural analysis rather than patients' perception of change. A recent meta-analysis of patient outcomes relating to CST with cancer patients was restricted because every study used a different PROM.

**Aim and methods:** The aim of this literature review was to identify what PROM's had been used to measure the quality of doctor-patient communication in RCT's. Each measure was then assessed regarding its suitability for a trial evaluating the effect of CST in hospital outpatient clinics.

**Results:** Fourteen PROM's which assessed doctors' communication within a specific consultation were identified in 24 studies. Seven PROM's were found not applicable for a study regarding the effect of CST for Doctors on PROM's in hospital outpatient clinics. Mainly these tools were too specific; the focus being on one aspect of communication (risk or shared decision making) or consultation outcome (treatment decision). The seven remaining PROM's which have previously been used in a RCT to assess doctor-patient communication and appeared applicable to a study set in hospital outpatient clinics were assessed using seven criteria that investigators should consider when choosing a PROM: appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility.

**Conclusion:** Few identified PROM's were developed beyond the piloting phase or had extensive psychometric information. Consultation And Relational Empathy measure (CARE) and Patient Enablement Instrument (PEI) were judged the most applicable PROM's against the seven criteria. CARE measure assesses the doctor's communication and empathy within the consultation and PEI gauges how enabled the patient is.

Abstract number: FC 3.5  
Abstract type: Oral

### When Your Patient Friends You on Facebook: Social Media's Growing Promise and Pitfalls for the Palliative Care Practitioner

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Increasing utilization of social media sites such as Facebook and Twitter as well as the ability to interconnect a variety of personal blogs, photographs and "favorite" websites, raise interesting questions for the palliative care provider. For some, social media sites offer a way to mobilize support for associated professional organizations; the authors recently "liked" the European Association of Palliative Care Facebook page, joining 456 others in doing so. Twitter has become a way for palliative care practitioners to post recent scientific articles, reports in the lay press pertaining to palliative care and engaging in conversations in real-time at professional

meetings. For others, social media allows a venue to post about their sadness at the death of a beloved patient, "vent" about a difficult family situation or arrange videoconferencing with peer mentors to maintain relationships developed in training (Google+). All of these uses may co-exist alongside information, photographs and postings about the practitioner's personal life.

This juxtaposition of professional and personal lives in such a public venue raise new questions about how to preserve the professional image of ourselves as practitioners trusted by patients and families at some of the most vulnerable moments in their lives. In addition, the rapid expansion of social media has outpaced the medical professions ability to develop policies and guidelines to address issues of professionalism, personal privacy and patient confidentiality.

In this interactive session we will explore the following scenarios in both small and large group settings:

1. How to respond to patient requests for interactions on social media sites, such as Facebook.
2. How best to make use of social media in a professional setting while maintaining a separate online "citizenship" for one's personal use.
3. How to respond to a breach or potential breach of patient confidentiality on social media sites by a colleague or trainee.

**Abstract number:** FC 3.6

**Abstract type:** Oral

### What Is the Role of Family/Friends Present at Breaking Bad News Consultations in the Subsequent Sharing of News with Other People? Lessons Learned for Developing a Supportive Intervention

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**Background:** Breaking bad news (BBN) of a lung cancer diagnosis is a daily event for clinicians: in 2008, 1.61 million patients received diagnoses worldwide. Much attention has been paid to BBN by clinicians. In contrast, how patients then share this bad news with other adults has not been studied, yet patients say it is one of the hardest things they have to do.

**Aim:** To examine the role of family/friends who accompany patients to bad news consultations (accompanying persons; APs) in then supporting patients with lung cancer to share their diagnosis. This is part of a study to develop intervention(s) to support people in sharing bad news with significant others.

**Sample:** 13 APs of 15 patients with advanced lung cancer and 15 clinicians involved in BBN consultations.

**Methods:** Qualitative interviews with patients and APs; interviews/focus groups with clinicians, digitally recorded, transcribed verbatim. Thematic framework analysis.

**Results:** APs were very involved in sharing news but also faced difficulties with this. They attended diagnosis-giving consultations to support patients and receive information conveyed. APs described having to deal with their own reactions while supporting the patient with both receiving and sharing bad news. They reported how sharing bad news with others could involve the emotional work of repeating updates on how the patient was, yet they were not supported in this process. For some, two different sets of news were shared:

- (1) what the patient wanted to be conveyed (which may have been more restricted information) but also
- (2) their own view of the situation, shared with a more limited group from whom they sought support.

**Conclusion:** APs play an important but poorly recognised role in supporting patients share bad news including taking responsibility for telling others. An understanding of their experiences is crucial for developing an intervention to prepare and support people with sharing bad news.

## Policy

**Abstract number:** FC 4.1

**Abstract type:** Oral

### Paying for Palliative Care Services: Lessons from International Experience

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**Background:** Funding models for specialist palliative care influence provision and service development. As palliative care integrates into mainstream health care provision, opportunities to develop funding mechanisms arise. We compare different funding models and draw critical lessons from international experience.

**Aim:** To assess models and methods for financing and commissioning palliative care services.

**Methods:** Initial literature scoping yielded limited evidence on the subject as international policy documents are difficult to identify, access, and interpret. We therefore undertook country expert consultations within our research network, to identify and appraise international models of palliative care financing. The countries included - Australia, England, Germany, Hungary, Republic of Ireland, New Zealand, Netherlands, Norway, Poland, Spain, Sweden, Switzerland, USA and Wales - represent different levels of service development and a variety of funding mechanisms.

**Results:** Funding mechanisms for specialist palliative care in different countries vary as much as provision of palliative care itself. We develop a typology for funding models based on the variety of funding flows. Using examples from specific countries, our recommendations are based on these observations: Provider payment is rarely linked to population need, and mostly based on historic resource allocations. Although the quality of services is assessed at the provider level in most countries, provider payment is rarely linked to the quality of services.

**Conclusion:** Funding mechanisms hold the potential to provide powerful policy levers that reward excellence. They need to be used with care to ensure best practice and minimise perverse incentives. The palliative care community needs to be involved in the opportunities to reshape funding and reimbursement mechanisms, to improve patient care, reward high quality and ensure equity.

**Funding:** Palliative Care Funding Review, Department of Health

**Abstract number:** FC 4.2

**Abstract type:** Oral

### What Factors Are Associated with National Health Service Spend on Specialist Palliative Care in England? A Nationwide Ecological Study

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**Aim:** To identify patterns and factors associated with National Health Service (NHS) spend on specialist palliative care services in England.

**Methods:** Ecological study using data gathered from UK Department of Health, National End-of-Life Care Intelligence Network, Office of National Statistics and Hospital Episode Statistics. We applied multi-variable linear regression to study the relationship between

- 1) Primary Care Trust (PCT) spend per death on specialist palliative care, and
- 2) factors associated with i) healthcare use in last year of life (such as age, diagnosis, ethnicity, socioeconomic status, living alone), and ii) specialist palliative care provision (such as proportions of home, hospital and hospice deaths).

**Results:** Data from 78% (119) of all Primary Care Trusts in England was analysed. In 2010/11, PCT spend on specialist palliative care varied from £200 to £2,700 per death (mean £907). Higher PCT spend on specialist palliative care was associated with lower proportion of hospital deaths ( $\beta$  -0.26, 95% CI -0.35 to -0.16), higher proportion of non-white ethnic minority population ( $\beta$  0.18, 95% CI 0.14 to 0.23), higher proportions of self-reported poor health ( $\beta$  0.40, 95% CI 0.19 to 0.61), and higher proportion of cancer deaths ( $\beta$  0.59, 95% CI 0.31 to 0.86,  $p < 0.001$ ). These four factors explained one third of the variation in PCT spend (adjusted  $R^2$  0.341).

**Conclusion:** NHS spend on specialist palliative care by PCTs is independently associated with hospital deaths, with higher proportions of hospital deaths occurring in those PCTs which spend relatively less on specialist palliative care. This underlines the importance to commissioners of balancing health care spend across settings. Meeting the predominant public preference for home death is likely to require a shift in resources from the acute to the community sector.

**Abstract number:** FC 4.3

**Abstract type:** Oral

### How Much Does it Cost to Treat Pain? Preliminary Results of a Pilot Study to Monitor and Report the Price of Opioids in the World

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**Introduction:** High prices affect access to treatment and medications. Opioid Price Watch (OPW) project was developed by the International Association for Hospice and Palliative Care (IAHPC) in alliance with the World Health Organization Department of Essential Medicines.

**Objective:** To Improve access to opioids for legitimate medical use, through dissemination of information on their availability, prices and affordability.

**Method:** A survey and economic model were developed to determine the cost and affordability of opioid treatment. Analgesics included in the study were fentanyl, hydromorphone, methadone, morphine and oxycodone. Affordability was calculated as number of salary days required to pay for one month treatment. A descriptive cross-sectional study was developed and a study sample was selected using the principle of stratified random sampling based on the IAHPC membership list. 20 participants were selected from 4 socioeconomic levels and invited to participate. Preliminary data was used to identify the cost and affordability of morphine.

**Results:** Preliminary data from 7 countries on the availability and cost of morphine indicate that in 3 countries morphine is available only for hospital use (Sudan, Tanzania and Nicaragua). Of these, morphine is given for free in Tanzania. In other countries, the cost of mg/morphine ranged between \$0.003 and \$0.058 (Guatemala and Norway respectively). Affordability ranged between 1.62 and 9.83 days (Guatemala and the Philippines respectively). **Conclusion:** This is the first project with the purpose to monitor and report the availability, cost and affordability of opioid on a global scale. Preliminary data suggest that the cost of morphine does not show significant variations across the countries and confirms previous findings about limited availability. Additional analysis and data will be presented on the cost and affordability of morphine and on other medications.

**Acknowledgement:** This project is funded by IAHPC.

**Abstract number:** FC 4.4

**Abstract type:** Oral

### Barriers to Palliative Care Information in Central and Eastern Europe and the Commonwealth of Independent States

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**Aims:** Access to information including medical journals and educational opportunities is regarded as essential for health care professionals providing palliative care (pc). However, in many European countries, access to pc information is difficult. To gain a better understanding of potential barriers, the European Association for Palliative Care undertook a survey on pc information needs in 28 countries in Central/Eastern Europe (CEE) and the Commonwealth of Independent States (CIS).

**Methods:** A questionnaire was distributed in 16 different languages - online or as a hard copy version - via the national hospice and pc associations.

**Results:** In total, 584 health care professionals from 21 countries completed the questionnaire; the majority of them were physicians (47%), nurses (21%), and psychosocial staff (13%). The major barriers respondents encountered in accessing pc information were language, availability of and access to information. Expensive textbooks, subscription to scientific journals, and high congress fees relative to the low salaries were reported to impede access, but also political issues such as lack of leadership in pc, lack of a legal framework, or no access to authentic scientific literature. Particularly, difficulties finding accurate and reliable information in one's own language were reported. A lack of knowledge of relevant websites hampered access to adequate information with a reasonable effort. In relation to this, time was a frequently mentioned barrier, especially in the face of a high (clinical) workload. Many respondents mentioned the need for systematic and structured information.

**Conclusion:** To enhance access to pc information in CEE/CIS countries, affordable, systematic and up-to-date information

is needed, preferably in the participants' own language. The availability of one comprehensive source informing about pc would be desirable for health care professionals to keep themselves informed with a reasonable time investment.

**Abstract number:** FC 4.5  
**Abstract type:** Oral

## Exploring Public Awareness of Palliative Care

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**Background:** International research suggests that the general public appear to be confused about what palliative care is and who provides it (Hirai et al. 2011; McCarthy et al. 2011). Evidence suggests that this can lead to negative impressions and consequences for the quality of care provided to the dying and bereaved (Seymour et al. 2010). Given the aging population and the increasing number of patients requiring palliative care it is vital to explore the public's perception of such services.

**Objective:** To explore public's perceptions of palliative care. **Methods:** A sequential exploratory mixed methods research design was used. Phase 1 involved a descriptive, self-report, survey. The sample for the study included members of the Patient and Client Council Membership Scheme\* (n=4000). A survey pack was distributed via on line and by post. Data was analysed using SPSS and descriptive and inferential statistics were used to summarise the data. Phase 2 comprised semi-structured telephone interviews with those respondents who indicated a willingness to participate from stage 1 (n=60). The purpose of the interviews was to provide greater insight into the perceptions on palliative care with a focus on strategies that could be developed to raise awareness among the general public. These interviews were tape recorded, supplemented by field notes and content analysed.

**Results:** Key themes emerged from the telephone interviews focusing on an overall perception of palliative care and the importance of developing targeted strategies for raising public awareness of palliative care. Over 583 questionnaires were returned (Postal=344; Online = 239). The analysis of the questionnaire is ongoing but is exploring inter-group comparisons and significant differences on variables such as age and gender

**Conclusions:** The general public have differing perceptions and views on palliative care and the findings can inform policy makers on strategies to raise awareness of palliative care.

**Abstract number:** FC 4.6  
**Abstract type:** Oral

## Assessment of Noninvasive Opioids Availability in Russia

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Approximately 300 thousand cancer and HIV/AIDS patients die in Russia every year. According to research from the Global Access to Pain Relief Initiative, Pain and Policy Studies Group, and Human Rights Watch, in 2009 in Russia, only 18.7% of patients who died from cancer and HIV/AIDS received opioid analgesics. As a result, 183,134 patients died with untreated moderate to severe pain. Only injectable morphine, sustained release morphine tablets, and fentanyl patches were available for pain management.

**Aim:** To assess the availability of noninvasive opioids in adequate doses for cancer patients in Moscow and in the other 82 regions of Russia.

**Method:** This study is based upon expert opinion (K. Foley et al. 2006), which indicates the average oral morphine consumption for analgesia is 67.5 mg per day for 91.5 days.

**Results:** In 2008, 286,628 cancer patients died in Russia. Among them, 23,362 cancer patients died in Moscow. MST-continus consumption was 15,019 grams in Moscow and 5,365 grams in the other 82 regions of the Russian Federation. Fentanyl consumption was 28,912 morphine-equivalence grams in Moscow and 24,954 morphine-equivalence grams in the other regions. 2,431 patients received MST-continus and 4,681 patients received fentanyl patches in recommended doses in Moscow. However, only 868 patients received MST-continus and 4,040 patients received fentanyl patches in recommended doses in the other regions. 30.4% of cancer patients received noninvasive opioids in Moscow and only 1.9% of patients received noninvasive opioids in the other regions. Therefore, only 12,020 cancer patients (4.2%) in Russia were treated with noninvasive opioids in recommended doses.

**Conclusion:** The vast majority of cancer patients did not have access to noninvasive opioids. Sustained release morphine tablets and oral formulations of fast-acting morphine in adequate quantities should be available for pain management. There is an urgent need for improvement in pain policy in Russia.

## Family and Care Givers

**Abstract number:** FC 5.1  
**Abstract type:** Oral

### Psychological Distress in Family Caregivers of Terminally Ill Patients: Do High Caregiver Burden and Lack of Communication in the Family Increase Distress?

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**Aims:** Family caregivers of terminally ill patients are in a vulnerable position. Previous studies show that they are at an increased risk of psychological distress, e.g. depression and anxiety. Caregiver burden and lack of communication between the patient and the caregiver about the illness and the impending death seem to influence psychological distress in the family caregiver.

The aim of this study was to perform a nation-wide study investigating the association of both perceived caregiver burden and lack of communication with psychological distress in caregivers of terminal patients.

**Methods:** During 2012, a list of all adult patients in Denmark having been granted drug reimbursement in connection with terminal illness was obtained on a weekly basis from The Danish Health and Medicines Authority. All newly registered patients were mailed a letter requesting them to pass on the enclosed questionnaire to their closest relative. The assessment battery included the Burden Scale of Family Caregivers (BSFC), a pre-death version of Caregivers' Communication with patients about Illness and Death (pre-CCID), Beck's Depression Inventory II (BDI-II) and the SCL-90 anxiety subscale.

**Results:** As of October 2012, a total of 6,600 patients have been contacted and 2,581 caregivers have answered the questionnaire (response rate 39.1%). Results from the total inclusion period, i.e. the year 2012, will be presented describing the scales of depression, anxiety, caregiver burden and communication. Furthermore, the association of caregiver burden and communication with psychological distress will be analyzed using regression models.

**Conclusions:** This study will provide valuable information on the association of caregiver burden and communication with psychological distress. The perspective is to optimize the intervention for family caregivers in an attempt to prevent depression and anxiety as a reaction to the high caregiver burdens or lack of communication encountered.

**Abstract number:** FC 5.2  
**Abstract type:** Oral

### Relationships between Lack of Support during End of Life Care and Carers' Bereavement Outcomes

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**Background:** Studies suggest that insufficient support for carers during end of life care has negative impact on outcomes in bereavement. The Carer Support Needs Assessment Tool (CSNAT) has been developed to measure carers' support needs.

**Aim:** To investigate how perceived lack of support measured through CSNAT related to carers' outcomes in bereavement. **Sample:** Main carers of patients under the care of six hospice home care services across the UK: 182 carers took part (22% response rate).

**Methods:** Postal survey 4-5 months post bereavement measuring perceived lack of support during end of life care (CSNAT), early and present grief (TRIG), physical and mental health (SF-12) and distress (Distress Thermometer). Bivariate relationships were investigated (Spearman). Further multivariate analysis will be reported.

**Results:** Perceived lack of support on CSNAT domains was significantly related to bereavement outcomes. Insufficient support with talking with the patient about his/her illness or looking after own physical and emotional problems all related to early and present grief and mental health. Early

grief was also related to insufficient support with spiritual beliefs, finance, practical help in the home and knowing who to contact or what to expect. Mental and physical health were furthermore associated with insufficient understanding of the patient's illness and insufficient support with physical problems, respectively, while distress was also related to lack of support with physical and emotional problems (all at p< 0.01).

**Conclusion:** CSNAT support needs domains are related to carers' outcomes in bereavement, both supporting the criterion validity of the CSNAT and emphasising the importance of ensuring that carers feel supported during end of life care.

**Abstract number:** FC 5.3  
**Abstract type:** Oral

### Family Carers' Management of Medications for the Person Dying at Home: Findings from the 'Unpacking the Home' Study

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**Research aim:** Current UK health policy aims to provide choice about place of care at the end of life and increase the numbers of people dying at home. However, this policy is predicated on the assumption that there are family carers available to take responsibility for caring. The 'Unpacking the home' study elicited the views and experiences of family carers who have cared for a dying family member at home. This paper examines a key element of carers' responsibilities, the management of medications.

**Study design and methods:** Using a multidisciplinary social science approach, qualitative interviews were undertaken with 59 family carers (18 male, 41 female; mean age 71 years) in the north and south of England. The interviews were fully transcribed and subjected to a thematic analysis; a subset of 30 interviews also underwent narrative analysis.

**Results:** Family carers identified a number of important concerns about managing medication for the dying person at home. Although some support with medications is provided by physicians and nurses in the community, family carers take primary responsibility for drug administration. They reported anxiety about giving correct and timely dosages, and concerns about keeping their loved ones comfortable without overdosing or shortening their lives. For some, medications (especially opioids) have symbolic significance, and increasing analgesia signifies that the patient is deteriorating and approaching death.

**Conclusions:** Family carers require adequate information about drugs and their effects, and support in managing medication for a dying person. There is potentially a greater role for pharmacists in managing medications at the end of life, which would be of benefit to doctors and nurses as well as dying patients and their carers.

*This study was funded by Marie Curie Cancer Care.*

**Abstract number:** FC 5.4  
**Abstract type:** Oral

### Self-reported Quality of Life and Psychological Well-being in Patients with Primary Brain Tumours and their Caregivers

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Patients with primary brain tumours (PBT) encounter challenging symptoms many of which are unique to malignancies of the neurological system. Their caregivers also face unique challenges directly related to these symptoms. Palliative care services have an important role in addressing these needs.

**Objectives:**

1. To describe symptom burden and to measure the self-reported quality of life within the dimensions of physical, psychological, social and financial well-being of these patients.
2. To measure these parameters within caregivers and their effects on the relationship with the patient.
3. To screen for anxiety and depression within this caregiver group.

**Methods:** This is a cross-sectional quantitative survey. All adult patients who have a radiological or histological diagnosis of a PBT, are recruited through referrals to a regional palliative care service over a six month period. Consenting patients complete a validated questionnaire, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-

C30) supplemented by the brain cancer specific modules (EORTC QLQ-BN20). Consenting caregivers complete two validated tools, the Zarit Burden Interview and the Hospital Anxiety Depression Score (HADS). Patient and caregivers can participate independently of each other. Data will be entered on an Excel spreadsheet and analysed using SPSS 12.0.

**Results:** Data collection on-going.

**Conclusion:** Interim data suggests that patients with PBT have a significant symptom burden. Caregivers face challenges unique to neurological malignancies. Understanding quality of life issues for these unique patients and their caregivers, as well as psychological well-being of caregivers, allows healthcare professionals to predict likely needs so that they can provide appropriate support and send supportive and effective communication.

**Abstract number:** FC 5.5

**Abstract type:** Oral

### Burden on Family Carers and Difficulty in Covering Costs of Care at the End of Life: A Cross-national Retrospective Study via Representative Networks of General Practitioners

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**Background:** Given a growing number of people with long disease trajectories and a preference for home death, need for family care is expected to increase. However, population-based data on the prevalence of burden in family carers of people at the end of life and of care-related financial burden are scarce.

**Objectives:** To describe and compare, with respect to patients at the end of life in Belgium, the Netherlands, Italy and Spain, the number and associated factors of family carers feeling overburdened and of families with difficulty in covering costs of care.

**Design and methods:** Cross-national retrospective study. In 2009 and 2010, representative GP networks weekly registered every non-sudden death among their patients ( $\geq 18$  years) using a standardised form surveying the patient's last three months of life including carers' burden. Analysis involved descriptive statistics,  $\chi^2$ -tests and multiple logistic regression analyses.

**Results:** We studied 4,466 deaths. For 28% (Belgium), 30% (Netherlands), 35% (Spain) and 71% (Italy) GPs judged that carers felt overburdened ( $p < .001$ ). For 8% (Spain), 14% (Belgium), 36% (Netherlands) and 43% (Italy) they reported difficulty for families in covering the costs of care ( $p < .001$ ). Carers' burden and difficulty in covering costs were more likely for younger patients (Belgium, Italy). Cancer (versus non-cancer) death was associated with lower difficulty in covering costs (Italy, Spain). Residing in a nursing home, as opposed to at home, predicted lower carers' burden in all countries except the Netherlands.

**Conclusions:** In all countries studied, and particularly in Italy, GPs observe overburdened family carers and difficulties in covering costs of end-of-life care. Carers of patients at home and carers of younger patients may be at particular risk of burden. This should be considered particularly when advocating a shift in end-of-life care from institutions to home.

**Funding:** European Union Seventh Framework Programme (2007-2013).

**Abstract number:** FC 5.6

**Abstract type:** Oral

### "I Suddenly Have Strength to Carry on" - The Stressors and Resources of Carers of Patients with Incurable Progressive Illness in Two African Countries

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**Background:** Central to palliative care in sub-Saharan Africa is the provision of care by family carers. To support carers, a comprehensive understanding of carer burden is needed, yet there is limited evidence in this area from Africa.

**Aim:** To investigate the burden experienced by carers of patients receiving palliative care in South Africa and Uganda.

**Methods:** Qualitative interviews were conducted with a purposive sample of family carers of patients at 5 palliative care services. We defined carer burden as the carer's physical and emotional response to the stressors of caregiving and used the framework of the Stress Process Model (Pearlin et al. 1990), focussing on the two most relevant domains: stressors and mediators. Data were analysed thematically in English.

**Results:** 37 carers (mean age 45) were interviewed in 4 languages. Most were women related to the patient. Primary carer stressors related to the day-to-day care and emotional support of the patient; secondary stressors included financial hardship, family responsibilities and social isolation. Mediators were interconnected and included external resources (family, community and patient-carer relationship) and internal resources (spiritual beliefs and confidence).

**Conclusions:** Findings highlight, for the first time, the multidimensional nature of the burden experienced by carers in sub-Saharan Africa, and support the utility of Pearlin's Stress Process Model in understanding this population. The effects of primary and secondary stressors on burden and well-being are mediated by carers' social, relational, spiritual and psychological resources.

Strengthening one resource strengthened others, but equally the failure of one resource could have far-reaching detrimental consequences. In supporting carers, policy makers and service providers must recognise that the alleviation of carer burden requires supporting carers' resources as well as relieving the stressors they experience.

**Funders:** Big Lottery Fund UK

## Non-Cancer

**Abstract number:** FC 6.1

**Abstract type:** Oral

### The Challenging Landscape of End Stage Kidney Disease - What Palliative Care Is Needed?

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**Background:** The haemodialysis (HD) population has grown exponentially in recent years. Prognosis is poor and palliative care needs remain unclear (Kurella, 2010).

**Aims:** This study examines symptom burden (SB), health related quality of life (HRQoL), demographic and HD factors to better understand the palliative care needs of this population.

**Methods:** An international multi-centre cross-sectional study. Two validated clinical tools - the Palliative care Outcome Scale (POS-s Renal), a measure of SB and the EQ5D, a measure of HRQoL, were administered to prevalent HD patients in the UK and Ireland.

**Results:** 896 HD patients, mean age 64 (SD 16.38), 60% male, 37% with diabetes were included. Mean number of symptoms was 8 (range 0-17). 21% had >11 symptoms and 40% reported between 5 and 10 symptoms. The most commonly reported symptoms were shortness of breath at 69% (95% CI 66-72%), poor mobility 64% (95% CI 61-67%) and pain 60% (95% CI 57-63%), which were described as severe or overwhelming by over 20% of these patients. Factors associated with higher symptom burden included female gender (median POS score 14v11 for males,  $p=0.03$ ), and transplant ineligibility (median POS score 13v10 for those on pool,  $p=0.0104$ ). There was a significant difference between symptom burden of Irish v UK patients (12.8v15,  $p=0.0002$ ). High total POS score had a negative association with HRQoL ( $\rho=-0.465$ ,  $p<0.0001$ ). Age and HRQoL were negatively associated ( $p=0.0078$ ). Mean perception of health (EQ5D visual analogue scale) score in those with ages 70-80 was 58(SD 23) by comparison to the UK population norm of 75 (SD 18.2).

**Conclusion:** In this international study of the haemodialysis population, symptom burden is high and health-related quality of life is significantly poorer than in age-matched

population norms. Routine symptom assessment, with judicious specialist palliative care input, should form an essential component of comprehensive clinical care of this polysymptomatic group.

**Abstract number:** FC 6.2

**Abstract type:** Oral

### 'My Dreams Are Shattered down and it Hurts Lots' - A Multi-centre Qualitative Study of HIV-related Problems and their Management in Kenya and Uganda

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**Background:** Despite the huge burden of HIV in sub-Saharan Africa, there is little evidence of the multidimensional needs of patients with HIV infection to inform the person-centred care across physical, psychological, social and spiritual domains stipulated in policy guidance.

**Aim:** To describe the problems experienced by people with HIV in Kenya and Uganda and the management of these problems by outpatient services.

**Methods:** In-depth qualitative interviews were conducted with HIV patients, caregivers and service staff at 12 HIV outpatient facilities (6 in Kenya, 6 in Uganda) and analysed thematically.

**Results:** 189 people were interviewed (83 patients, 47 caregivers, 59 staff). The impact of pain and symptoms and their causes (HIV, comorbidities, treatment side-effects) were described. Staff reported that effective pain relief was not always available. Psychosocial distress (isolation, loneliness, worry) was exacerbated by stigma and poverty, and detrimentally affected adherence. Illness led to despair and hopelessness. Provision of counselling was reported, but spiritual support appeared to be less common. Neither pain nor psychosocial problems were routinely reported to service staff. Collaboration with local hospices and income-generation activities for patients were highlighted as useful.

**Conclusions:** The findings demonstrate the multiple and interrelated problems associated with living with HIV and how psychosocial and spiritual distress can contribute to 'total pain' (Saunders, 1964) in this population. Holistic care and assessment that take into account psychological, socio-economic and spiritual distress are required alongside improved access to pain-relieving drugs, including opioids.

**Funder:** United States Agency for International Development.

**Abstract number:** FC 6.3

**Abstract type:** Oral

### Psychosocial Burdens in 165 Patients with ALS - Is There a Need for Involvement of Palliative Care Services?

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**Introduction:** The incidence of amyotrophic lateral sclerosis (ALS) is about 3-4/100,000. Most patients experience progressive paralysis, dysarthria, and severe dysphagia during the course of the disease. Death occurs after 3-4 years - usually due to respiratory insufficiency. It is difficult for patients as well as for their caregivers to cope with the relentless progression of physical disabilities. The study was aimed to systematically assess psychosocial burdens of ALS patients and their family. Furthermore, a possible need for the involvement of palliative care services was investigated.

**Methods:** We conducted detailed interviews with seven ALS-patients and their care-givers. The interview protocols were used to generate semi-structured questionnaires which were mailed to 229 ALS patients and their care giver. **Results:** The return rate was 85%. 29 patients have been deceased in the meantime. 165 questionnaires were suitable for further evaluation. Patients rated their present quality of life (QoL) on a numerical scale from 0-10 (at standard deviation  $\pm$  mean)  $3.5 \pm 2.6$ . The QoL before the disease was rated at  $7.9 \pm 2.8$ . Caregivers rated their own QoL even lower ( $3.3 \pm 2.7$ , before disease  $6.4 \pm 3.7$ ). The majority of patients worried that their caregivers possibly could not have enough leisure time ( $6.6 \pm 3.5$ ). Many patients indicated to

## Free communication sessions

have guilt feelings ( $6.6 \pm 3.5$ ). 84% of patients would be interested in support from palliative care services in order to master the psychosocial burdens.

**Conclusions:** A variety of unmet psychosocial needs can be identified in ALS patients and their caregivers. Professional care for ALS patients should pay attention to the massive burdens of care givers. Guilt feelings are frequently found in ALS patients and should be discussed. The majority of ALS patients and their families would be interested in support from palliative care services-if only offered to them.

**Abstract number:** FC 6.4

**Abstract type:** Oral

### 'Everything's Changed. Every Single Thing.': Exploring the Experiences of Renal Patients Regarding Commencing Haemodialysis, the Impact on their Life, and their Preferences for Future Care

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**Background:** Recent reports have highlighted a need to improve end of life care for people with End Stage Renal Disease (ESRD), particularly due to the increasingly elderly, frail and co-morbid renal population, for whom all dialysis is essentially palliative.

**Aims:** To explore the experiences of people with ESRD regarding starting dialysis, its impact on quality of life, and their preferences for future and end of life care.

**Methods:** Semi-structured qualitative interview study of people with ESRD. Participants reflected on starting dialysis, the impact on quality of life, and their preferences for future and end of life care. Twenty patients at two UK NHS hospitals, were purposively sampled by age, time on dialysis, and symptom burden using the POS-5 (Palliative Outcome Scale - Symptoms) Renal. Interviews were transcribed verbatim and analysed using thematic analysis in the framework approach. Recruitment ceased once data saturation had been achieved.

**Results:** Themes emerged around the trauma of starting dialysis, denial, fear, grief at losing their health, and the life changing impact of dialysis for patients and families. Experiences at the dialysis unit varied. Challenges included getting information, communicating with staff, and the 'conveyor belt' dialysis units. Positives included the kindness of some staff, and the equipment quality. Participants also reported a lack of opportunities to talk about the future, and to be involved in decisions. However, discussion of these sensitive issues was more acceptable to some than others.

**Conclusions:** Renal patients have considerable unmet advance care planning needs. Despite the paradigm shift towards a care focus, there is a need to improve end of life care for this population, and to normalise discussion of deterioration, goals and preferences. However, an individualised approach is essential - one size does not fit all.  
**Funding:** This work is a key component in a project led by NHS Kidney Care.

**Abstract number:** FC 6.5

**Abstract type:** Oral

### Palliative Medicine and Stroke - When Should We Be Involved?

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**Background:** Stroke is the third leading cause of death in Ireland and the single largest cause of adult disability. 20% of patients die in the first month and 35% are significantly disabled following a stroke. Outcomes are best within dedicated stroke units. Challenges to provision of palliative care in this subgroup include the unclear illness trajectory impacting on decisions re: timing of referral, allocation of services, service delivery, and symptom control.

**Objective:** To describe admissions to the stroke unit in 2010 in terms of their palliative care needs. To identify potential triggers for referral to palliative care services.

**Methods:** Retrospective chart review of admissions to UCHG stroke unit during 2010. An audit tool was developed for data collection. Statistical analysis completed using SPSS.

**Results:** 63 patients identified 58.73% male 41.3% female. Median age 74years (43-98yrs). 74.6% lived with family prior to admission, 15.9% living alone, 9.5% in nursing home. Median length of stay 13days (1-61 days). 76.2% with baseline KPS  $\geq 90$  (median 100, range 40-100). 31.7% with discharge KPS  $\geq 90$  (median 60, range 0-100). 8 patients (12.7%) died. 6.3% of admissions to the unit were referred to Palliative medicine, all for end of life care. Admission GCS  $< 8$  (chisq8.276 df 1 sig 0.004), TACS stroke subtype (chisq8.117 df 3 sig 0.044) and Rankin score  $\geq 4$  (chisq22.408 df 4 sig 0.000) associated with higher mortality. Patients discharged home (50.8%), long stay unit (22.2%), nursing home (11.1%), hospice (1.6%) and other hospitals (1.6%).

**Conclusions:** In our sample, palliative care services were involved only for end of life care. Bamfords stroke subtype (TACS), admission GCS, Rankin score could help guide prognostication. Assessment of symptom control was limited by poor documentation. The palliative care needs of stroke survivors need to be highlighted. An algorithm for referral to palliative care will be developed for inclusion in the integrated stroke pathway.

**Abstract number:** FC 6.6

**Abstract type:** Oral

### Promoting Access to Palliative Care for those Living with Life-limiting, Long Term Conditions: The Right Way Forward

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**Aims:** The palliative care approach improves care of patients with advanced conditions but family doctors and hospital clinicians often report difficulties in recognising when a patient is at risk of dying in the next 12 months, particularly in unpredictable, non-cancer dying trajectories. This study identified complex challenges limiting access to palliative care for people with advanced organ failure.

**Study design and methods:** Ward staff in four units of a large Scottish hospital screened all patients with advanced kidney, liver, heart or lung disease after an unplanned admission using the SPICIT<sup>™</sup> (the Supportive and Palliative Care Indicators Tool) which identifies patients likely to benefit from supportive and palliative care. We reviewed the admission and care planning processes of SPICIT<sup>™</sup> positive patients using a mixed methods approach in line with the initial development phases of MRC Framework for complex interventions.

**Results:** The SPICIT<sup>™</sup> identified 130 patients with clinical indicators of advanced conditions. Many had multiple unplanned admissions, poor symptom control, a deteriorating performance status and increased care needs. A third died within 6 months. We identified several barriers to holistic, proactive care: unplanned admissions due to sudden acute deteriorations, rapid throughput of patients in hospital wards, complex often negative attitudes to "palliative care", and a discharge process focused on rapid resolution of medical problems. Patients and families used "healthy" denial to cope and "lived each day as it comes".

**Conclusion:** The SPICIT<sup>™</sup> helped clinicians identify patients with unmet needs at risk of dying in 12 months and enabled ward staff to consider the value of more proactive, identification, assessment and care planning. Hospital specialists need to offer palliative care alongside appropriate disease management in a way that respects patients' coping styles whilst offering them meaningful choices about their current and future care.

## Education

**Abstract number:** FC 7.1

**Abstract type:** Oral

### Family Carer Perspectives on Palliative Care Education and Service Provision for People with Learning Disability

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The international literature highlights concerns regarding the palliative care that people with learning disabilities are often offered (Michael, 2008; Wageman et al, 2010). There are also limited referrals of people with learning disabilities to hospice services (Stein, 2008; Ryan et al, 2010). Yet palliative care services need to be tailored for this

population, and their family carers.

**Aim:** The aim of this doctoral study was to develop a multi-media resource, to enable professionals to provide palliative care to people with learning disabilities and their family carers.

**Design:** A sequential, exploratory mixed methods design was used. In Phase 1 a purposive sample of five family carers of people with learning disabilities were recruited to semi-structured interviews. Data were thematically analysed (Newell and Burnard, 2006) and findings reflected holistic care aligned with the National Good Standard Framework for End-of-Life Care (GSF). This informed a proforma in Phase 2 a regional scoping study of end-of-life service provision to people with learning disabilities within sixty-six services. Descriptive statistics were used.

**Results:** Four themes emerged from the interviews: 'resilience in caring', 'information and preparation', 'co-ordinating care' and 'learning needs of professionals'. A response rate of 71.2% (n=47) was obtained from the scoping study which provided evidence of services' response to family carers of people with learning disabilities needing end-of-life care. A multi-media resource using a robust service user perspective, including that of a family carer, was developed.

**Conclusions:** The long term caring role of family carers of people with learning disabilities enables expertise to inform professional education and practice in palliative care. Findings suggest professionals should recognise this long term role and work in partnership with family carers in addressing the needs of people with learning disabilities at end-of-life.

Funder: HSC R&D Division

**Abstract number:** FC 7.2

**Abstract type:** Oral

### Mapping the Teaching of Palliative Medicine in European Universities: Report from a 2012 EAPC Survey

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**Background:** Teaching Palliative Medicine (PM) at medical schools is a relatively new topic in the scientific literature.

**Aim:** To conduct an exploratory study of the teaching of PM in the university across 53 European countries.

**Method:** A questionnaire was designed to explore the situation in each country: questions included the number of universities teaching PM; the level of education; whether the subject is elective or mandatory; and the existence of Chairs/other positions of professor, etc. A combination of quantitative/qualitative analysis was undertaken on the data. The questionnaire was part of the EAPC Facts Questionnaire (FQ) which was completed by a 'key person' in 47/53 European countries; the information from the FQ is incorporated within the Second Edition of the EAPC Atlas of Palliative Care in Europe.

**Results:** PM is taught at medical schools in the university in at least 21 European countries. PM is taught at each medical school in nine countries (Switzerland, Norway, Austria, Hungary, Slovenia, France, Cyprus, Malta, and Moldova). In other countries (Poland (9/15), Spain (21/41), Latvia (2/4), Lithuania (4/9), Germany (21/36), Macedonia (1/3), Czech Republic (2/7), Portugal (2/7), Italy (3/45) and also UK (no detailed data available, NDDA) Georgia (NDDA), and Turkey (NDDA) PM is offered at some medical schools. PM as a subject may be either compulsory or optional but there is a trend towards it being compulsory. Chairs in PM exist in UK, Hungary, Germany, Poland, Norway, Netherlands, Sweden, Slovakia, Lithuania, Georgia, Denmark and Austria. In some countries, Faculties of Medicine only have associate professors (Belgium, Spain, Netherlands and Slovenia).

**Conclusion:** In 2012, PM is already being taught in a significant number of universities and countries within Europe. Chairs of PM have been identified in countries with high development of palliative care (PC) and may be used as a further indicator of PC development.

**Abstract number:** FC 7.3

**Abstract type:** Oral

### The Impact of a Novel, Online Learning Module on Specialist Palliative Care Nurses' Pain Assessment Knowledge and Practices

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**Background:** Managing complex pain is core business for specialist palliative care services and nurses play a key role in this process. Despite, guidelines recommending routine pain screening, assessment and reassessment practices, there is often sub-optimal evidence of this occurring, which impact on pain management. Addressing entrenched clinical practice is challenging, and requires consideration of a range of targeted strategies, including multi-faceted educational interventions.

**Aim:** To test the acceptability, feasibility and impact of a novel on-line learning pain assessment module using a spaced and repetitive learning format (Spaced Education) on specialist palliative care nurses pain assessment knowledge, attitudes and practices.

#### Methodology:

**Study design:** A quasi-experimental pre-post test design. Intervention Pain assessment scenarios were developed by an expert panel and delivered to participants via email using a Spaced Education.

**Methods:** Survey and chart audit data was collected at four time points: baseline (T1), immediately post intervention (T2), eight weeks (T3), and sixteen weeks (T4)\*. The survey assessed changes in pain assessment knowledge and attitudes, while the chart audit appraised the quality of pain assessment documentation.

**Statistics:** Descriptive statistics and Multivariate Analysis of Variance comparing the pre-post test mean survey scores.

**Results:** Participants (n=74), predominantly registered nurses (82%) working in two specialist palliative care services enrolled to complete the pain assessment module. Overall pain assessment knowledge increased post intervention: [T1] (7.23, SD±1.49); [T2] (8.07, SD±0.94); and [T3] (8.22, SD±0.94). Pain assessment confidence increased from T1 to T2 (7.38 vs. 8.74). This improvement was reflected in the chart audit data, where pain assessment documentation increased from T1 to T2 (2.48 vs. 4.20 per admission), with the majority (87%) of pain assessments undertaken by intervention participants at T3.

**Conclusion:** This pilot suggests that Spaced Education offers the potential of being an effective format for delivering specialised clinical content that may translate into practice change. Further evaluation of this on-line learning methodology is warranted using more robust research designs.

\* In progress

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Abstract number: FC 7.4

Abstract type: Oral

### Lost for Words? Communication Training for Medical Students as Part of the Palliative Medicine Curriculum

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**Background:** Communication with patients in a palliative care context - especially on malignant diagnosis or restricted prognosis - require high level communication skills. At the University of Bonn non-professional actors, e.g. volunteers in palliative care or amateur actors embody scripted roles in order to create a realistic setting. The role plays reduce inhibitions and fears related to emotional aspects of medical work. As a result difficult communication can be managed with greater self-confidence, and closer to the patient's needs.

**Method:** Communication training was introduced in the palliative care curriculum for medical students in winter 2011/2012. This mandatory block course combines 28 hours of lectures, workshops, self-experience, and role-plays. Fourteen "actor patients" were trained with six role scripts that had been based on patient stories. The role plays are performed in small groups of 6 students and moderated by members of the palliative care team including physicians, nurses and psychologists. Each 10-minutes role play starts with a warm-up exercise for both the student acting as the doctor and the actor. Formalized feedback is given the first by the student himself and the actor, followed by the watching students, and rounded up by the moderator identifying strengths and weaknesses.

**Result:** In standardised feedback forms students evaluated this training as extremely helpful and realistic. The intense performance of the actor patients as well as their age fitting their role were important factors. The effectiveness of the role plays depended predominantly on realistic description of patients and diseases in the storyboards.

**Conclusions:** Student evaluation demonstrated the feasibility and effectiveness in teaching and education. Transfer of this method to training programs and continued medical education of physicians and nurses are planned.

Abstract number: FC 7.5

Abstract type: Oral

### Competencies of Nurses Working in Specialized Palliative Care Services in Romania

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**Aim:** To determine the level of competencies of nurses working in specialized Palliative Care (PC) services, to highlight the barriers in implementing those competencies and the potential positive results once PC is recognized as a specialty for nurses.

**Method:** Prospective survey of nurses working in PC specialized services, done between January - May 2012. The questionnaire was developed based on EAPC recommendations: 3 levels of education and 7 clinical domains, graded on 1 to 5 Likert scale and 2 open questions regarding barriers and positive results.

**Results:** Out of 170 nurses currently working in the existing 20 PC specialized services - according to the PC directory 2010, 148 returned the completed questionnaire (87%). The respondents declared that, in their clinical practice, they implement competencies that belong to level A education - 84%, to level B education - 13%, to level C education - 3%. Out of 7 domains of competence, 6 positively correlated with the general level of education (p between 0.000 and 0.016). The majority of competencies from each domain preponderantly implemented in the clinical practice belong to level A education. The top 3 barriers in implementing competencies are considered to be: lack of specialized education (40), lack of financial resources (37), lack of professional autonomy (33). The top 3 positive results predicted to happen once PC is recognized as a specialty for nurses in Romania are: enhancing the quality of services delivered (63), raise in professionalism/self-esteem (41), professional autonomy (37).

**Conclusions:** The majority of respondents have a basic level of education in PC, acquired during basic training or through continuous medical education program (level A). The results underline the need for further training of nurse to reach competencies at C level ideally a Nursing Specialization Program in Palliative Care for Romania.

Abstract number: FC 7.6

Abstract type: Oral

### E-learning Palliative Care Program in Latin America: Improvements in Knowledge and Self Perceived Comfort Level

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Palliative Care (PC) offers effective methods for the control of distressing symptoms in patients with advanced diseases. Courses via internet were delivered in Spanish for nurses and physicians based on a constructivist approach with asynchronous and synchronous activity. Modular-based: ten modules; each lasting one-week long with specific topics, such as communication, pain management, delirium. Problem-based: every module analyzed the clinical situation and therapeutic approaches for each stage of the longitudinal case with specific topics.

**Objective:** To describe changes in knowledge and self perceived comfort levels of learners after taking the PC online course.

**Method:** Learners were asked to complete an online questionnaire pre and post course; it consisted of a knowledge quiz and a survey assessing self perceived comfort levels considering major PC areas: symptom control, communication and psychosocial support. Pre and post responses of 60 nurses and doctors enrolled in 3 courses (2009-11) were analyzed.

**Results:** A total of 41 doctors and 19 nurses enrolled in the courses; 75% completed it.

There was a significant increase in knowledge between the pre- and post-course assessments in all courses.

Over the three years there were significant changes in comfort levels reported by learners in the assessment and treatment of pain and other symptoms. There were no significant differences in comfort levels related to the assistance and communication with patients and their families.

**Conclusion:** Results provided evidence of the effectiveness of the course in increasing knowledge and self perceived comfort levels to assess and treat pain and other symptoms. The e-learning Palliative Care Program in Latin America is a useful tool which facilitates access to training of palliative care doctors and nurses.

## Ethics

Abstract number: FC 8.1

Abstract type: Oral

### Medical, Philosophy and Law Students' Attitudes towards Euthanasia in Flanders, Belgium: Role of Academic Background, Philosophy of Life, Relevant Knowledge and Experience

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**Research aims:** Professionals with different academic backgrounds are involved in end-of-life decisions (ELD). It can be expected that persons with different academic backgrounds have different perspectives to ELD. With Belgium having a legal euthanasia practice involving physicians, lawyers, and ethicists, differences were investigated between medical, law, and philosophy students in terms of attitudes towards euthanasia and existence of the euthanasia law. Moreover, associations of these attitudes with other characteristics were examined.

**Study design and methods:** In 2012, all 1390 students of the faculties of medicine, law and philosophy at Vrije Universiteit Brussel were invited by e-mail to fill in an online, anonymous questionnaire. Dependent variables were attitudes towards euthanasia and existence of the law. Independent variables were student's discipline, philosophy of life, attendance of a course about end-of-life actions, experience with euthanasia or palliative sedation in a relative or friend, and years of education. Logistic regression analysis was performed.

**Results:** 391 questionnaires were returned; 4% of the students completely rejected euthanasia and 4% rejected the existence of the euthanasia law. More medical students (OR=2.67), students without experience (OR=2.16) and catholic students (OR=2.02) accepted euthanasia only under certain conditions instead of always. A positive attitude towards the existence of the euthanasia law was more likely among catholic (OR=16.76) and humanist students (OR=8.44) compared to other life stances, including Muslim.

**Conclusion:** Existence of the euthanasia law was equally supported by students with different academic perspectives. More medical students accepted euthanasia only under certain conditions. The need for clear communication about these conditions should be emphasized in students' training. Philosophy of life is a factor to be considered in understanding differences in these attitudes.

No funding.

Abstract number: FC 8.2

Abstract type: Oral

### Palliative Sedation from the Perspective of Terminally Ill Patients - A Report from a Qualitative Study

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**Research aims:** Palliative sedation until death (PS) is associated with highly debated ethical issues and often provokes serious concerns in health care professionals and relatives. This paper investigates the subjective ideas and wishes of palliative care patients themselves regarding the option of PS.

**Methods:** In a semi-structured interview study on terminally ill cancer patients' wish to die (N=30; 116 interviews) we also asked patients and relatives about their views on PS. Data analysis: Grounded Theory and Interpretive Phenomenological Analysis.

**Results:** Two topical levels emerged:

- (1) Informative level: Many patients reported that they knew little about PS if anything at all. Only few patients felt well informed. Generally, patients understood that in PS they will sleep continuously until they die, and they will find redemption from suffering. Most patients who received information reported that already the knowledge about the availability of this option gave them reassurance and reduced fear.
- (2) Level of moral significance: Patients were careful about the moral implications of PS, asking i.e. whether and how PS can be meaningfully distinguished from (assisted) suicide. Others were concerned about the burden for their loved ones having to assist them without the possibility to communicate. Several patients who desired to die, but for whom hastening death was not a moral option, saw PS as a morally acceptable alternative. Relatives struggled with the prospect to loose contact

with their loved ones, but found it more important to accept 'social death' over seeing their relative suffer.

**Conclusions:** These results show that patients and relatives have relevant moral questions to solve in regard to the option of PS. Improvement of information and open conversation about PS in clinical contexts is ethically important, as knowledge about the availability and the understanding of the concept of PS can considerably improve palliative patients' situation.

**Abstract number:** FC 8.3  
**Abstract type:** Oral

## Ethical Aspects in Palliative Care for Patients with Cardiac Disease - Case Series Observations

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**Background:** Epidemiology, prognosis, symptom burden and other reasons favour palliative care support also for patients with underlying cardiac disease. It is unclear, though, to what extent a disease specific palliative care approach for patients with cardiac disease is required. Here, we focus on disease specific and distinguishing ethical questions in the care for patients with cardiac disease that have to be taken into consideration when expanding palliative care on this particular group of patients.

**Method:** We therefore retrospectively analysed institutional data (palliative care unit, outpatient clinic, consultation service, home care) with respect to patients with cardiac disease and describe a case series of ten index patients suffering from congestive heart failure that illustrate disease specific ethical questions and conflicts.

**Results:** The ethical issues discussed comprise: redefining palliative treatment goals, role of focal symptoms for involving palliative care services, terminal care, advance care and emergency procedure planning, the role of disabling internal devices (ICD) as part of a palliative care concept, palliative care for patients with external left ventricular assist devices (LVAS) and for patients where heart transplantation is still under discussion, the role of formal ethics consultation, and non-cardiac palliative care patients with unexpected cardiac complications.

**Discussion:** Ethical decision making is shown to be a major component of specialized palliative care support for patients with cardiac disease, and the given ethical conflicts focused on disease specific issues not fully congruent to ethical issues in palliative care for cancer patients. Therefore, as palliative care aims to reach out for patients with cardiac (and other non-cancer) disease, answers to these new ethical questions have to be found urgently, and a disease adapted palliative care approach seems to be even more needful.

**Abstract number:** FC 8.4  
**Abstract type:** Oral

## The Belgian Model of End-of-Life Care: Heresy, Experiment, Prototype?

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**Research aims:** Physician-assisted dying (PAD) is legal only in the Benelux countries. Elsewhere palliative care (PC) and PAD are often considered incompatible for fundamental reasons and antagonistic because PAD might stunt the development of PC, endanger vulnerable patients and compromise public confidence in health care.

How does the Belgian experience inform this debate?

**Methods:** Review of the historical, legislative, regulatory and epidemiological data

**Results:**

- the Flemish Federation of Palliative Care has endorsed "comprehensive PC", including the possibility of PAD, in order to prioritise the patient's values and to promote "total care" also in the practice of PAD. However, individual caregivers' conscientious objections are respected
- concomitant with the euthanasia law, a PC law mandated universal access to PC, doubled its public funding and integrated PC in social security. In 2007 PC was at an overall development level similar to the UK, ahead of several EU countries
- the largest per capita participation in the EAPC conferences was Belgian.
- among all deaths in 2007, ~30% benefited from PC and 2% were by PAD, half of the latter after a PC pathway.
- spiritual and existential care is more intensive in cases of PAD.
- vulnerable patients are under-represented among PAD recipients, there is more consultation before end-of-life decisions and life-abbreviation without explicit request has decreased.
- confidence in the health-care system has increased from

87% in 1999 to 92% in 2008.

- minor transgressions of the law remain unprosecuted but e.g. non-reporting is becoming less frequent.

**Conclusions:** In Belgium PC and legal PAD were more synergistic than antagonistic. As ethically disputable practices have rather decreased, "practical slippery slope" effects did not materialise. However, as extensions of the scope of the law are envisaged, there is some suggestion of a "logical slippery slope".

**Abstract number:** FC 8.5  
**Abstract type:** Oral

## Forgoing Artificial Nutrition or Hydration (ANH) at the End of Life in Belgium

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**Objectives:** The purpose of this study is to examine the frequency of decisions to forgo-withhold or withdraw-artificial nutrition or hydration (ANH) at the end of life in Belgium and to describe background characteristics of the patients and the decision making process.

**Methods:** Postal questionnaires regarding end-of-life decisions (including ANH) were mailed to physicians certifying a large representative sample (n=6927) of Belgian death certificates in 2007.

**Results:** Response rate was 58.4%. A decision to forgo ANH occurred in 6.6% of all deaths (4.2% withheld, 3.0% withdrawn). Being female, dying in a care home or hospital, and suffering from nervous system diseases (including dementia) or malignancies were the most important patient-related factors positively associated with a decision to forgo ANH. Physicians indicated that the decision to forgo ANH had had some life-shortening effect in 77% of cases, and estimated this effect at one week or more in 21%. Forgoing ANH was requested by the patient in 10%. Not consulting with the patient was mostly due to incompetence (coma or dementia). The family and other caregivers were mostly involved in the decision making.

**Conclusion:** An important proportion of deaths in Belgium are preceded by a decision to forgo ANH. These are ethically challenging decisions for all involved as nourishment epitomizes the basic care for a person in need and ANH decisions impact on patients' longevity. The finding that only 10% of patients themselves requested ANH to be forgone shows that the family and care team are mostly burdened with these decisions. Though physicians in Belgium are legally entitled to withhold or withdraw any clinically 'pointless' treatment on their own accord, the gravity of ANH decisions calls for a model of shared decision making, preferably with the patient. Developing a protocol for timely discussion (particularly in institutional end-of-life care settings) may help to ensure such a decision model.

**Abstract number:** FC 8.6  
**Abstract type:** Oral

## The Association between Past Grief Reactions, Quality of Hospice Care Assessments and Bereaved Caregivers' Perceptions of Parenteral Hydration during the Last Weeks of Life

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**Context:** Barriers to the conduct of clinical trials with palliative care patients and caregivers are numerous, yet evidence based end of life clinical practice is vital.

**Aims:** To identify the demographic, clinical, psychosocial and health system-related factors associated with the overall benefits of parenteral hydration (PH) for hospice cancer patients during last weeks of life as reported by bereaved caregivers.

**Methods:** Bereaved caregivers previously enrolled in a randomized, double-blind controlled trial investigating the efficacy of PH in hospice cancer patients were interviewed 3-23 months after their loved one's death to identify their attitudes and beliefs regarding PH using a 16-item, Likert-type scale, their quality of hospice care perceptions (Family Evaluation of Hospice Care) and their past and present grief levels (Texas Revised Inventory of Grief). Secondary data analyses were conducted to identify predictors of caregiver PH perceptions using linear regression analysis.

**Results:** Seventy-six interviews with bereaved caregivers were completed (78% response rate). Most caregivers agreed/strongly agreed (76%) that PH was beneficial for

their loved one. The majority (84%) reported that the quality of hospice care received was "very good" or "excellent" and 46% were classified as having an absence of grief following their loved one's death. Factors significantly associated with favorable PH perceptions were: 'excellent' ratings of hospice care (P = 0.003), absence of past grief (P = 0.035) and female caregiver gender (P = 0.040).

**Conclusion:** Findings suggest that clinical research in hospice populations is feasible and significantly associated with improved levels of satisfaction with standard care and initial adjustments to death. Longitudinal studies with diverse groups of caregivers are needed to establish the direction of these associations and examine how PH in the hospice context may influence satisfaction with care and the bereavement process.

## Palliative Care in the Elderly

**Abstract number:** FC 9.1  
**Abstract type:** Oral

### Implementation and Audit of the 'Proactive Elderly Persons' Advisory Care' Planning Project or Modified 'PEACE Project': A Collaboration between Geriatric and Specialist Palliative Care Services to Improve End of Life Care for Elderly Patients Using a Future Care Planning Tool

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The Proactive Elderly persons' Advisory Care' planning project, or modified PEACE Project, was undertaken in an acute hospital between February and August 2012. The project aimed to introduce a future care planning document for elderly patients approaching the end of their lives which would prevent inappropriate and potentially harmful hospital readmissions. The project focussed on elderly patients from nursing homes, where evidence suggests that hospital readmission rates at the end of life are high and that palliative care provision needs to be improved. Almost all patients eligible for the project had cognitive impairment which prevented their participation in care planning. Most often therefore, the PEACE document recorded discussions between carers and the Geriatric team which could advise on best interest decisions at a future date.

The original PEACE document was developed at Kings College Hospital, London. Locally, a number of modifications to this document were made through consultation with the Palliative Care team including compliance with the Mental Capacity Act 2005, reference to 'Just In Case' medications and the Liverpool Care Pathway in the last few days of life, and inclusion of a DNACPR decision. In contrast to the Kings' project, local Hospice services supported the introduction of the PEACE tool into nursing homes.

An audit of patient outcomes was completed in October 2012. Of the 42 patients eligible for the study only 2 patients were readmitted to hospital; both for treatment of acute infection in accordance with their PEACE plan. At follow-up 16 patients had died; but importantly none were readmitted to die in hospital. 39 patients had contact with hospice services, and each of the 16 who died had a DNACPR decision in place. The PEACE project shows that future care planning for complex, elderly patients approaching the end of their life is possible, and may prevent inappropriate hospital readmission and promote better palliative care.

**Abstract number:** FC 9.2  
**Abstract type:** Oral

### Hospitalizations of Nursing Home Residents with Dementia in the Last Month of Life: Results from a Nationwide Study

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**Introduction:** Nursing home residents with dementia at the end of life may find hospitalizations burdensome; evidence from epidemiological studies in Europe is sparse, as is knowledge about who is involved in hospitalization



decisions and whether or not information was transferred with the resident.

**Methods:** We used a survey with cluster-randomized sampling among Belgian nursing homes in 2010. Nurses from the sampled nursing homes registered retrospectively information about care in the last three months of life of residents who died with dementia.

**Results:** In the final month of life 19.5% of nursing home residents with dementia (N=198) were hospitalized, including 4.6% admitted to an intensive care unit. For 11.1% of all residents a do-not-hospitalize advance directive was present, for 54.0% a do-not-hospitalize GP-order. None of the hospitalizations occurred at the request of the resident; 37% were at the request of relatives; curative or life-prolonging treatments were the most frequent reasons given. In-house palliative care consultants were involved in none of the hospitalization decisions. Information about the resident's nursing care or medical treatment was transferred in almost all hospitalizations, information about wishes and preferences for future care in 19%. Residents without a do-not-hospitalize GP-order were more likely of being hospitalized (AOR: 4.9; 95%CI: 2.1-11.1). Eventually, 8.5% of hospitalized residents died outside the nursing home.

**Discussion:** The hospitalization rate in the last month of life in Belgian nursing home residents with dementia was significant. Timely and open communication with residents and relatives about future hospitalizations and documentation of do-not-hospitalize advance directives or GP-orders in the resident's medical files may prevent avoidable hospitalizations.

**Abstract number:** FC 9.3

**Abstract type:** Oral

### Living or Existing: An Action Evaluation of the Namaste Care Programme in 6 Dementia Homes with Nursing

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**Aim:** To evaluate the NAMASTE CARE programme in 6 nursing homes to establish the impact of the programme on: quality of life for residents with advanced dementia, family perceptions of care, and staff satisfaction.

**Design:** An action evaluation where the evaluator works with staff to implement and evaluate the NAMASTE CARE programme.

**Methods:** 6 nursing homes specialising in dementia care were purposively selected to implement NAMASTE CARE. Resident criteria: Bedford Alzheimer's Nursing Severity Scale score of 17 or more. Residents were recruited through personal consultees.

Quantitative measures:

- Residents: Baseline demographics including medications and recent interventions; Charlson Index; Symptom Management in End of Life Dementia (SM-EOLD); Doloplas2; Neuropsychiatric Inventory-NH. Measures repeated monthly.
- Families: Comfort Around Dying EOLD Satisfaction with Care EOLD.
- Staff: pre/post implementation staff satisfaction questionnaires

Qualitative measures:

- Staff focus groups - pre/post implementation.
- Family focus groups - post implementation.
- Nursing managers interviewed - post implementation.

**NAMASTE CARE programme implementation:**

- Full day workshop for key champions; 2 days in each home educating all staff and demonstrating the programme. Weekly follow up visits by nurse researcher.

**Result:** Initial results highlight benefits including reduced agitation, improved interaction and communication in residents. Final collection of data will be complete by January 2013 and analysis will be presented at the conference.

**Conclusion:** The NAMASTE CARE programme has the potential to transform end of life care for residents with advanced dementia. The programmes focus on comfort and pleasure reducing agitated behaviour and thus the reliance on anti-psychotic medication. Family and staff are increasingly satisfied with the care as they realise the benefits of the programme outweigh medical interventions such as expensive inappropriate hospitalisation.

**Abstract number:** FC 9.4

**Abstract type:** Oral

### Meeting the Prime Ministers Challenge - Improving End of Life Care for People with Dementia Following the Gold Standards Framework Dementia Care Training Programme

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**Context:** The importance of End of Life Care for people with dementia is increasingly important. There is evidence of the problems of inappropriate hospital admissions for people with dementia, and that hospital admissions may not always be beneficial for people with dementia, and that hospitalisation can actually do them harm in many cases, with an increase in mortality and morbidity compared with those without dementia. In addition they suffer poorer quality of life sometimes during hospital admissions, due to severe disorientation, distress and anxiety, sometimes leading to behavioural issues. There is some evidence (Alzheimer's Society Survey) that the chances of receiving inappropriate interventions and dying during admission for people with dementia are double the average rate. In addition, care for people with dementia on a hospital ward poses particular problems for hospital staff, sometimes leading to inappropriate over use of psychotropics and sedatives.

**Method:** The programme GSF Training in Dementia Care covers 4 key areas:

1. Increased awareness of the diagnosis and prevalence of dementia.
2. Improved communication and Advance Care Planning with people with dementia.
3. Reductions in inappropriate hospitalisation and being cared for and dying in their usual place of residence.
4. Improved assessment and management of pain and distress in people with dementia.

The programme is available on DVD or through the GSF distance learning Virtual Learning Zone, with appropriate resources. We report on a pilot study of 100 learners in different settings and disciplines details to be supplied.

**Results:** The training programme is anticipated to show improvements in staff confidence in caring for people with dementia towards the end of their life, and in the four key areas of reducing hospitalisation, increasing ACP discussion, supporting carers and better use of assessment tools for pain and distress. These findings are in line with the UK's PM Challenge in dementia.

**Abstract number:** FC 9.5

**Abstract type:** Oral

### What Influences Place of Care and Death of Older People with Advanced Disease, Including Dementia? A Systematic Review of Qualitative Evidence

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**Aim:** Planning for quality end of life care in terms of access to services and preferred place of death needs to build on best available evidence. We systematically reviewed qualitative evidence on preferences and factors influencing place of care and death for older people with advanced non-cancer conditions, including dementia.

**Methods:** Part of a large systematic review on place of death for patients with non-cancer. Six electronic databases, reference lists, cited references were searched. Original studies relating to older people with advanced disease, in all languages, study types and publication status were included. Study quality was assessed with a standard scale. A narrative synthesis was conducted.

**Results:** 23 qualitative studies relating to older people were identified, with 7 of these specific to dementia. The studies investigated issues of:

1. Hospice care: access to hospice care was problematic. Hospices were poorly attuned to dementia care.
2. Home care: against an explicit normative ideal for home care at the end of life, studies revealed what determined changes towards hospital care.
3. Entry into care homes: diverse and difficult decisions for families precede placements.
4. Decision making: older people's preferences varied and changed towards death.

Preferences were not necessarily related to values and were often influenced by considerations of family burden.

**Conclusions:** Advance care planning is crucial in achieving preferred place of care and death for older patients and those with dementia. Preferences and factors influencing place of care/death were complex, influenced by families' needs, and frequently evolved over time.

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**Department of health disclaimer:** The views & opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

**Abstract number:** FC 9.6

**Abstract type:** Oral

### Better Dying in Residential Care-homes with the Liverpool Care Pathway - An Intervention Study

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Integrated care pathways are increasingly developed and used in health care in general, as well as in end-of-life (EOL) care. The Liverpool Care Pathway for the Dying Patient (LCP) is one such integrated pathway, originally developed to guide care, aid decision-making and improve quality of care in the last hours and days of life for patients with cancer. However, there has been a lack of robust research regarding the effect of care pathways to improve EOL care, particularly in non-cancer settings. This is in part due to the many challenges in conducting such studies in this population.

The aim of this study was to evaluate the effects of the LCP on patients' symptom distress and well-being during their last days in life compared to usual care (UC) in a total population of residential care homes (RCH) in one municipality in northern Sweden.

In this controlled before-and-after study of all 19 RCH in the municipality, with approx. 1,000 residents, were included. The RCH are organized in two different administrative areas. To avoid contamination between groups, one administrative area was randomly allocated to intervention and the other to control. All RCHs in each area were included. After a 15 months baseline-period, UC continued in the control area, while the staff implemented and used the LCP according to guidelines during the following 15 months in the intervention area.

The perspective of close relatives, after the death of the elderly person, was evaluated using the Edmonton Symptom Assessment System (ESAS) and Views of Informal Carers - Evaluation of services (VOICES). Multiple linear regression analysis shows significant improvement in assessments of several symptoms on ESAS between baseline and follow-up in the intervention area, but not in the control area.

This study thus indicates that implementing LCP can be beneficial for EOL care in non-cancer settings for the elderly.

### Assessment

**Abstract number:** FC 10.1

**Abstract type:** Oral

### Clinical Tools to Assist with Specialist Palliative Care Provision

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**Aims:** The aim of this project was to recommend key clinical tools that may assist with the admission and coordination of care provision for patients and family caregivers across specialist palliative care settings.

**Methods:** The process of developing the list of recommended tools involved four phases:

1. a survey with the objective of documenting which clinical tools are currently used in the palliative care sector in Victoria, Australia;
2. a literature review, with the objective of identifying further clinical tools specific to palliative care;
3. an appraisal process, in order to establish a shortlist of clinical tools that merit detailed consideration;
4. a multi-disciplinary expert specialist focus group meeting, with the objective of endorsing a suite of clinical tools that meet the aims of this project for the specialist palliative care provision in Victoria, Australia.

The analysis was guided by nine domains of palliative care: Multi-Domain or Needs Assessment; Pain; Family/Caregiver Needs; Emotional Distress; Spirituality; Symptoms; Performance/Function; Quality of Life; Prognosis; Care of Dying Patient.

**Results:** By progression through the 4 phases, 12 key clinical tools were identified, which cover the above domains of palliative care and the requirement for a suite of clinical assessment tools to facilitate initial screening assessments, on the one hand, and comprehensive assessment in a particular domain and follow-up, on the other.

**Conclusion:** The results of this project provide a valuable resource that can enhance assessment and care planning within specialist palliative care.

**Funding:** The project was funded by the Department of

# Free communication sessions

Health in Victoria, Australia, to support the initiatives of the Palliative Care Clinical Network.

Abstract number: FC 10.2  
Abstract type: Oral

## Screening for Depression in Specialist Community Palliative Care: Does Using a Single Question Identify Depression as Well as Clinical Interview?

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**Background:** Depression affects a quarter of patients receiving palliative care and is associated with reduced quality of life. Screening for psychological problems at key points in the patients' pathway is recommended but there is no consensus as to how to do this.

**Aims:** To test the precision of a single screening question for depression against a semi-structured interview in patients referred to specialist community palliative care.

**Methods:** The single question ("have you felt depressed, most of the day, nearly every day for two or more weeks?") was compared with the validated Mini International Neuropsychiatric Interview (MINI). Sensitivity, specificity, positive predictive value, and negative predictive value were calculated. The study was approved by an NHS research ethics committee.

**Results:** Fifty patients, 24 women and 26 men were included. Forty nine patients had malignant disease. 14 patients had depression diagnosed by the MINI and 10 answered 'yes' to the single question, with 8 positive on both tests, and 34 negative on both tests. Sensitivity of the single question was 0.80 (95%CI 0.44 to 0.97) and specificity was 0.85 (0.70 to 0.94). The positive predictive value was 0.57 (0.29 to 0.82) and the negative predictive value was 0.94 (0.81 to 0.99).

**Conclusion:** The screening question has good sensitivity and specificity in community palliative care patients. It is likely to be most useful for screening to identify those patients who need more in depth assessment of their mood.

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sector.

Abstract number: FC 10.3  
Abstract type: Oral

## Validation of an Inflammatory Based Biomarker Prognostic Score (mGPS) in Combination with Performance Status in an International Cohort of Advanced Cancer Patients

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**Background:** Performance status in combination with the inflammation based Glasgow Prognostic Score (mGPS) has been proposed as an approach to prognosis in advanced cancer. Work to date has examined this in a single dataset. The aim of this work is to validate this approach (performance status in combination with mGPS) in an independent dataset.

**Methods:** Analysis was conducted on an international biobank of patients with cancer. Prognostic markers previously identified as being of potential value were assessed: EORTC QLQ-C30 patient reported outcomes, performance status and mGPS (using C-reactive protein and albumin). The relationship between these variables and survival was assessed using Kaplan-Meier and Cox regression methods.

**Results:** Data were available on 631 patients from 6 countries. The majority of patients (85%) had good performance status (ECOG1-2) and were under the care of an oncology department (78%). The median survival was 7.03 months (IQR 2.5-7.33). On multivariate survival analysis, mGPS was superior to performance status in terms of survival prediction: HR 1.45, 95%CI 1.28-1.63, p<0.001 versus HR 1.35, 95% CI 1.15-1.60, p<0.001. Performance status and mGPS were the most powerful prognostic markers. When used in combination, mGPS and performance status act synergistically improving survival prediction; survival at 3 months ranged from: 93%(mGPS0, ECOG1) to 18% (mGPS2, ECOG3).

**Conclusions:** The findings support mGPS in combination with performance status and externally validate this approach in an independent dataset of advanced cancer patients. The findings also demonstrate the mGPS may be a stronger prognostic factor than performance status in advanced cancer patients.

Abstract number: FC 10.4  
Abstract type: Oral

## Assessing Decision-making Capacity at the End of Life: Concordance between Clinician-rated Capacity and Performance on the MacCAT-T

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Despite the clinical, ethical and legal magnitude of end-of-life decision-making, little is known about the decision-making capacity of patients with advanced cancer. Clinicians are largely responsible for determining when these patients are no longer competent to make treatment decisions. The purpose of this study is to assess decision-making capacity in terminally ill cancer patients, specifically concordance between clinician-rated capacity and performance on a validated measure of capacity. Patients with advanced cancer receiving inpatient palliative care (n = 58) completed the MacCAT-T, a semi-structured interview that evaluates decision-making capacity with regard to four commonly-used legal standards of competence: ability to express a choice, understand information relevant to treatment decisions, appreciate the significance of the treatment decision and rationally manipulate relevant information. Impairment on each subscale was calculated using a comparison group of healthy age-matched adults (n = 50). Participants' physicians independently rated decision-making capacity. Participants were largely female (56.9%), Caucasian (65.5%), and mean age was 69.5. Most participants were able to express a treatment choice (67.2%). However, participants evidenced moderate and severe levels of impairment on the appreciation (17.2%, 39.7%), understanding (37.9%, 27.6%) and reasoning (39.7%, 37.9%) subscales respectively. Cohen's coefficient kappa was used to assess inter-rater reliability between physician-rated capacity and performance on the MacCAT-T. Agreement between ratings was slight, kappa ranged from 0.06 to 0.16. Although clinician assessments are considered the gold standard in capacity assessment, agreement between clinician assessment and performance on the MacCAT-T was poor. These findings should inform the development of instruments to measure key functional abilities relevant to specific domains of capacity as they pertain to the different legal standards.

Abstract number: FC 10.5  
Abstract type: Oral

## Satisfaction with Palliative Care in a Nationally Representative Sample of Cancer Patients

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**Aims:** To study satisfaction with palliative care among patients with incurable cancer and a life expectancy of less than 6 months.

**Methods:** The Danish Medicine Agency Registry allows identification of incurably ill patients in the palliative care phase: these patients are entitled to free medicine, and are registered when this is granted following application from their doctor. We were allowed to contact consecutive cancer patients granted free medicine, and mailed the FAMCARE-P16 patient satisfaction questionnaire. Each item has five response categories: very dissatisfied/dissatisfied/undecided/satisfied/very satisfied. The proportion of dissatisfied/very dissatisfied patients was estimated for each of the 16 items.

**Results:** Of 458 patients who were alive when contacted, 188 (41%) responded. Cancer sites: 26% lung, 14% colorectal, 8% pancreas, 7% breast, 6% prostate, 39% other. Women: 48%. Above 70 years: 43%. Within the previous 3 months almost all patients had been in contact with a hospital and their GP, half had received help from a nurse/helper in their home, and a third had been in contact with palliative care specialists. The proportions of dissatisfied/very dissatisfied patients ranged 2-19% on the 16 items. The highest levels of dissatisfaction was seen for 'Speed with which symptoms are treated' (19%), 'Information provided about your prognosis' (18%), 'Doctor's attention to your description of symptoms' (15%), 'Information given about side effects' (13%), and 'How thoroughly the doctor assesses your symptoms' (13%). The lowest level of satisfaction was seen for 'The availability of nurses to answer your questions' (2%).

**Conclusion:** The Danish Medicine Agency Registry allows identification of incurable cancer patients irrespective of where they are treated and thereby makes it possible to

study the level of satisfaction with palliative care in a nationally representative sample. The results indicate dissatisfaction with key aspects of palliative care.

Abstract number: FC 10.6  
Abstract type: Oral

## Clinical Signs of Impending Death in Cancer Patients

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**Aims:** The fundamental process of dying has not been well characterized in cancer patients. We determined the prevalence, onset and likelihood ratios (LRs) for clinical signs associated with the dying process in advanced cancer patients.

**Methods:** We systematically documented 80 physical signs on consecutive advanced cancer patients admitted to palliative care units at 2 tertiary care cancer centers every 12 hours from admission to death or discharge. We examined the frequency and median time of onset of each sign from death backwards, and calculated their LRs associated with death within 3, 5 and 7 days.

**Results:** 203/357 patients died. 20/80 signs had very high positive LR (>10) for impending death. Multivariate logistic regression analysis identified that inability to close eye lids, non-reactive pupils, grunting of vocal cords, and respiration with mandibular movement were associated with imminent death within 3 days (Table 1). Death rattle, drooping of nasolabial fold, and decreased response to verbal stimuli were associated with death in 5 days and 7 days (Table 2). The positive LRs for doublet combinations of these signs were between 20 and 30. These signs occurred in 30-70% of patients and mostly in the last 3 days of life.

**Conclusion:** We identified highly specific physical signs associated with impending death among advanced cancer patients.

Table 1. Signs of Impending Death in 3 Days

Sign	Prevalence (%)	Median Onset in Days (95% CI)	Sensitivity % (95% CI)	Specificity % (95% CI)	Negative Likelihood Ratio (95% CI)	Positive Likelihood Ratio (95% CI)
Inability to close eye lids	93 (46)	1.5 (1.0-1.5)	21.4 (20.9-21.8)	97.9 (97.7-98.1)	0.8 (0.8-0.81)	13.6 (11.7-15.5)
Grunting of vocal cords	86 (43)	1.5 (1.0-2.0)	19.5 (19-19.9)	97.9 (97.7-98.1)	0.82 (0.82-0.83)	11.8 (10.3-13.4)
Respiration with mandibular movement	92 (46)	1.5 (1.0-2.0)	22 (21.5-22.4)	97.5 (97.3-97.6)	0.8 (0.8-0.81)	10 (9.1-10.9)
Non-reactive pupils	53 (26)	2.0 (1.5-3.0)	15.3 (14.9-15.7)	99 (98.8-99.1)	0.86 (0.85-0.86)	16.7 (14.9-18.6)

Table 2. Signs of Impending Death in 5 and 7 Days

Sign	Prevalence (%)	Median Onset in Days (95% CI)	Sensitivity % (95% CI)	Specificity % (95% CI)	Negative Likelihood Ratio (95% CI)	Positive Likelihood Ratio (95% CI)
<b>Death rattle</b>						
Day 5	112 (55)	1.5 (1.0-2.0)	19.9 (19.4-20.4)	98.7 (98.5-98.9)	0.81 (0.81-0.82)	18.7 (16.5-20.9)
Day 7	112 (55)	1.5 (1.0-2.0)	18.3 (17.8-18.7)	99.2 (99-99.3)	0.82 (0.82-0.83)	19.7 (17.7-21.7)
<b>Drooping of nasolabial fold</b>						
Day 5	138 (68)	2.5 (1.5-3.0)	29.6 (29.1-30.1)	97.6 (97.4-97.8)	0.72 (0.72-0.73)	15.7 (13.7-17.8)
Day 7	138 (68)		27.1 (26.6-27.6)	98.1 (97.9-98.3)	0.74 (0.74-0.75)	18.5 (16.3-20.8)
<b>Decreased response to verbal stimuli</b>						
Day 5	121 (60)	2.0 (1.5-4.0)	26.5 (26.1-26.9)	97.4 (97.2-97.6)	0.75 (0.75-0.76)	12.6 (11.1-14.2)
Day 7	123 (61)		24.6 (24.2-25)	98 (97.8-98.2)	0.77 (0.77-0.77)	15.3 (13.4-17.2)

## Place of Death

Abstract number: FC 11.1  
Abstract type: Oral

### The Hospital as a Place of Death

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**Aim:** To explore bereaved family caregivers' experience of care of older patients (with and without dementia) dying on acute hospital wards.

**Background:** Hospital is considered an undesirable place to die. Current UK policy aims to avoid unscheduled admissions and increase the number of patients who die at home. Nevertheless, the majority of deaths occur in hospital, and this number is set to rise as the proportion of the population dying in advanced age with complex comorbidity and associated intensive care needs continues to increase. There is a pressing need for greater understanding of the experience of death in acute hospital settings and how this may be improved.

**Setting:** 4 acute wards in a UK general hospital.

**Method:** Qualitative study including triangulated data from ward observation (245 hours), interviews with staff (38), bereaved family carers (13), and patient medical records review (42). Thematic analysis using constant comparative method.

**Results:** The experience of dying varied across wards and family responses were strongly determined by prior expectations of outcome and the circumstances of each case. However, the hospital was not generally viewed as an undesirable or inappropriate place to die. Some families wanted their relative to remain on the ward. Others altered their initial preference as they came to doubt their capacity to cope at home. Some families reported negative or even traumatic experiences. Others described a 'good' (or 'good enough') death as depicted in the dominant paradigm of palliative care. However, the findings indicate substantial shortcomings in staff responses and ward facilities and hospitality for family caregivers engaged in the effort, sometimes involving a prolonged vigil, to accompany the patient to the moment of death.

**Conclusion:** Rather than being vilified, the hospital needs to be rehabilitated and better resourced to improve the care of dying patients and their families.

**Abstract number:** FC 11.2

**Abstract type:** Oral

### Trends and Projections for Place of Death in One of the Most Ageing Populations in Europe (Portugal, 1988 - 2030)

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**Background:** With a population of 10 million and more than 100,000 deaths per year, Portugal has the 5<sup>th</sup> most ageing population in the European Union (EUROSTAT 2010). Evidence on projections for place of death in Portugal to inform service development is lacking.

**Aim:** To examine past trends in hospital deaths by age and sex, and to project future trends until 2030, to inform palliative care services development in Portugal.

**Study design and methods:** Whole-population study of adult (18+ years) deaths in Portugal (continent, Açores and Madeira) from 1988 to 2010. Death certificate data were provided by the Portuguese Statistics Institute. Age- and sex-specific hospital death proportions were determined. We projected future age- and sex-specific hospital deaths, applying the average annual slopes of the last five years (2006-2010) to EUROSTAT mortality projections.

**Results:** Annual numbers of deaths increased 11.1%, from 95,154 in 1988 to 105,691 in 2010, and are projected to rise further by 5.6% in 2030 (111,584 deaths). Proportions of hospital deaths increased steadily by a mean of 0.8% or 1030 deaths per year, from 44.7% (42,571 deaths) in 1988 to 61.7% (65,221 deaths) in 2010, in all age groups (except the youngest, 18-34 yrs), with a rise of >20% in the older age groups (64-75 and 85+) and was more prominent in women. Assuming the last five-year trends continue, the proportion of hospital deaths will increase to 74.6% in 2030 with 18,070 more annual hospital deaths.

**Conclusions:** If current trends are maintained, hospital deaths will rise by more than a 1/4 by 2030 despite contrary preferences. It is likely that Portuguese hospital resources are insufficient to cope with this situation. Home palliative care services are scarce and not planned to increase in the next years, but if hospital death trends are to be reversed, and patients' preferences for dying at home are to be accommodated, investment in home care support is crucial.  
**Funding:** Calouste Gulbenkian Foundation.

**Abstract number:** FC 11.3

**Abstract type:** Oral

### Place of Death Correlates with Bereaved Relatives' Grief Intensity: A Population-based Case Control Study of Home and Hospital Death

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**Aim:** To determine whether grief intensity in bereaved relatives varies according to place of death.

**Methods:** Case-control study nested in a population-based mortality followback survey of adult patients who died from cancer and their relatives (n=596 dyads), London (UK, 2009/10). Cases were 175 patients who died at home and controls were 177 patients who died in hospital. Grief intensity was measured by the Texas Revised Inventory of Grief (TRIG), assessed by relatives (median 7 months after patient's death). Relatives reported their feelings and behaviours at time of death (TRIG I) and of TRIG completion (TRIG II). Higher scores reflect greater grief intensity. We compared TRIG I and II scores in the two groups using t-tests and conducted multivariate linear regressions of the scores (place of death as exposure variable).

**Results:** Grief intensity was similar in the home and hospital groups [M 20.52 (SD=7.91) and 20.78 (SD=8.25) respectively, in TRIG I sub-scale ranging 8-40, t-test(318)=-0.281, p=0.779; M 45.02 (SD=11.26) and 43.11 (SD=14.10) respectively, in TRIG II sub-scale ranging 13-65, t-test(299)=1.327, p=0.185]. However, once confounders were taken into account (stronger grief reactions associated with spouses/partners, presence at time of death, family discussion of place of death preferences and time off work during the 3 months before the patient died), grief levels were less intense when the patient died at home compared to hospital. Associations with place of death were significant both for grief around the time of death (p=0.020) and in subsequent months (p=0.023).

**Discussion:** In a population-based sample, using a validated measure and adjusting for key confounders, we observed that relatives of patients who die at home experience less intense grief than relatives of patients who die in hospital. Interventions to enable home death may minimise bereavement-related distress. This may have implications for demand of health services.

**Funding:** Cicely Saunders International

**Abstract number:** FC 11.4

**Abstract type:** Oral

### Hospital Death of People with Dementia and Pneumonia in Belgium: Study of Incidence and Risk Factors Using Death Certificate Data

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**Introduction:** Only few people suffering from dementia would want to die in hospital. In particular for people with dementia with pneumonia a hospitalisation at the end of life may be of little benefit and result in unfavourable outcomes. The aim of this study is to estimate the incidence and risk factors of hospital death in people dying from or with dementia and pneumonia.

**Methods:** We used death certificate data of all deaths in Belgium in 2008 (N=101685) to examine characteristics of deaths caused by both dementia and pneumonia. Information about the urbanization level of the place of residence, available hospital beds, residential (without continue skilled nursing) and skilled nursing home beds in the proximity of the deceased was linked through the ZIP-code of the place of residence.

**Results:** Overall, of patients dying from or with dementia and pneumonia (N=1420), 47.2% died in hospitals. Of those living in nursing homes at the time of death, 25.6% died in hospitals. Risk factors for hospital death were being single (AOR:2.83, 95%CI:1.30-6.16) and living in urbanized areas (AOR:2.48, 95%CI:1.47-4.18) for those living in their private home at the time of death and a higher availability of residential nursing home beds (AOR per unit: 1.02, 95%CI:1.01-1.03) for those living in nursing homes. Those who died from or with Alzheimer disease and pneumonia were less likely to die in hospital as compared to unspecified

dementia and pneumonia, both in those living at home (AOR:0.36, 95%CI:0.20-0.62) and in residential care (AOR:0.47, 95%CI:0.31-0.70).

**Conclusion:** Nearly half of the people dying from or with dementia and pneumonia died in hospitals; a quarter of those living in care homes. The results suggest shortcomings in the Belgian healthcare system in avoiding unnecessary hospitalization of vulnerable populations.

**Abstract number:** FC 11.5

**Abstract type:** Oral

### Perceived Quality of Home Cancer Care at the End of Life: Which Factors Are Associated with Bereaved Relatives Being Highly Satisfied with the Care Provided by GPs?

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**Background:** Studying relatives' satisfaction with home cancer care at the end of life is important when examining quality of care. It is particularly crucial to determine the factors related to high satisfaction with GP home care as this is known to facilitate home death.

**Aims:** To examine bereaved relatives' satisfaction with end of life home care received by cancer patients and to examine associations between satisfaction with GP care and service and non-service factors.

**Methods:** Mortality followback survey. From death registrations in four health regions in London (UK, one year period 2009-10) we identified the persons who registered deaths from cancer. They completed a postal questionnaire on the care that patients had received in the last three months of life by GPs, palliative care specialists, and other nurses (district/community/private). Analysis involved descriptive statistics and multivariate logistic regression of being highly satisfied with GP care (excellent/very good vs. good/fair/poor/very poor).

**Results:** Questionnaires were completed for 596 decedents (39% response rate) of whom 548 stayed at home at least one day in the last three months of life. Excellent/very good care was reported by 49% of respondents for GP care, 78% for specialist palliative care and 68% for care by other nurses. High satisfaction with GP care was associated with good GP-family communication (OR=8.1 [3.3; 19.8]), perceived GP competence (OR=9.1 [3.3; 24.9]) and symptom relief (OR=16.7 [4.9; 56.5]) and was more likely in cases of home as opposed to hospital death (OR=3.8 [1.6; 8.6]). No effect of age and socioeconomic deprivation was found.

**Conclusions:** Although bereaved relatives' satisfaction with end of life home cancer care is generally high, it is less so for care by GPs. Satisfaction with GP care may be increased, and home death potentially facilitated, by helping GPs to improve pain and symptom control and communication.

**Funding:** Cicely Saunders International, EU FP7

**Abstract number:** FC 11.6

**Abstract type:** Oral

### Pain in People with Dementia: Deployment of Pain Assessment in a Long Term Care Institution

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Situation in Long term care institutions specialized on care of older adults with dementia in the Czech Republic will be discussed, regarding to communication about pain with clients and within the interprofessional team.

The grant NT11325 of the Ministry of Health of the Czech Republic: "Long-term care for seniors: quality of care in institutions" is focused on indicators of quality of care. Pain may be considered one of the most important indicators, data mapping prevalence of pain in LTC institutions are being collected. The project, "Geriatric and Organisational Supervision" is seeking possible ways of intervention.

Methods used for assessment in non-verbal residents: PAINAD and MOBID scale are instruments for pain assessment in people with advanced dementia, using observation. For both of these scales Czech version was published. PAINAD and MOBID were offered as tools for education of interprofessional team of Czech LTC institutions and eventually one or both were accepted for regular use for assessment of pain in people with advanced dementia. The

## Free communication sessions

experience with Czech version of PAINAD and MOBID in practice will be discussed.

Methods used for intervention: education, train the trainers, consultancy and organisational self-assessment. Results: Pain was present in more than 70% of residents with dementia at baseline. Preliminary results on the effect of pain assessment deployment in a Czech long term care institution for people with dementia will be presented.

Especially in advanced stages of dementia with communication deficits, challenging behaviour may be the most noticeable sign of pain. It is vital that professional carers are able to understand this possible interrelation between BPSD and pain/discomfort, being trained to recognize non-verbal signs of pain.

Supported: By the grants NT11325 and NT13705 of the Ministry of Health of the Czech Republic.

### Children and Young People/ Spirituality

Abstract number: FC 12.1

Abstract type: Oral

#### Educating Adult Palliative Care Teams about the Needs of Transition Age Young People: What Do they Need to Know?

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Aims: The prognosis of life-limiting conditions of childhood has improved and an increasing number of young people are accessing adult Specialist Palliative Care (SPC) services. Adult SPC teams are inexperienced in caring for the complex needs of these young people and have some concerns regarding skills, knowledge and service capabilities. We aimed to identify the training needs of SPC teams regarding the care of young adults.

#### Methods:

Delphi: An online Delphi process collated expert opinion in format, delivery and content of the package. Round 1 participants (n=44) answered free text questions, generating items for Round 2. In Round 2, 68 participants rated the extent to which they agreed/disagreed with the items on 5-point Likert type scales. Median and mean scores assessed the importance of each item. Interquartile range scores assessed level of consensus for each item; items lacking consensus were re-rated by 35 participants in Round 3.

Focus Groups: Focus groups were held with young people pre-transition, post-transition, parents/carers of young people post-transition and staff from a local adult hospice. Discussions explored the care and support needs of young people and their families, and the training needs of SPC teams. Data were analysed using thematic analysis.

#### Results:

Delphi: Consensus was reached on a range of suggested formats, on who could deliver the training, and on several clinical, psychosocial and practical topics. Training should be delivered as a continuous/rolling programme and not as a one-off.

Focus Groups: Discussions centred on: challenges of caring for young people; barriers to transition; staff education and training; facilitating transition.

Conclusions: Recommendations include a continuous/rolling programme of education, tailored for content and mode of delivery, and incorporated into working practice. A template to guide handover and a single point of contact would facilitate the transition process.

Abstract number: FC 12.2

Abstract type: Oral

#### Understanding Posttraumatic Growth in Parents of Children with Life-limiting Illnesses

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Research aims: Caring for a child with a life-limiting illness (LLI) is a stressful and unenviable circumstance. While there is growing evidence that posttraumatic growth can co-occur with stressful events and activities, less is known about how this growth occurs or how growth can be nurtured. The goal of this study was to explore the process of growth among parents who are or have been caring for a child with a LLI. Methods: This was a mixed methods study using quantitative data gathered from 273 parent caregivers of children with LLI from Canada and the U.S.A. and qualitative

data from interviews with a sub-set (n=23) of parents.

Survey packages included demographic information and previously verified scales measuring meaning in caregiving, optimism, self esteem, spirituality, depression, caregiver burden, and posttraumatic growth. Structural equation modeling identified models of possible factors that allow these parent caregivers to experience growth. Semi-structured interviews were transcribed and analyzed using thematic analysis to explore parents' experiences of growth. Results: The most promising structural equation model shows that particular personal resources reflected in personal wellbeing are precursors to the process of positive meaning making, which in turn contributes to growth. Interviews with parents clarify the ways in which growth occurs and how professionals may help or hinder the process.

Conclusions: Parents' experiences of caring for children with LLI are unique and complex. This research highlights the importance of meaning making in the emergence of posttraumatic growth and describes how positive meaning making is experienced by parents. This contributes to better understanding of the process of growth for parents and suggests tools to help professionals support families. This research was supported by the Canadian Institutes of Health Research.

Abstract number: FC 12.3

Abstract type: Oral

#### A Delphi Study to Identify Global Priorities for Research into Children's Palliative Care: Preliminary Results

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Aims: In 2011, ICPCN commissioned a Delphi study to identify global priorities for research in children's palliative care (CPC). Although other Delphi studies have been conducted on CPC, none have an international focus. The aim is to use the results to inform the international CPC community of perceived research needs to inform the development of an international research agenda.

Method: Following a literature review a research protocol was developed. Phases 1&2 commenced, following IRB approval. Experts from 10 countries and a variety of disciplines, developed a base line list of priority areas for research & identified individuals to be involved in the Delphi rounds. Once the Delphi survey was finalized & the participant list aggregated, the Delphi process was undertaken (Phase 3). An online survey was sent to potential participants asking them to rate areas for research in terms of priority. These were reviewed & followed by a 2nd Delphi round. In Phase 4 a final list of the priorities for global research will be developed.

Results: To date, 145 participants completed the Delphi process [largest number from Europe (32%), lowest the Middle East (1%)]. Areas for research identified in the base line list of priority areas were reduced to 70 following content analysis. Results from the 1st Delphi round show 20 areas of research identified as priorities by 75% or more of the respondents. The majority of the priorities identified were clinical (83%). Preliminary results suggest the top priorities include research into managing pain without strong opioids, measuring outcomes of care, funding & the need for CPC. The 2nd Delphi round is currently underway. Challenges to undertaking the study included IRB approval, identifying participants, & terminology.

Conclusion: Global priorities for research into CPC are being identified & will inform the research agenda for ICPCN & its partners, particularly in areas that will benefit from regional & international collaboration.

Abstract number: FC 12.4

Abstract type: Oral

#### Identifying Research Priorities in Spiritual Care Research: Final Results of the EAPC Spiritual Care Taskforce's International Survey

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Background/aim: Spiritual care is a core component of palliative care, but neglected in clinical practice and research. An aim of the EAPC Spiritual Care Taskforce is to inform the development of evidence-based spiritual care by

determining research priorities.

Methods: From April-Sept 2012 delegates (n=6000) of the EAPC Lisbon congress and national and international associations were invited to participate in an online survey developed by the Taskforce's Research Subgroup.

Respondents chose the 5 most important research priorities from a list of 15 topics. Free text questions asked about additional research priorities and the single most important research question. Demographic data were collected. Descriptive statistics were used to rank listed research priorities. Thematic content analysis was used to identify and rank additional research priorities and most important questions.

Results: 971 responses (713 European) were received from 87 countries. Mean age 49, 64% female, 65% Christian, 10% spiritual but not religious. 52% reported their work as 'mainly clinical', including 293 palliative care physicians, 112 nurses and 111 chaplains. There was wide agreement in the priorities identified in the quantitative and qualitative data. Highest priority areas were:

- 1) Responding to spiritual needs - evaluating interventions, determining effectiveness,
- 2) Helping staff talk about spiritual issues - conversations models, overcoming barriers in attitudes and
- 3) Identifying those with spiritual needs - screening, assessment.

Understanding patients' spiritual needs and preferences in multi-faith, multi-cultural populations was a cross-cutting theme. < 2.5% said no further research was needed in spiritual care.

Conclusion: There is unanimous international support for research focussing on spiritual care interventions, conversation models and screening and assessment. Knowledge of priority areas can guide patient-centred, inclusive and culturally sensitive research.

Abstract number: FC 12.5

Abstract type: Oral

#### Psychosocial Support to Seriously Ill Cancer Patients with Under-aged Children in Palliative Care

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#### Aim of project:

- 1) identify parental need for child-oriented support,
- 2) barriers to involve children in the terminal process,
- 3) determine an effective framework for support.

Design: Patients with children < 18yrs in specialist palliative care, were offered semi-structured conversations at referral till 6 months post-death of patient. Conversations, with a psychologist and a social counsellor, took place in the home and covered topics and concerns brought up by parents supplemented by therapists drawing upon an earlier pilot study and family-focussed grief theory. At each session parents completed MYCAW questionnaires stating main concerns and topics of discussion were registered. Upon completion of therapy the surviving parent provided a content and structure-oriented evaluation.

Results: 32 families participated with a median number of conversations of 3 pre- and 3 post-death. Mean time of participation before death was 58 days. The majority of parents had many worries about their child and was ill-equipped to inform and prepare the child for the forthcoming death. Barriers inhibiting dialogue between parents and child were due to fear of unduly burdening the child, lack of recognition of the severity of the illness situation and uncertainty of how to handle the child's reactions.

Structural aspects of importance to parents were home visits, conversations with parents alone, the possibility of including the child in conversations and flexibility in providing conversations according to parental need. Conclusion: There is an unmet need among terminal cancer patients and their spouses to engage with palliative professionals about child-related concerns. Parents exhibited improved confidence in providing care and support to their child. Child-focussed support and therapy interventions for parents should be provided according to parental need and focus on provision of information to the child, preparing the child for the death of a parent and on the child's coping.

Abstract number: FC 12.6

Abstract type: Oral

#### Assessing Spiritual Distress in Residents of Care Homes for Older People Using the FACTI-SP: A Cognitive Interviewing Study

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**Background:** An increasing number of older people live and die in care homes, but relatively little is known of their spiritual needs or how to assess them. Although many residents do not have a recognisable terminal illness; multiple health problems and losses, increasing frailty and dependency, and awareness that they are likely to die in the home can result in psychological and spiritual distress.

**Objective:** To examine how care home residents interpreted and responded to the FACIT-Sp-12, a frequently used and validated measure of spiritual distress.

**Methods:** A convenience sample of 17 older people living in three care homes in London was recruited. Residents completed FACIT-Sp-12 in face-to-face interviews and cognitive interviewing was employed to explore resident responses. A Framework approach was used as the basis for analysis. The framework of themes was developed *a priori* based on the four stages from Tourangeau's cognitive model. These comprised comprehension of the question; retrieval from memory of relevant information; decision processes; and response processes.

**Results:** Most residents completed the FACIT-Sp-12 with relatively little missing data. Residents had most difficulty with comprehension of questions, particularly where concepts were more abstract (e.g. harmony, productivity), and in selecting appropriate response options (e.g. categories didn't reflect their views, or were not meaningful in the context of the statement).

**Conclusions:** The FACIT-Sp-12 could provide valuable insights into the spiritual concerns of care home residents, however, data may be neither valid nor reliable if they do not comprehend the questions as intended and respond appropriately. Providing clear and detailed instructions, including definition on the concepts involved would improve the validity of this measure for this population, and older people in other settings, reduce missing data, without substantially affecting the reliability or validity of the measure.

## Pain and other Symptoms

**Abstract number:** FC 13.1

**Abstract type:** Oral

### Do Corticosteroids Have Immediate Analgesic Effect in Cancer Patients with Metastatic Disease? A Randomized, Placebo Controlled Trial

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**Aims:** Corticosteroids (CS) are used for additional pain control in cancer pain patients receiving opioids. In a systematic review we concluded that CS may have a moderate analgesic effect in cancer pain, but with "very low" level of evidence. Therefore, this randomized comparative study was conducted to investigate if CS are useful to treat cancer pain.

**Methods:** Adult cancer patients with average pain last 24 hours  $\geq 4$  (NRS 0-10) despite ongoing opioid treatment were recruited from five centres. After randomization the patients received methylprednisolone 16 mg twice daily or placebo for seven days in a double-blind design. Primary outcome was average pain intensity on day seven (NRS 0-10); secondary outcomes were analgesic consumption (oral morphine equivalents), overall satisfaction (NRS 0-10), fatigue, and appetite (EORTC QLQ-C30 (0-100)). Twenty-two patients were needed in each group to show a clinical significant difference of 1.5 (NRS 0-10) with a  $p < 0.05$  and a power of 0.90.

**Results:** Fifty patients were included from April 2008 to January 2012, and 47 completed the study. On day seven there were no differences in average pain intensity (CS: 3.6, (CI: 2.8 - 4.4); placebo 3.7 (3.0 - 4.4)) or in change in opioid consumption (day seven versus baseline: CS 1.19 (1.00 - 1.38); placebo 1.20 (0.90 - 1.51)). CS reduced both fatigue (CS: -17 (-27 - -6); placebo 3 (-5 - 11) ( $p < 0.01$ )), and loss of appetite (CS: -24 (-38 - -11); placebo 2 (-8 - 11) ( $p < 0.01$ )). Overall satisfaction was 5.4 (4.1 - 6.7) in the CS versus 2.0 (0.7 - 3.3) in the placebo group ( $p < 0.01$ ).

**Conclusion:** Methylprednisolone 32 mg daily did not improve pain or decrease analgesic consumption in cancer patients with advanced disease, but the patients treated with CS reported better treatment satisfaction and clinically significant improvement in fatigue and appetite compared

to the placebo group.

**Funding:** Telemark Hospital Trust

**Abstract number:** FC 13.2

**Abstract type:** Oral

### Adding Low Dose Methadone to Regular Opioid Treatment - Results on Pain Control and Adverse Effects in 53 Patients with Cancer-related Pain

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**Background:** Previous studies have reported improved pain control after adding low dose methadone to regular opioid treatment in severe cancer-related pain, but clinical experience suggests increased prevalence of adverse effects.

**Aim:** To investigate the relation between pain control, opioid doses and adverse effects when adding low dose methadone to regular opioid therapy for treatment of cancer-related pain.

**Method:** All patients over 18 years receiving oral methadone in addition to another opioid at the Palliative Center at Stockholms Sjukhem from 2006-2011 were identified from patient records. Doses of regular opioid, opioid P.R.N. and methadone were studied together with levels of pain control and side effects during the first week on methadone.

**Results:** 53 patients were included. The mean regular morphine equivalent dose (MED, excluding methadone) was 347 mg/day at initiation and 475 mg/day on day 7. The mean P.R.N. MED was 368 mg/day on day 1 and 47 mg/day on day 7. The mean total MED was 715 mg/day on day 1 and 535 mg/day on day 7. The mean methadone dose on day 1 was 8.5 mg/day and 13.8 mg on day 7. Four patients (8%) were assessed as having none or mild pain when starting methadone, 20 (38%) had moderate and 29 (55%) severe pain. On day 7, 70% had none or mild pain, 20% moderate and 10% severe pain. Nine patients (17%) showed signs of confusion on day 1 and 22 (55%) on day 7. Six patients (11%) showed signs of sedation on day 1, and 20 (50%) on day 7. Mean survival time from addition of methadone was 17 days.

**Conclusions:** The addition of low dose methadone was associated with decreased total opioid doses and improved pain control, but increased cognitive and sedative side effects. The positive effects on pain control are in line with the few previously published studies, but increase in side effects indicates the need for more rapid down titration of opioid doses. Accumulated evidence now warrants randomized controlled trials.

**Abstract number:** FC 13.3

**Abstract type:** Oral

### The Evaluation of a Nurse Practitioner-led Pain Management Team in Long Term Care

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**Aim:** This study evaluated the effectiveness of implementing a Nurse Practitioner (NP)-led, inter-professional (IP) pain management team in long-term care (LTC) team on improving

- resident outcomes (i.e., pain, functional status, agitation, depression);
- clinical practice behaviours (i.e., documentation of pain assessments, use of non-pharmacological and pharmacological interventions);
- quality of pain medication prescribing practices; and
- IP collaboration.

We also obtained some preliminary information on the costs of implementing this approach.

**Design:** Using a controlled before-after study, six LTC homes were allocated to one of three groups:

- 1) an NP-led Pain Team;
- 2) NP but NO pain management team; or
- 3) no NP, no pain management team.

Over the one-year intervention period, there was a 32% dropout rate for the full intervention group, Group 1 (45/139), 30% dropout rate for the partial intervention group (33/108), and a 25% dropout rate for the control group (24/98).

**Results:** Implementing an NP-led Pain Team in LTC significantly reduced residents' pain and improved functional status compared to usual care without access to an NP. Positive changes in clinical practice behaviours (e.g., assessing pain, developing care plans related to pain management, documenting effectiveness of pain interventions) occurred over the intervention period for both the NP-led Pain Team and NP-only groups; these changes did not occur to the same extent, if at all, in the control group.

**Conclusion:** The findings from this study showed that implementing an NP-led Pain Team can significantly improve clinical practice behaviours of LTC staff and improve resident pain and functional status. LTC homes should employ an NP, with preference for the NP being situated onsite as opposed to an offsite consultative role, to facilitate more consistent and timely access to pain management.

**Abstract number:** FC 13.4

**Abstract type:** Oral

### The Relationship between Pain Management Index (PMI) and Pain Interference. Are Negative PMI Values all Problematic?

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**Background:** To examine the adequacy of pain treatment for cancer patients, the pain management index (PMI) is frequently used. The PMI is calculated based on the concordance between the pain severity and the class of analgesics prescribed. The validity of the defined concordance, however, needs to be confirmed, especially in cross-cultural settings.

**Methods:** We analyzed the baseline data of a performance improvement project for pain treatment in Japan. Between July and October 2012, we prospectively asked all enrolled patients for presence/absence of pain in the past 24 hours, if present, the level of worst pain on a 0-10 numeric rating scale (NRS, 0:none, 10: worst imaginable), pain medications used, and the pain interference in their daily activities. The PMI was calculated by subtracting the drug class score (0: none, 1: non-opioid analgesics, 2: weak opioids, 3: strong opioids) from the pain severity score (0: NRS 0, 1: NRS 1 to 4, 2: NRS 5 to 6, 3: NRS 7 to 10). The PMI ranged from -3 to 3 with the negative values conventionally considered as inadequate pain treatment. We analyzed the proportion of pain interference for the each level of PMI using the reports in the first three days of hospital stay.

**Results:** During the period, 489 cancer patients had pain or took any analgesics, and gave 1013 answers in total. Overall, PMIs were negative in 637 (63%) answers. However, among the patients with a PMI of -1, only 35% reported that pain interfered their daily activities, which was not significantly higher than that among those with a PMI of 0 (43%,  $P=0.11$ ). Reports of pain interference were more frequent among those with PMI of -2 and -3 (72% and 66% respectively,  $P < 0.01$ ).

**Conclusion:** The PMI of -1 may not necessarily indicate the inadequate pain treatment. The PMI of -2 or less may be more appropriate criteria to examine the adequacy of pain treatment.

**Funding:** This project is funded by the grant-in-aid from the Ministry of Health, Labour, and Welfare of Japan.

**Abstract number:** FC 13.5

**Abstract type:** Oral

### Depression and Use of Anti-depressants in Patients with Advanced Cancer. Results from an International Multi-centre Study

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**Background:** Depression is common in advanced cancer patients and is often unrecognized and inadequately treated. Use of antidepressants (ADs) in this patient population is shown to be effective for symptom relief.

**Aims:** To examine the use of ADs in international large sample of advanced cancer patients.

**Methods:** In an international, cross-sectional study (the EPCRC-CSA) symptoms in patients from 17 centers across eight countries were assessed. In addition medical variables including disease status, medication and Karnofsky Performance Status (KPS) were registered by health care providers, while information about subjective symptoms was completed by patients. Depression was self-reported

using the Patient Health Questionnaire (PHQ-9), based on the DSM-IV criteria, and on a 0-10 NRS.

**Results:** Out of 1051 patient registrations, 969 patients completed the PHQ-9 depression measure. Of these, 48% were females, mean age of 62 years (SD 12.4), mean KPS of 71 (SD16.3) and 84% had metastatic disease. Mean pain intensity score for the last 24 hours was 2.1 (SD 2.3). 131 (13.5%) patients used ADs for symptoms other than pain. 133 (13.7%) patients met the PHQ-9 criteria for major depressive disorder (MDD), of whom 33 (24.8%) were receiving ADs for symptoms other than pain. Mean NRS-score for depression was 1.9 (SD 2.3) for the entire sample, 1.6 (SD 2.1) for all patients categorized as depressed, 2.8 (SD 2.7) for those receiving ADs, and 4.7 (SD 2.6) for those depressed and receiving ADs.

**Conclusion and discussion:** Low numbers of patients with MDD are receiving AD. There is a need to increase the awareness of depression in patients with advanced cancer. It is reason to believe that more patients may benefit from ADs.

**Acknowledgment:** EURO IMPACT, European Intersectoral and Multidisciplinary Palliative Care Research Training, is funded by the European Union Seventh Framework Programme (FP7/2007-2013, under grant agreement n° [264697]).

**Abstract number:** FC 13.6

**Abstract type:** Oral

### **Definition, Categorisation Framework and Terminology of Episodic Breathlessness: Consensus by an International Delphi Panel**

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**Aims:** Episodic breathlessness is a common and distressing symptom in patients with advanced disease. Still, it is not yet clearly defined. The aim of this study was to agree on a definition, categorisation framework and terminology of episodic breathlessness.

**Methods:** A web-based Delphi survey (three rounds) was conducted with international experts in the field of breathlessness. A structured questionnaire was used to identify specific aspects and to reach agreement on statements on definition, categorisation and terminology on a 5-point Likert scale. Responses were analysed anonymously. Descriptive analysis was used and consensus was defined in advance as  $\geq 70\%$  agreement. Comments were analysed using framework analysis.

**Results:** 31/68 (45.6%), 29/67 (43.3%) and 33/67 (49.3%) experts responded in the 1st/2nd/3rd round, respectively. Participants were from USA, Canada, Europe and Australia, between 20-79 years, about 60% male, and  $>75\%$  rated their own expertise regarding breathlessness as moderate to high. After the 3rd round, consensus was reached on a definition (84.4% agreement), categorisation (96.3%) and terminology (episodic breathlessness) (92.9%). The final definition includes general aspects on the symptom occurrence, e.g. its intermittent, time-limited character and independence of underlying continuous breathlessness, as well as qualitative aspects of the symptom, e.g. a severe worsening of intensity or unpleasantness of breathlessness in the patient's perception. Episodes may be predictable or unpredictable, depending on whether any triggers can be identified.

**Conclusion:** Based on this Delphi survey, there is high agreement on clinical and operational aspects of episodic breathlessness among international experts. The consented definition and categorisation may serve as a catalyst for clinical and basic research on episodic breathlessness in order to improve symptom control and quality of life.

# Poster discussion sessions

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Assessment and Symptom Management  
End of Life and Services

## Assessment and Symptom Management

Abstract number: PD 1.1  
Abstract type: Poster Discussion

### Delirium in Patients Admitted to an Inpatient Palliative Care Unit

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**Introduction:** Palliative patients have a high risk of delirium. The diagnosis is mainly clinical. Terminal sedation may be required.

**Objectives:** To determine the frequency of delirium in a palliative care unit (PCU) in patients to income (DI) or during hospitalization (DDI) and describe the characteristics of patients, type of delirium, triggers, treatment and survival, and how many terminal sedation is required.

**Methodology:** Observational, retrospective, longitudinal of all patients admitted to a palliative UCP for a period of 6 months, excluding those who die in the first 24 hours. Delirium is considered if were descript in the clinical chart and /or was reflected in the medical criteria of DSM-IV delirium.

**Results:** N: 175 patients, 1 patient was dismissed by death in < 24 hours, 64% were male, mean age 76 years (43-108), 95% cancer, 103 (59%) present delirium: DI: 56 (51%) and DDI: 47 (49%). Terminal delirium: in 74 cases (72%), with a median survival of 7.5 days (1-43). Terminal sedation in 9 cases (12%).

The Most frequent type of Delirium was hypoactive (39%) been in the same percentage Hyperactive and mixed 31%. The most frequent triggers were pharmacological 62% being present more than one factor in most of cases (62% drug, Metabolic 54%, Infections 39%, 7% organic brain disease, Other 6%). Metabolic factors are most frequent in the DI and pharmacological and infectious in the DDI. Haloperidol was the most commonly used drug for delirium. The drug most commonly used for sedation was midazolam (mean dose 50-100mg/dia), 67% was associated with Levomepromazine (50-100mg/dia).

**Conclusions:** The frequency of delirium and precipitating factors found are similar to other studies, with different predominant factors in the DI regarding DDI. The hypoactive delirium was the most commonly diagnosed and most widely used drug were haloperidol. Rarely was necessary terminal sedation in our PCU.

Abstract number: PD 1.2  
Abstract type: Poster Discussion

### Cognitive Performance in Cancer Patients Receiving Palliative Chemotherapy

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**Objective:** To compare the cognitive function in patients with cancer with that of healthy volunteers.

**Methods:** Cross-sectional study, in which 181 outpatients with cancer in palliative chemotherapy and 191 healthy volunteers were assessed. Data were collected between 2011 and 2012. Trail Making Test A and B (TMT), Digit Span Test (DST), Continuous Reaction Time (CRT), Finger Tapping Test (FTT) and Mini-Mental State Examination (MMSE) were used to evaluate different domains of cognitive function. Hospital Anxiety and Depression Scale (HADS), Karnofsky Performance Scale (KPS) and Fatigue Pictogram were also used. Chi-square test, T-test and Wilcoxon test were applied.

**Results:** Patients mean age was 50.7y (SD=10.6), schooling mean 11.3y (SD=3.4), KPS mean 88% (SD=9.7), pain intensity mean 1.1 (SD=2.2, variance 0-10), depression mean 5.7 (SD=3.8, variance 0-18) and anxiety mean 6.6 (SD=4.2, variance 0-20). Colorectal (38.7%) and breast (21%) cancers were the most frequent diagnoses, 53% had metastasis. Both groups were similar regarding schooling and income and had mild to moderate fatigue. Groups, however, differed in age (volunteers mean 40.9 y, SD=13.4). Patients had slower performance compared to controls in TMT-B [113 sec. (SD=87.1); 95 sec. (SD=79.9), respectively, P< 0.001]. There were no significant differences between groups in the other neuropsychological tests and both had good performance considering cut-off scores.

**Conclusion:** Similar cognitive performance was observed between both groups; however, patients had worse cognitive performance in one test which requires interaction among attention, psychomotor speed, and mental flexibility.

It may suggest impairment for complex tasks and it can compromise patient's performance at work and daily life. One should consider that this sample had good physical performance, no significant pain or fatigue and no depression or anxiety. Samples with different clinical condition could present different results.

Abstract number: PD 1.3  
Abstract type: Poster Discussion

### An Experimental Model in Cancer Pain to Investigate the Effects of Pain and Opioids on Cognitive Function

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**Aims:** To study the effects of pain and opioids on sustained attention.

**Methods:** Randomized, double-blind, placebo controlled, cross-over study with 23 healthy Caucasian male volunteers (age 20-28 y). Sustained attention, the ability to respond rapidly to external stimuli for an extend period of time, was evaluated by Continuous Reaction Times (CRT) software. Results were presented in 10<sup>th</sup> (fastest times), 50<sup>th</sup> and 90<sup>th</sup> percentiles (slowest times). Three sessions for each participant were conducted.

**1st session:** CRT was tested under the influence of experimental pain of mild and moderate intensities induced by a pneumatic tourniquet cuff with a computer-controlled air compressor;

**2nd session:** CRT was tested under the influence of placebo (saline) or remifentanyl 0.1 µg kg<sup>-1</sup> min<sup>-1</sup>;

**3rd session:** a model of pain relief as well as breakthrough pain was instituted by adjusting the tourniquet cuff on the calf to increase pain sensation after pain relief with remifentanyl or placebo. Assessments occurred when the volunteers reported stable pain or 10 minutes after steady-state infusion. The Ethics Committee has approved the study.

**Results:**

**1st session:** Moderate and mild pain slowed CRT significantly from baseline, but no differences when comparing mild with moderate pain.

**2nd session:** slower performance on remifentanyl when compared to placebo (50<sup>th</sup>: P=0.007; 90<sup>th</sup>: P< 0.001).

**3rd session:** A decrease in pain intensity was observed with remifentanyl, while the placebo effect was minimal (P< 0.001); volunteers had slower CRT when receiving remifentanyl (10<sup>th</sup>: P=0.02; 50<sup>th</sup> and 90<sup>th</sup>: P< 0.001). When pain was increased (breakthrough pain), only a minor effect was noted prolonging reaction time (50<sup>th</sup>: P=0.045).

**Conclusion:** Remifentanyl had effect on sustained attention, while pain intensity seems to have little interference on it. The results suggest that opioids interfere more with cognitive function than pain itself.

The study is supported by The Danish Cancer Society.

Abstract number: PD 1.4  
Abstract type: Poster Discussion

### Renal Itch - Systematic Evidence on New Tools in the Fight

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**Background:** Pruritus is a common problem in end-stage kidney disease, with up to 77% of dialysed and 74% of conservatively managed patients reporting itch.

It impacts on mental and physical function, sleep, and is associated with depression and worse survival. Despite this it remains poorly managed.

**Aim:** To identify, assess and synthesize the evidence on management of renal itch, to better inform patient care.

**Method:** Systematic literature search using Medline and Pubmed was performed using the keywords "itch", "pruritus", "renal failure" and "management", and supplemented by reference list and cited reference searching.

**Results:** 31 papers from Medline and 20 from Pubmed were included with 30 further papers from reference lists.

Systemic and topical treatments were reported as being effective in renal itch with most evidence from

haemodialysis patients and little in conservatively managed patients.

Good evidence supports multiple systemic treatments including cholestyramine (1 RCT), opioid k-receptor agonists (2 randomised control trials (RCT)), thalidomide (1 RCT), gabapentin (2 RCT) and sodium cromolyn (1 RCT). There is limited evidence to support the use of mirtazapine (case report), ganisetron (open label trial (OLT)) and ketotifen (case report).

Topical therapies include simple emollients and oils (2 OLT, 2 RCT), oils containing polidocanol (1 OLT), pramoxine lotion (1 RCT), tacrolimus ointments (2 OLT) and capsaicin creams (2 RCT, 1 OLT).

Non-pharmacological therapies have shown efficacy in itch but with less robust evidence. UVB light showed usefulness in OLTs. Homeopathy has been studied in a RCT with good reduction in itch. Acupressure and acupuncture have limited evidence compared to sham procedures (2 review papers).

**Conclusion:** This work elucidates the management options when managing renal itch. These treatments can be used in the more stable haemodialysis patient troubled by it but can also be used in the more unwell palliative and co-morbid renal patients.

Abstract number: PD 1.5  
Abstract type: Poster Discussion

### The Use of Pain Assessment Tools in the Acute Setting

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**Aims:** People with severe dementia admitted to acute hospitals often receive poor care, many die in this setting and are at risk of under-detection and under-treatment of pain. An aim of the BePaid study (Behaviour and Pain in Dementia Study) was to assess the detection of pain in this setting in this population.

**Design and methods:** A longitudinal cohort study in 2 UK acute hospitals. Each participant was assessed every 3-5 days during admission, using the following tools: PAINAD (Pain Assessment in Advanced Dementia) at rest and during movement, the FACES Pain Scale and the question 'Do you have any pain?' (self-report is considered to be the "gold standard").

**Results:** 230 patients were recruited. 14% of our sample had little or no verbal expression. On the PAINAD, 28% of participants were assessed as in pain at rest but 65% had pain on movement. In total, pain was observed at nearly 50% of all visits during the study. On the PAINAD scale, 28% were rated as mild pain (score 1-3), 11% as moderate (score 4-6) and 5% severe (score 7-10). The PAINAD had good inter-rater reliability (Kappa = 0.74). The FACES pain scale was less effective; 49% were unable to complete this scale for themselves. Our self-report measure was of limited utility; 28% assessed on the PAINAD as being in pain answered that they were not in pain.

**Conclusion:** The PAINAD scale was a usable and reliable tool for measuring pain in the acute setting. The data highlights the importance of observing for pain at rest and during movement. People with dementia had difficulty completing the FACES pain scale, and also at times said they were not in pain when an observational tool suggested that they were not. Clinicians working with in the acute hospital need to be aware of the complexities of pain assessment, using a mixture of observational and self-report tools may be the best way to detect pain in people with severe dementia. This project is funded jointly by Alzheimer's Society and the BUPA Foundation.

Abstract number: PD 1.6  
Abstract type: Poster Discussion

### A Systematic Review of Prognostic Tools in Advanced Cancer

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**Introduction:** Accurate prognostication is necessary in advanced cancer to ensure optimal management. Numerous prognostic tools have been developed but few meet the required standards of outcome measure development and validity.

**Aim:** Examine the prognostic tools for use in advanced incurable cancer and assess their accuracy of survival prediction.

**Methods:** A systematic review was undertaken. Databases



(Medline, Embase Classic and Embase) were searched, to identify studies examining prognostic tools in advanced incurable cancer. Descriptive and quantitative analyses were performed on eligible studies.

**Results:** Initial search yielded 616 articles. 52 articles met the selection criteria. The prognostic tools identified were the PaP (Palliative Prognostic Score) (8 studies), D-PaP (Delirium-PaP) (2 studies), BCI (B12/CRP Index) (2 studies), PPI (Palliative Prognostic Index) (6 studies), PPS (Palliative Performance Scale) (18 studies), mGPS (modified Glasgow Prognostic Score) (7 studies), and the GPS (Glasgow Prognostic Score) (9 studies). Summary of statistical results for each tool: mGPS HR range 1.346 - 2.712; GPS HR range 1.51-2.35; PaP log rank range 25.65-322.65 and HR 0.214-0.722; PPS OR range 1 - 3.21, HR range 0.039 - 18.022, RR 0.178 - 0.427, c statistic 0.74 overall; PPI PPV range 78-93% and sensitivity range 63-85%; D-PaP log rank 326.87 and C-index 0.73; BCI (graphic and tabular results) log(B12)b HR 1.2 and log (CRP)b HR 1.23 on cox model findings. All 7 tools predicted survival in advanced incurable cancer. The external validity of the PaP and mGPS/GPS tools was also demonstrated in single cancer types, emphasising versatility and applicability.

**Conclusion:** The PaP, D-PaP, BCI, PPI, PPS, GPS and mGPS have been extensively validated in patients with advanced incurable cancer. The heterogeneity of the statistical analysis and study populations means that direct comparison is challenging.

**Abstract number:** PD 1.7

**Abstract type:** Poster Discussion

### Identification of a Tool to Measure Quality of Life in Paediatric Palliative Care Patients

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**Aims:** Quality of life (QOL) represents a central evaluation criterion in palliative care. Therefore methods for a reliable and valid measurement of QOL are needed. Multiple-item-measurements have the advantage of covering different dimensions, providing a complete profile of QOL. Single-items were thought to be a cost effective, easy and less exhaustive alternative to measure QOL. Aim of this study was to identify a useful tool for measuring QOL in children with life-limiting conditions.

**Design:** This study included 102 children (age range: 8-18 years) suffering from life-terminating diseases and their caregivers. The participants were identified using IMPACT-criteria [Craig et al. 2008]. The interviews contained multiple-item questionnaires (Kindl-R, Kidscreen-27) and two single-items.

**Results:** The correlation coefficient after Pearson was found to be 0.64 between the summated scores of Kindl-R and Kidscreen-27 of the child versions. The scores of the proxy versions of Kindl-R and Kidscreen-27 showed a correlation coefficient after Pearson of 0.67. Dividing the results of the scores into two groups by building one group of low QOL and one of normal and superior quality of life showed a sensitivity of 0.83 and a specificity of 0.68 between the results of the child version of the Kindl-R and the proxy version of the single-item with the question "How high would you estimate the today's QOL of your child?"

**Conclusion:** The Kindl-R and Kidscreen-27 displayed correlation coefficients, suggesting the tests to be suitable for measuring QOL in paediatric palliative care. Regarding the summated scores and comparing them with the results of the single-items, the single-item "How high would you estimate the today's QOL of your child?" is a good screening test to identify children with low QOL.

**Abstract number:** PD 1.8

**Abstract type:** Poster Discussion

### How well Do European Palliative Care Guidelines Consider the Assessment and Management of Pain for People with Impaired Cognition?

Sampson E.L.<sup>1</sup>, Lewis J.<sup>2</sup>, Pautex S.<sup>3</sup>, Shvartzman P.<sup>4,5</sup>, Van den Block L.<sup>6</sup>, Sacchi V.<sup>7</sup>, van der Steen J.T.<sup>8</sup>, Van Den Noortgate N.J.<sup>9</sup>, COST ACTION TD1005: Pain Assessment in Patients with Impaired Cognition especially Dementia

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**Aim:** To assess whether European general palliative care guidelines consider the needs of people with cognitive impairment (CI) (dementia, learning disability, delirium), examine which pain assessment tools are recommended and describe pain management recommendations.

**Methods:** Cross-national European survey using the EU funded Co-operation in Science and Technology (COST) Action "Pain & Impaired Cognition" network. Two members from each country identified their country's most widely used guideline. We recorded whether guidelines explicitly referred to people with CI and their pain management at the end of life through the use of validated tools and therapeutic strategies. Guideline methodological quality was assessed by the member from each country using the Appraisal of Guidelines Research and Evaluation (AGREE) scale.

**Results:** COST members from 13 countries assisted; UK, Netherlands, Italy, Belgium, Israel, Iceland, Finland, Norway, Romania, Spain (10) had generic palliative care guidelines. Cyprus and Switzerland did not. In Germany these were under development. In 8/10 countries the identified palliative care guideline included pain management, of these, 7 mentioned CI (3 dementia, 2 learning disability, 4 delirium, 1 coma/vegetative state). A range of pain assessment tools were recommended for people with CI; verbal rating scale, visual analogue scale, PACSLAC, PAINAD, Dolopius and DiSDAT. Only 2 guidelines (Netherlands & Finland) provided guidance on pain management in people with CI. The AGREE quality score varied from 62%-94%. Higher quality guidelines with more stakeholder involvement in development were more likely to consider people with CI.

**Conclusion:** Only 2 of 10 European palliative care guidelines we assessed advised on pain management in people dying with CI. Because in Europe 7.3 million people have dementia and 1/3<sup>rd</sup> of people over the age of 65 will die with this disease, national palliative care guidelines should consider this population.

**Abstract number:** PD 1.9

**Abstract type:** Poster Discussion

### Building Research Capacity in a Sub-Saharan Academic Setting: Lessons to Share

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**Aims:** Few academic services for integrated palliative care team exist in sub-Saharan Africa with minimal evidence of their effectiveness. A key aim of our unit is the establishment of a context rich research capacity to develop new and existing researchers and thus increase research activity, publication and enhance the evidence base to provide optimal patients care.

**Design:** Local stakeholders (hospital practitioners, volunteers, NGOs, charity workers) with national and international partners (Ministry of Health, NGOs, Universities) developed a 5 year research capacity building strategy. These included research skills masterclasses and research modules within the Uganda based BSc in palliative care, research dissertations, a national research workshop and a pioneering Advanced Research School. Regular academic supervision and mentorship is offered and research roles built in to all unit personnel. Grant funding was sought to support these activities.

**Results:** To date 40 participants completed masterclasses, 32 studied the BSc modules, 130 attended the workshop and 25 the Advanced Course, and one PhD is underway. 20 research projects are complete, 21 led by new researchers, 12 of whose work has been presented at conferences. The strategy has resulted in a measurable increase in African based research activity.

**Conclusion:** Building research capacity and integrating an evidenced based approach requires multiple approaches, with medium to long term planning to support the translation of knowledge into further publications, rich collaborations and improved practice. Collaborating nationally, regionally and internationally, research capacity can be supported and result in early increases in research activity. This paper will discuss the development, challenges faced and lessons to share to ensure an effective strategy.

## End-of-life and Services

**Abstract number:** PD 2.1

**Abstract type:** Poster Discussion

### The Impact of Volunteers Support in the Care of Palliative Patients and their Families: Systematic Review of Qualitative and Quantitative Research

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**Research aims:** Despite the general acknowledgment of volunteers' contribution to palliative care, and the interest at least in the UK (as demonstrated by current research funding) of increasing their role in direct care, the effect volunteers have on patient and family outcomes has not been systematically evaluated. To undertake a systematic review of the evidence on the impact on patient and family well being of volunteers with direct contact with patients and families in specialist palliative care.

**Study design and methods:** We searched relevant electronic databases, scanned reference lists of included studies, contacted relevant researchers in the field, and undertook handsearches of selected journals to find quantitative and qualitative studies which met our inclusion criteria. We applied quality appraisal criteria. Because of lack of extractable data, we undertook a largely narrative review.

**Results:** We found 6 quantitative and 3 qualitative studies undertaken in both hospice and home-care settings. The evidence on the impact of volunteers on patient and family outcomes is sparse. Many studies are cross-sectional in design and focus on satisfaction ratings showing high satisfaction with care involving volunteers. Two comparative studies show better outcomes or higher satisfaction for patients receiving care involving volunteers compared with either those receiving care not involving volunteers or with lower volunteer involvement. Companionship was the volunteer activity most commonly appreciated by study respondents. Studies do not consider possible harms or disbenefits of volunteer involvement.

**Conclusions:** Research into the impact of volunteers in specialist palliative care settings is weak and would benefit from well designed studies comparing outcomes for patients and families with and without volunteer involvement. This will help to plan better services to make the best use of available resources.

**Funded by:** The Dimbleby Marie Curie Cancer Care Research Fund.

**Abstract number:** PD 2.2

**Abstract type:** Poster Discussion

### Teenagers' Advice to the Health Care Staff Caring for Dying Parents of Teenage Children

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**Background:** To lose a parent to death is among the most traumatic event a child can experience. Still, little is known about what kind of support teenage children losing a parent to cancer would have wanted from the health-care staff.

**Aim:** To investigate cancer-bereaved teenagers' advice to the health care staff caring for dying parents of teenage children.

**Method:** The study is part of a nationwide population-based epidemiological study of 622 out of 851 (participation rate 73%) cancer-bereaved youth who lost a parent between the ages of 13 and 16, in 2000 to 2003. Data was collected with study-specific questionnaire 6 to 9 year post-loss. In this paper we investigated the answers to the last question in the survey: *Which advice would you like to give the health-care staff that encounters teenage family members of parents with cancer?* Manifest content analysis was used for the analysis.

**Result:** The teenagers describe a variety of advice for the care staff. However, the majority of advice concerns the teenagers' own need for open, honest and clear information. Some state that parents are not always able to provide their children with this information and that responsibility should shift to professionals. Answers also touch on how staff should act and what they should do when meeting a teenager who has lost or is about to lose a parent to cancer.

**Conclusion:** Swedish youths having lost a parent to cancer have given us advice, including clear-cut communication about the prognosis in different disease stages and pointing

## Poster discussion sessions

out that the non-sick parent may fail to communicate the truth. It is unclear to what extent we can implement these advances directly or need a formal prospective evaluation of a change in routines.

**Abstract number:** PD 2.3

**Abstract type:** Poster Discussion

### Factors Associated with Dying at the Place of Wish: A Cross-country Comparison of Cancer Patients with the EURO SENTI-MELC Study 2009-2010

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#### Aims:

- 1) To study demographic and clinical factors associated with dying at a preferred place for cancer patients
- 2) To study cross-country differences in the intensity of factors

**Methods:** A mortality follow-back study was undertaken in 2009-2010 via representative nationwide networks of general practitioners (GPs) in Belgium (BE), the Netherlands (NL), Italy (IT) and Spain (ES). GPs reported aspects of end-of-life care of deceased patients weekly on a standardised questionnaire. All non-sudden cancer deaths aged 18+ were included. Association between 7 factors (age, gender, number of GP contacts, communication about palliative care, GPs provision of palliative care, patients' treatment wishes, patients' decision-making capability) and preference met on place of death separately (excluding Spain) was assessed through bivariate and multivariate logistic regressions.

**Results:** A total of 1920 deceased patients were identified. 837 patients were included in the final analyses if GPs were informed about the preference. Over 70% of the sample aged 65 or above, 54% being male and most frequently had lung malignancy. Bivariate analyses showed having more than four contacts with GPs in the last week of life (ORs [95% C.I.]: IT:3.0 [1.2-7.6], NL:8.0 [1.6-39.8], BE:9.3 [3.0-28.7]) and receiving GPs provision of palliative care until death (ORs [95% C.I.]: IT:4.2 [2.4-7.2], NL:7.4 [3.2-17.3], BE:11.6 [6.1-22.2]) are the only factors associated with dying at the place of wish. Provision of palliative care by GPs until death remains the only significant factor in the multivariate analyses consistently in all countries. (ORs [95% C.I.]: IT:4.6 [2.5-8.5], NL:14.2 [3.0-39.8], BE:9.3 [3.0-28.7])

**Conclusion:** Receiving palliative care provided by GPs until death is associated with realising a cancer patient's preferred place of death after adjusting for demographic and clinical characteristics. Though the cause-and-effect is unclear, the data show GPs' crucial role in providing primary palliative care in all countries.

**Abstract number:** PD 2.4

**Abstract type:** Poster Discussion

### Patient and Family Experiences of Palliative Care in Hospital: What Do We Know? An Integrative Review of the Literature

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**Aim:** The aim of this review is to synthesise current international evidence regarding experiences of palliative care in an acute hospital setting from the perspectives of patient and family.

**Design:** A systematic review of the literature was undertaken followed by a process of data extraction and synthesis. Quantitative and qualitative studies that provided data regarding experiences of palliative care in a hospital setting from the perspectives of patients and families were included. Major and recurring sub-themes were identified from a summary of the data.

**Results:** The search identified 301 studies which were examined for relevance to the review topic; 32 studies

satisfied the inclusion criteria. Five recurring themes were identified. Hospitalised patients experienced a significant symptom burden with relatively poor symptom control. Patients and families reported difficulties communicating with health professionals. The hospital environment was criticised for being noisy and lacking privacy. Although families generally felt they were involved in decision making as much as they wanted to be, a number of factors were identified as impacting on their ability to participate effectively in end of life decision making. Being treated with kindness and respect by hospital staff were valued highly. **Conclusion:** Despite the fact that most people express a preference to be cared for and die at home or in a hospice, hospitals play a significant role in providing palliative care. This review has identified that, largely as a result of study design, our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. These experiences carry significant burden for patients and families. Further research is required to explore the total patient and family experience taking into account all aspects of care including a focus upon the potential benefits of hospital admissions in the last year of life.

**Abstract number:** PD 2.5

**Abstract type:** Poster Discussion

### Palliative Care in Brazil: Service Profile

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**Introduction:** Palliative care emerged in Brazil in the 1990s, expanding since. There are no studies on service availability and delivery. It is estimated, however, that there is a dearth of resources for the demand. According to official data, 725,000/1,031,691 (70%) deaths in 2006 were of patients with chronic diseases or cancer, likely in need of palliative care assistance. This study is one result of the First Brazilian Encounter of Palliative Care Services, held in September 2012 in São Paulo.

**Objectives and methods:** To establish the availability and characteristics of palliative care services in Brazil. Specifically, team composition, type of services provided, patient population, and funding sources. We conducted descriptive analyses of the data submitted by participating services, who were invited from all over the country.

**Results:** 31 palliative care services were surveyed, from 15 cities around Brazil. Oncologic patient population prevails (19 of 26 services that answered, 73%). A minority of services cater to pediatric populations (4/26, 15%). Twenty services reported team composition as follows: 20/20 (100%) had physicians and nurses, 16/20 (80%) psychologists, 15/20 (75%) had social workers, physiotherapists and dietitians, 7/20 (35%) had speech therapists, 5/20 (25%) had spiritual assistants, 4/20 (20%) had pharmacists, 3/20 (15%) occupational therapists and 2/20 (10%) music therapists. Twenty three services (74%) reported on service modalities, with the majority (16/23, 70%) delivering care in more than one setting (inpatient units, hospices, home care, and others). The majority of the services are government-funded (64%).

**Conclusions:** This sample provides insight on Palliative Care delivery in Brazil. It seems that it is widely varied across the country, ranging from well-established multiprofessional teams to smaller initiatives. To our knowledge, this is the first study on palliative care delivery in Brazil. Further more generalizable studies are needed.

**Abstract number:** PD 2.6

**Abstract type:** Poster Discussion

### Hospitalization in End Stage, Oldest Old, Dementia Patients: Is this what We - and they - Want?

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**Introduction:** End stage dementia in oldest old patients (pts) is characterized by multiple symptoms and high levels of morbidity. International guidelines point at maintaining quality of life, suggesting home care or hospice assistance, in consideration of uncertain benefits from hospitalization. These pts in contrast, still appear to be a common "phenomenon" in acute wards where therapeutical approach seems questionable.

**Aim of the study:** Investigate the approach, treatment regimens and outcome in end stage oldest old dementia pts in our acute medical ward.

**Study design:** Observational, retrospective. From January 1<sup>st</sup> to 31<sup>st</sup> December 2011. Inclusion criteria: pts admitted to our medical ward deceased within 6 months from admission; severe dementia (Dementia Severity Rating Scale 6-7); unable to walk, pressure ulcers from immobilization, unable to express verbally; Karnofsky score < 30-40%; age > 75

years (y).

**Results:** On 2829 admissions, 339 pts were included (11.9%; male/female = 112/227). Mean age: 88.8 y (69% of pts were over 85 y). Admission diagnosis: fever 34.8%; cachexia/dehydration 14.1%; dyspnea 12.9%; stupor/coma 11.8%; bowel disfunction 6.5%; stroke 4.4%; pain 2.6%; others 11.8% (nutritional access dislocation, bleeding, cancer). Globally, 71.7% underwent antibiotic therapy of which 99% via intravenous line; 64.3% had intravenous hydration. Invasive procedures (nutritional accesses, urinary catheters, central venous lines, ventilation) were performed in 35.1% of pts. 34.8% deceased during hospital stay. Of 221 dismissed pts, 41.1% had at least one hospital admissions before death.

**Conclusions:** There is striking evidence that oldest old dementia pts are still treated in acute wards where therapeutical approach seems not different from younger non palliative subjects. Knowledge must be implemented to find strategies aiming at reducing hospitalization, modifying approach and increasing quality of life in palliative pts also in acute settings.

**Abstract number:** PD 2.7

**Abstract type:** Poster Discussion

### Effectiveness of Music Therapy in Advanced Cancer Patients Admitted to a Palliative Care Unit

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**Introduction:** Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved Music Therapy program.

**Aims:** To analyze the effectiveness of music therapy interventions for patients with advanced cancer admitted to a palliative care unit (PCU). Study design: Prospective randomized controlled study. Inclusion criteria: patients with advanced cancer, older than 18 years, Karnofsky performance status of 30 or more.

**Methods:** All patients (treatment group and control group) were evaluated: musical history, state anxiety, level depression (HADS), well-being (analogue scale of well-being 0: worse, 10 better well-being) and physical and emotional symptoms (sum of 9 items) pre-session and upon entry and final Music Therapy treatment sessions. Treatment group received 4 Music Therapy sessions on alternating days, with each musical intervention lasting 30 to 45 minutes.

**Results:** N=70 (35 treatment, 35 controls). The characteristics of both, treatment group and control group, were similar. Statistical differences between cases and controls were found in the following parameters: well-being scale, number of symptoms, as well as anxiety and depression (HADS) (Table 1).

Table 1. Parameters at the beginning and at the end

	Case (beginning)	Case (end)	Control (beginning)	Control (end)	P value
Well-being scale	5.3	7.7	5.9	5.1	<0.001
Symptoms	11.0	7.3	7.6	6.7	<0.01
HADS	22.2	16.8	16.5	18.6	<0.001

Statistical differences were not found in asthenia and pain (marginal).

**Conclusions:** Music Therapy in advanced cancer patients admitted to a PCU showed benefits in quality of life, anxiety and depression, and decreased the number of symptoms. This study suggest that Music Therapy is recommended for advanced cancer inpatients.

**Abstract number:** PD 2.8

**Abstract type:** Poster Discussion

### What Does "Spiritual Care" Stand for in Pediatric Palliative Care? A Well-grounded Approach: The Web-based Ontology of Spirituality

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**Background:** Most articles on spiritual care in pediatric palliative care focus on single aspects such as the spirituality of the parents or the spiritual quality of life. Other articles show the usefulness of spiritual care in this context. Our aim was to explain the complexity of spiritual care in pediatric palliative care practice.

**Method:** We analyzed the records of 143 patients from a German specialized outpatient pediatric palliative care unit (SOPPC) between 2004 and 2009. All members of the multidisciplinary team use those records for documentation. Sections are: **sociodemographic data, medical report, nursing, social work, and additional information.** Although there is no separate section on spiritual care, spiritual, religious, and cultural aspects could be identified throughout the records. The methodology was developed following an IT-based ontology. We collected and structured all data on spiritual, religious and cultural aspects in order to develop a comprehensive concept of spirituality within SOPPC.

**Results:**

Main topics concern implicit spiritual needs (beyond faith) in relation to culture, concepts of 'family', understanding of death and nursing problems.

1. Explicit spiritual themes are: "Why?" (mostly combined with: "Who is guilty?"), almightiness/helplessness, transcendence, eternal love and eternity/finiteness.
2. The spirituality and spiritual needs of the child may differ from those of the family. Spiritual care interventions address the child, the family or both.

Analyzing cases based on this ontology may help in realizing spiritual care interventions that meet the specific needs of the children and their families: **ritual, pastoral counseling, meaningful silence, spiritual guidance.**

**Discussion:** The ontology provides a model to describe the complexity of spiritual care in pediatric palliative care and allows for the integration of spiritual care into current practice.

**Abstract number:** PD 2.9

**Abstract type:** Poster Discussion

**A Strategic Development Using 'High' Facilitation to Implement and Sustain the Gold Standards Framework for Care Homes in 71NHs across 5 PCTs**

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In 2008, St Christopher's Hospice, UK set up the Care Home Project Team to implement the Gold Standards Framework for Care Homes (GSFCH). The team covered a population of 1.4 million with 71 NHs and consisted of 5.5 FTE clinical nurse specialists (CNSs) funded through local charities. A 'high' facilitation model was adopted to counteract the 'low' context of care homes.

**Aim:** To implement the GSFCH and set up a sustainability initiative to: reduce inappropriate hospital deaths; empower NH staff/general practitioners in advance care planning (ACP), Liverpool Care Pathway or equivalent (LCP), and do not attempt resuscitation (DNaCPR) orders to improve quality of end of life care.

**Methods:** CNSs worked across specific areas to build relationships with local NH managers, their general practitioners and local commissioners. Over a 5-year period, all NHs completed the programme. Audit details were undertaken prior to NHs commencing the GSFCH. NH managers were encouraged to join a local sustainability cluster group (7-8 NHs). The groups met regularly and consisted of:

- a palliative care (PC) Induction Day/6 monthly - all new staff (didactic)
- 4-day PC training - nurses/carers (experiential)
- Action learning/bi-monthly - NH managers (critical thinking)

**Results:** Inappropriate deaths in hospital were reduced by 21% across the five PCTs. In 2007/8 prior to commencing GSFCH, 57% residents (n=324) died in 19 NHs undertaking the programme. In 2011/12, across 71 NHs, 78% residents (n=1,351) died in the NH. Similar data is represented in increased use of LCP, DNaCPR, and ACP. The team is now fully funded by local PCTs.

**Conclusion:** Specialist palliative care is in a position to work strategically with NHs to develop high quality EoLC. It requires CNSs, who understand the 'low' context of care homes, to develop relationships in order to empower NH staff. Although results are encouraging, it is now important to measure the quality of care during the last month of life.



# Poster sessions – set 1

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Pain  
Other Symptoms  
Assessment & measurement tools  
Audit & quality control  
Basic & translational research  
Bereavement  
Education  
End of Life Care  
Epidemiology  
Ethics  
Family & Care Givers  
Medical Sociology  
Organisation of Services  
Policy  
Psychology & communication  
Research Methodology  
Non-Cancer  
Palliative Care in the Elderly  
Palliative Care in Children and Adolescents  
Advocacy & Media  
Spirituality

Pain

Abstract number: P1-001  
Abstract type: Poster

**CRPS-I with Neoplastic Origins Treated with Perineural Catheter Placement**

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**Introduction:** Complex Regional Pain Syndrome I (CRPS-I) clinically appears with paraneoplastic manifestations. The clinical case we present, shows results of a female patient affected by CRPS-I, secondary to a left brachial plexus infiltration caused by mammary carcinoma, treated with continuous infraclavicular brachial plexus block.  
**Clinical case:** A 55 years old woman arrived at the algological observation with a diagnosis of locally infiltrating mammary carcinoma. She had already undergone a left breast quadrantectomy with subsequent homolateral armpit emptying. The patient reported pain located on the left arm and showed signs and symptoms of CRPS-I associated with a neoplastic lesion. The patient showed continuous pain (vNRS=8-9), paresthesia, hyperalgesia, perspiration anomaly in the painful area, dyschromia and thermoregulatory modifications of the left upper limb, associated with hypostenia of the arm, tremor and dystonia. A neuropathic component became more evident with the manifestation of tingling, pin and needles, hypoanalgesia, allodynia.

After a therapy with opioids failed, we judged adequate to use an invasive regional analgesic technique, valid for the manifestation of a neurovegetative syndrome, with a severe neuropathic characterization. An infraclavicular catheter has been placed following the Raj technique. The analgesia obtained with ropivacaine HCl 0.2% after the initial bolus of 3ml, has generated the total anaesthesia of the arm areas affected by CRPS-I, while several bolus of ropivacaine HCl 0.2%, for a maximum of 1ml each bolus, every 6-7 hours, has assured an excellent resolution of pain (vNRS=0-1).  
**Conclusion:** The technique presented in this case, has been able of minimizing the pain, reducing the motor and sensorial disability of the injured limb, improving the patient's psychological aspect and her quality of life in the short and medium term.

Abstract number: P1-002  
Abstract type: Poster

**Procedural Pain in Older Terminal Ill Patient: The Role of Buprenorphine**

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**Introduction:** Pain associated with difficult wounds often remains undiagnosed and under-treated. Only 6% of patients with chronic ulcers are treated with an effective analgesic therapy, even though 75% of them indicate the pain as moderate or severe. Untreated pain negatively influences the process of healing as well as the patient's compliance and quality of life.

**Clinical case:** An 84-year old woman (weight: 45 kg) with an ulcerated cutaneous T-cell lymphoma, localized in right scapulo-humeral articulation, came to our attention. She had severe pain (v-NRS=10) radiating to the upper limb and ipsilateral cervical region. Pain disrupting her night sleep. She was prescribed transdermal buprenorphine (BUP-TD) 17.5µg/h/84h and tramadol 50mg as needed. After 7 days, the patient showed a reduction in pain intensity (v-NRS=6). Nonetheless, episodes of breakthrough pain (BTP) continued with vNRS=10, BTP>6 episodes/24h. No side effects were noticed, except for slight sleepiness. BUP-TD was incremented to 35µg/h and tramadol replaced with sublingual buprenorphine (0.2 mg). Pain was controlled (v-NRS=2) and night sleep improved. However, pain could still not be controlled during wound dressing, and patient refusing to undergo the procedure of debridement. Therefore, sublingual buprenorphine was prescribed 30 min before wound curettage. An adequate level of analgesia was obtained, which greatly improved patient compliance. During the following month, she was subjected to wound dressing two times per week, during which pre-emptive use of sublingual buprenorphine was made.

**Discussion:** The use of buprenorphine is extremely flexible when counteracting hyperalgesia and managing pain, even in case of mixed pain from difficult wound. The reported case highlights how BUP-TD formulation associated with sublingual administration, exploits pharmacokinetics in the

phases immediately prior to starting the procedure of debridement, with good efficacy and tolerability also in older patient.

Abstract number: P1-003  
Abstract type: Poster

**Pregabalin Withdrawal Symptoms**

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**Aims:** Pregabalin (PGB) is an antiepileptic drug indicated for neuropathic disorders and fibromyalgia. In Japan, PGB is approved only for treating neuropathic pain. PGB has been labeled a Schedule V drug with the lowest potential for abuse.

**Methods:** We review 2 cases of patients who discontinued PGB and showed unexpected extreme symptoms.

**Results:** Case 1, a 69-year-old man with malignant myeloma was taking 75 mg of PGB once daily with 20 mg oxycodone for neuropathic pain caused by fracture of the 10<sup>th</sup> vertebra. Because of nausea, he could not take PGB without taper. Thirty hours later, he developed hyperactive delirium. After administration of PGB (75 mg), the delirium rating scale (DRS) score decreased from 24 to 3.

Case 2, a 50-year-old man with renal cell carcinoma and bone metastasis was being treated with sunitinib. For leg neuralgia, he received 150 mg of PGB twice daily for 28 days with 40 mg oxycodone and acetaminophen. He discontinued PGB and acetaminophen by himself. Thirty hours later, he felt disoriented and called an ambulance. He developed delirium with fatigue and appetite loss. Restarting of PGB ameliorated most symptoms, and DRS score decreased from 16 to 2.

**Conclusion:** Two patients were continued on the same dosage of PGB without euphoric feelings that was suspected to be abuse before delirium. However, rapid discontinuation of PGB may increase the risk of delirium by eliminating inhibition of excitatory neurotransmitters. PGB binds to calcium channels and acts as a gamma-aminobutyric acid analog that is a major inhibitory neurotransmitter in the brain. PGB is approved for treatment of generalized anxiety disorders. Gastrointestinal (GI) symptoms like vomiting are common among cancer patients. Proper precautions are necessary when prescribing PGB to patients who are predisposed to develop GI symptoms. It is necessary to consider patient education and how and when to taper PGB dosage.

Abstract number: P1-004  
Abstract type: Poster

**Hungarian Students' Fears of Opioids: Results of a Word Association Study and Implications for Interventions**

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**Aims:** Cancer patients and their relatives often fear of opioids which is a major obstacle to the efficient pain control. The direct aim of the study is to gather information on the preconceptions on pain medication by investigating the specific meanings of the word 'morphine' among Hungarian students by a specific word association method. The study is one of the pilots of a broader study among cancer patients and their family members on attitudes toward pain medication. The final aim is to design effective interventions for improving cancer pain control in Hungary.  
**Methods:** 625 healthy adults (age 22±2.43 years) were asked to give the first 3 words that come into their minds when reading the word "morphine". The online questionnaires collected additional information on demographic data, health status, and experiences with pain control of the subjects. The occurrence of cancer in the family was also detected.

**Results:** The answers show mainly negative attitudes towards morphine. The most frequent association was "illegal drug". 88,1% of the subject give negative associations like 'addiction', 'harm', 'death', and 'kill'. Only 36% of them mentioned more positive associations like 'pain control' or 'relief'. These results were independent from the occurrence/nonoccurrence of cancer in the family (Pearson Chi-square=141.25 and 253.25 = respectively, n.s.) The presentation gives more detailed analysis of the results.

**Conclusion:** Working in a hospice institution the author often experience reluctance on the patients' side to accept adequate pain medication, which interfere with the professional efforts to alleviate suffering. In order to handle these patients' and family members' barriers to pain control,

we have to recognize and understand the preconceptions and fears, which - as this study proves - are being formulated long before and independently from the occurrence of cancer in the family. Thus well established educational programs are needed in this field in Hungary.

Abstract number: P1-005  
Abstract type: Poster

**Early and Late Opioid Switching Work to Improve Clinical Outcomes**

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**Background:** There is no difference between morphine and oxycodone on a population level, however there is wide inter-individual variation in response within and between these two drugs. Opioid switching is common clinical practice when patients fail to respond to the first-line strong opioid.

**Aims:** To explore the circumstances around and results of opioid switching.

**Methods:** A randomised controlled trial of morphine versus oxycodone for cancer-related pain was conducted (n=200). Doses were titrated according to response using the immediate release preparations. Where inadequate analgesia or intolerable side effects, patients were switched to the alternate opioid, and re-titrated. The dose conversion ratio of morphine: oxycodone, 2:1 was used in both directions. Pain and adverse reaction scores were recorded at the points of clinical response and non-response.

**Results:** There were 2 distinct opioid switching types: early switching when pain was uncontrolled and/or intolerable side effects experienced despite dose titration and late switching when an initial good response was subsequently lost. Per protocol analysis showed 50/165 patients required opioid switching. Pain and side effect scores at the point of switching were similar for both early and late opioid switchers. Response to second-line opioid was similar in both early and late opioid switching.

**Discussion:** Opioid switching improved clinical outcome in both early and late groups. Failure of opioid response may be driven by different mechanisms: early switching may indicate an innate, genetically determined intolerance whilst late switching may be due to an acquired tolerance. Several factors are known to interfere with opioid responsiveness, including disease progression, change in type of pain, the development of pharmacological opioid tolerance and the accumulation of metabolites.

Abstract number: P1-006  
Abstract type: Poster

**The Rise of Oxycodone**

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**Introduction:** Ireland's opioid consumption is the 8<sup>th</sup> highest in Europe. However our morphine consumption was 20% lower and our oxycodone consumption was 60% higher in 2010 compared to 2006.

**Aim:** To report the changes in oral WHO Step III opioid usage from 2000-2011 in a 560 bed Irish teaching hospital.

**Methods:** Inpatient pharmacy dispensing reports for all oral Step III opioids were reviewed for 2000 and 2011. Results were analysed and compared in terms of percentage change and by conversion to morphine equivalent doses.  
**Results:** There has been a 464% rise in Step III opioid usage in our institution from 2000-2011. There was almost 7 times as much oxycodone dispensed as morphine in 2011, equating to almost 14 times the oral morphine equivalent. The use of this one drug has increased by more than 21 fold since 2000. There was also a corresponding 240% drop in the amount of morphine used.

**Discussion:** The manufacture and consumption of opioids is increasing worldwide, but it is not obvious what has caused the relatively greater surge in oxycodone usage. The appointment of consultants in oncology and palliative medicine at our institution has no doubt contributed to the total opioid usage reflecting an improvement in practice. Most of the current evidence on pain management does not support the use of any one Step III opioid over another. The recently published NICE guidelines on opioids in palliative care recommend morphine as the first line sustained release agent. Furthermore the local guidelines at our institution also recommend morphine as first line as it is as effective and low cost. In Ireland sustained release oxycodone is approximately three times more expensive than the equivalent morphine sustained release dose. This recent sudden and sustained rise in oxycodone consumption raises questions around medical education,

supervision and promotion influencing prescribing. Another hypothesis is reluctance among medical staff to prescribe 'morphine'.

**Abstract number:** P1-007

**Abstract type:** Poster

**Abstract withdrawn.**

**Abstract number:** P1-008

**Abstract type:** Poster

### Poor Pain Knowledge in Patients with Painful Bone Metastases; First Results from a Multicentre Randomized Trial on Pain Education

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Education of patients regarding pain management can improve patient empowerment and, consequently, reduce pain intensity. To investigate the effect of education on pain intensity, a multicentre phase 3 study is currently ongoing that randomizes a total of 450 patients between radiotherapy with or without nurse-led education regarding pain management in patients with painful bone metastases (worst pain score  $\geq 5$  on a 0-10 numeric rating scale (NRS)). The primary endpoint is pain intensity. Here we report on lack of pain knowledge in patients randomized in the education group.

Patient characteristics, pain intensity (NRS) and patients' thoughts regarding pain management are assessed at baseline, using a structured interview. Patients are asked whether they completely agree-completely disagree on a 5 point Likert scale with the following statements

- 1) cancer pain can be relieved effectively
- 2) pain medication should be given only when pain is severe
- 3) most cancer patients will become addicted to pain medication
- 4) it is better to give the lowest amount of pain medication, so that larger doses can be used later if pain increases
- 5) it is better to give pain medication around the clock than only when needed
- 6) non-pharmacological interventions can relieve pain
- 7) patients are often overmedicated
- 8) use of pain medication can be changed without consulting a physician.

Lack of knowledge is identified if the answers on statement 1, 5, 6 are completely or fairly disagree or on statement 2-4, 7 or 8 completely or fairly agree.

64 patients are included, mean age 64  $\pm$  10 years. Mean worst pain was 8.2  $\pm$  1.3. 60% used opioids. Most patients (91%) lacked knowledge of at least one statement (median 2, range 1-5). Lacks were found most frequently in statement 4 (66%), 2 (41%) and 3 (31%). Patients' knowledge was best about statement 6 (7% disagreed).

Most patients lack sufficient pain knowledge, which advocates pain education. At EAPC 2013, updated results will be provided.

**Abstract number:** P1-009

**Abstract type:** Poster

### Alfa Linolic Acid in the Management of Chemotherapy Induced Peripheral Neuropathy

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**Introduction:** Postchemotherapy neuropathy (chemotherapy induced peripheral neuropathy - CIPN) is one of the complications of cancer treatment. Neuropathy is a condition that has many causes, because of different mechanism of action chemotherapeutic agents on the nervous system.

The symptoms are: numbness, irritation and pain, usually in the extremities. Patients describes pain as burning, shooting pain with disturbing feeling of touch, warmth and the cold and motoric abnormalities. There is no one effective pain management. Many types of medications are used: anti-seizure medications, antidepressants and Capsaicin and Lidocaine patches. It is known that the CIPN escalation depends on the summary dose of chemotherapeutics, therefore limiting the treatment is the most often applied way of protecting sick persons against complications of this type.

**Goal:** Attempt to cure CIPN with alfa linolic acid ( $\alpha$ -LA).

**Method:** 11 patients were subjected to the treatment and observation from recognized clinically CIPN Pain localization: chest 4, low extremities 4, upper extremities 2, (two patients had pain of both 2), mouth (mucous) 1.

All patients were treated with opioids and adjuvants.

Pain at beginning of therapy in NRS scale was NRS7, 7. Patients received intravenous infusion (the dose of 600 mg) for 5 consecutive days. Therapy was continued at home in the 3x600mg p.o dose through two months.

**Results:** At 10 patients symptoms resolved or diminished intensity and/or area of pain sensations during the time of intravenous treatment. One patient didn't respond. Average pain score after infusions was NRS3.

At two patients symptoms returned after 3month. No major side effects were observed.

**Conclusion:** The linoleic acid seems to be interesting alternative in curing the neuropathy. In an observational study  $\alpha$ -LA was beneficial in cases where gabapentine was not successful. We didn't established the best dose of  $\alpha$ -LA and duration of treatment.

**Abstract number:** P1-010

**Abstract type:** Poster

### Inter and Intraindividual Variability of Breakthrough Cancer Pain (BTcP) Characteristics: A Prospective Evaluation from the ADEPI Survey

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**Background:** The existence of BTcP is controversial especially since the commercialization of new specific treatments. The reported prevalence of BTcP varies from 24% to 95% depending on its setting and definition. BTcP is a common symptom still underdiagnosed because frequency, time to peak intensity and duration of episodes vary both within and between individuals

**Methods:** In a prospective, national, multicentre survey (March to September 2010) in 11 centres treating cancer patients, practitioners evaluated during 1 week all patients experiencing severe cancer pain requiring opioids, using patient and observer-rated measures.

**Results:** 76 patients were included, 35 filled in the Patient Self-Report, 473 BTcP episodes were evaluated. The mean number of episodes per patient was 13.5  $\pm$  7.9. Mean (SD) intensity of BTcP episodes was different depending on the mode of evaluation: 7.5  $\pm$  1.7 according to the practitioner (numeric scale 0 to 10) and 5.1  $\pm$  2.1 according to the patient (VAS). Distribution of patients was different according to pain intensity of BTcP: VAS 5 and 6: 8%, VAS 7: 20%, VAS 8: 34.7%, VAS  $\geq$  9: 7%. Time to peak intensity was rapid for 53.8% and progressive for 46.2%. The mean amplitude of intrapatient intensity variation was 2.94  $\pm$  1.84 cm. Duration of episodes was < 30min for 54.1% of patients, 30 to 60 min for 37.8% and more than 60 min for only 8.1% of them.

**Conclusion:** This survey demonstrates the significant variability in all the characteristics of BTcP, both within and between patients and leads to reconsider the process of dose titration according to tolerability and acceptability profile. Physicians should be aware that there is not one but many different BTcP episodes. The successful diagnosis of breakthrough cancer pain depends on frequent and appropriate pain intensity evaluation. One optimal individualized management should be based on a better understanding of BTcP and a better knowledge of specific Rapid Onset of action treatments.

**Abstract number:** P1-011

**Abstract type:** Poster

### Low-level Laser Therapy in Pain Management and Physical Function in Palliative Care Patients

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**Aims:** Pain management is a major task in palliative care. Patients often experience cancer related pain. Nevertheless patients may also experience non-malignant pain such as musculoskeletal pain. Low-level laser therapy (LLLT) is used in physiotherapy for management of non-malignant musculoskeletal pain. Previous research has shown pain reducing effects by the use of LLLT. However, studies regarding management of non-malignant pain with LLLT in a palliative care setting are scarce. The aim of the study was to investigate if LLLT can help palliative care patients to

reduce non-malignant pain and improve physical functions. **Methods:** A single subject experimental design with an ABA-design was applied.

The first phase (A1): Baseline, no treatment, data collection at 3 times.

The second phase (B): Treatment phase, the participants were treated 2-3 times weekly, for a total of 5-11 treatments. Data was collected after all treatments.

The third phase (A2): Follow-up, no treatment, data collection at 1, 2, 3, 4 weeks, 2 months and 3 months after the last treatment. Four participants were included in the study and received LLLT for different origins of pain, such as fibromyalgia, vertebral compression fracture, low back pain, arthritis, neck pain and shoulder pain. Patient Specific Functional Scale and Visual Analogue Scale were used for evaluation. A cluster laser probe, (4 super pulsed 904 nm) was used for all participants. Data was plotted graphically for visual inspection.

**Results:** Decreases of pain intensity were found in all four participants with a clear change during the B phase in which the LLLT treatment was applied. Improvements in physical functions were also found indicating that findings affect body function and activity.

**Conclusion:** The LLLT treatment may be a beneficial treatment for managing pain of non-malignant origin in a palliative care setting, but more studies are warranted.

**Abstract number:** P1-012

**Abstract type:** Poster

### Use of Ketamine in Palliative Care

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**Aims:** Ketamine is an anaesthetic agent that can be used as an analgesic in palliative care. A variety of routes and regimens have been described. The literature provides only limited evidence to support particular regimens. A potential side-effect of ketamine use is urinary tract toxicity. A supra-regional audit was undertaken to look at the use of ketamine, and the attitudes and experiences of healthcare professionals of its use.

**Methods:** Healthcare professionals, including doctors, nurses and pharmacists, completed an internet survey on their attitudes towards the use of ketamine. Alongside this, data on the use of ketamine was collected prospectively via a data collection proforma.

**Results:** 50 professionals of varying professions and grades completed the survey on the use of ketamine. During the prospective 7 month data collection period, there were 39 uses of ketamine.

Professionals felt more confident in the use of ketamine compared to methadone, however only 58% had been involved in initiating ketamine in the previous 12 months. Confidence in managing urinary symptoms in patients taking ketamine was low.

There was a lack of consensus over the preferred route of use. Professionals' previous experiences of using ketamine influenced the route and regimen selected. Titration regimens also varied between different units and clinicians. The majority of patients' opioid dose remained unchanged after the initiation of ketamine. Where it was decreased, this was done after side-effects were observed rather than as ketamine was first introduced. The degree to which patients were monitored during the titration phase differed from unit to unit.

**Conclusion:** There is currently no standardised regimen for using ketamine in palliative care. Professionals' previous experience of ketamine influences their practice. Regional guidelines on the use of ketamine as an analgesic will be introduced as a result of this audit.

**Abstract number:** P1-013

**Abstract type:** Poster

### Use of Methadone in Palliative Care

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## Poster sessions

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**Aims:** Methadone is used as an analgesic in palliative care. The evidence base for its use is limited. The complex pharmacology of methadone means that individual responses to it vary, and it can therefore be difficult to titrate. When rotating to methadone from another opioid, there is a lack of consensus over approaches to dose conversion. A supra-regional audit of existing regional guidelines on the use of methadone was conducted. An additional survey of healthcare professionals working in palliative care was also conducted to evaluate their perceptions of and confidence in using methadone.

**Methods:** Healthcare professionals, including doctors, nurses and pharmacists, completed an internet survey on their attitudes towards the use of methadone. Alongside this, data on the use of methadone was collected prospectively via a paper proforma.

**Results:** 46 professionals completed the survey on their attitudes to the use of methadone in palliative care. During the prospective 7 month data collection period, methadone was used in only 10 patients.

Most patients were on large doses of opioids (equivalent to more than 500mg oral morphine daily) before conversion to methadone. Of the 10 patients commenced on methadone, 4 died before they could be discharged.

Only 30% of professionals surveyed had been involved in the initiation of methadone in the previous 12 months. All professional groups recorded an average confidence level of less than 7 out of 10 in using methadone.

**Conclusion:** Methadone is used infrequently in palliative care and tends to be used late in the disease process when other approaches have been unsuccessful. There is little consensus on dose conversion and titration methods. Many professionals lack confidence in its use. Following the results of the audit, regional guidelines have been updated.

Abstract number: P1-014

Abstract type: Poster

### Parecoxib ('Dynastat') CSCI Audit 2012 Marie Curie Cancer Care Belfast

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**Aims:** Parecoxib ('Dynastat') is a selective COX-2 inhibitor used in the short-term management of acute post operative pain through intramuscular or intravenous injection. There is a paucity of literature on the use of parenteral selective COX-2 inhibitors in palliative care. We have experience of using Parecoxib via continuous subcutaneous infusion (CSCI). This audit assessed current prescribing practice for our use of Parecoxib CSCI.

**Methods:** Retrospective chart audit of hospice in-patients treated with CSCI Parecoxib over 9 months. Data regarding indications, doses, duration of treatment, side effects and infusion site integrity was collected. Standard: 100% compliance for documentation of effectiveness of CSCI Parecoxib, baseline and repeat renal function.

**Results:** 10 patient episodes recorded. Of these, 9 had pain from bone metastases and 1 had pain from lymphadenopathy. Improvement in pain control using CSCI Parecoxib was documented in 7 cases. 1 additional patient found PRN subcutaneous Parecoxib more effective. Starting 24 hour dose ranged from 20-80mg and final 24 hour dose range was 40-80mg. Baseline renal function was recorded in 100% of cases and was repeated in 80%. 2 patients were in the terminal phase and repeat blood sampling was inappropriate. Deterioration in renal function was observed in 3 cases however no dose reductions were necessary. All infusions used 0.9% saline and no site reactions were observed. Median duration of infusion was 14.5 days. **Conclusion:** Results suggest there is a place for the use of Parecoxib via CSCI in the management of pain from bone metastases. This small audit has demonstrated that CSCI Parecoxib provided good pain relief not complicated by site reactions, suggesting the drug is both well absorbed and safe to use via this route. Monitoring of renal function is essential, however appropriateness depends on the individual patient. Further larger scale study into the application of Parecoxib via CSCI is needed.

Abstract number: P1-015

Abstract type: Poster

### The Prevalence, Risk Factors and Management of Opioid-related Adverse Events in Cancer Pain: A Nationwide, Cross-sectional Study of 2,395 Patients in Korea

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**Aims:** Although opioid therapy has been the mainstay treatment for cancer pain, the prevalence of opioid-related adverse events has not been reported in Korea. The study aims to investigate the prevalence, risk factors and management of opioid-related adverse events among cancer pain patients.

**Methods:** A cross-sectional analysis of 2,395 cancer pain patients from 30 teaching hospitals in Korea was performed with data extracted from patient charts and questionnaires. Clinical characteristics, prevalence and treatments for adverse events were assessed.

**Results:** Of 2,395, the overall common adverse events were constipation (40.3%), dry mouth (37.8%), and asthenia (37.4%). The common opioid-related adverse events were constipation (29.7%), dry mouth (17.2%), and somnolence (14.7%). For the management of adverse events, laxative use was most common (49.7%). Although about half of patients used laxatives for prevention-purpose, 18.5% of patients still developed constipation. The route of opioid administration was not associated with increased adverse events, especially for constipation. The impact of adverse events on daily activities was highest in constipation followed by asthenia, urinary retention and vomiting. Multiple regression analyses indicate that cancer type and stage, ECOG, pain intensity and opioid dose were associated with adverse events. In particular, opioid use duration > 6 days was associated with constipation with the odds ratio of 1.67 (CI 1.24-2.26).

**Conclusion:** This nationwide study evaluated the prevalence of opioid-related adverse events for the first time in cancer pain patients in Korea. As evidenced by the negative impact of adverse events on patients' daily activities, proper management is critical. Constipation in particular may need a mechanistic treatment approach where the cause of constipation may be addressed by opioid antagonist since laxatives were still limited in controlling constipation. This study was funded by Mundipharma Korea Ltd.

Abstract number: P1-016

Abstract type: Poster

### Meaning of Pain for Patients Living with Advanced Cancer and how it Influences Functional Behaviour: A Qualitative Research Study

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**Background:** Health related quality of life incorporates physical function and independence which are high priorities for patients with advanced cancer. These two inter-related domains can be compromised through the experience of cancer pain. Patient-held meanings of cancer pain may have potential to influence behaviours which determine functionality and quality of life.

**Study aim:** To explore the meanings of pain among patients living with advanced cancer and to understand how these influence functional behaviours.

**Method:** In-depth, semi-structured, qualitative interviews were conducted among 10 patients with advanced cancer who had experienced cancer pain for longer than 1 month. Patient participants were recruited from a hospice palliative care service. Data was analysed using Interpretative Phenomenological Analysis to identify emergent themes.

**Results:** Meaning of pain in advanced cancer is inextricably linked with loss and bereavement. Meaning of pain is a dynamic, temporal process underpinned by the following emergent themes:

(i) nature of cancer-related pain,

(ii) multidimensional impact of pain on patients' function and behaviour,

(iii) 'Web of Loss': a complex network of losses that result in

and perpetuate cycles of further loss and (iv) balance of hope and appreciation of life. The data suggests meaning of pain has an indirect influence on behaviour, mediated by coping strategies patients adopt, with potential to promote both constructive and maladaptive responses in functional behaviour.

**Conclusions:** The findings further our understanding of the experience of cancer pain and inform bio-behavioural approaches to palliative pain management. Recommendations include

(i) tailoring care to address the existential nature of cancer pain with attention to the presence of preparatory grief and (ii) promoting constructive coping strategies to support patients to make sense of their pain and maintain functional independence within the limitations of advancing disease.

Abstract number: P1-017

Abstract type: Poster

### Cancer Pain Management in a Northern City of Turkey: Physicians' Attitudes and Prescribing Practices

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**Aim:** Although majority of cancer patients experiencing pain can be treated successfully by a variety of applications, yet many patients complained about the pain. The inadequate management of pain partly lies in the attitude and knowledge of physicians towards pain control. This study aimed to evaluate the opinions, knowledge and the constraint of physicians dealing with cancer patients towards the pain management especially on opioid use in a Northern city of Turkey.

**Materials and methods:** The study sample was selected from physicians dealing with cancer patients in a second line healthcare facility (the only county hospital). A questionnaire of 9 items were prepared and handed to the physicians. Some of the main items included in the questionnaire were the demographic and professional information about the physician, the frequency of opioid use in cancer patients, the fear of opioid use due to the addiction and respiratory depression. The questionnaires were returned and evaluated by SPSS 18.0 (Chicago, IL).

**Results:** One hundred and thirty questionnaires were distributed and 86 were completed and returned back 86 (66.1%) were male with the mean age of 37.97±8.5 years. 74 % were experienced with more than 5 years in their profession. The frequency of opioid prescribe was distributed as never in 28.9%, seldom in 24.1%, sometimes in 26.5%, frequently in 14.5%, always in 2.4%. The prediction on the frequency of addiction in cancer patients after opioid use was distributed as no idea in 56.6%, very low in 15.7%, moderate in 18.1%, high in 7.2% and very high in 2.4%. The fear about the respiratory depression in opioid using patients was always in 1.2%, very little in 14.4%, generally in 10.8%, seldom in 22.9%, never in 18.1% and no idea in 32.1% physicians.

**Conclusion:** The experience of physicians dealing with cancer patients in pain management of our region is limited. Especially the opioid use was hindered by the fear of respiratory depression and opioid addiction.

Abstract number: P1-018

Abstract type: Poster

### Opioids: Improving Safety and Reducing Risk

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**Aims:** Opioid medications are widely used in palliative care and pain services. The use of these medications should be subject to evidence-based guidelines with robust safety mechanisms. We discuss the role of our Opioid Safety and Improvement Group, which is interdisciplinary and has representation from several specialties including palliative care, pain and oncology. The group develops innovative approaches to the management of patients taking opioid medications, demonstrating improvement at all stages of the patient pathway.



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**Background:** There are some drugs of frequent use in advanced cancer patients under chemotherapy (cisplatin, cetuximab) or for other indications (antibiotic, PBI) that may decrease serum concentrations of Mg through gastrointestinal or renal mechanisms. Preclinical studies in animals have shown that Mg potentiates the analgesic effect of opioids and can prevent hyperalgesia perhaps through its effect on the N-methyl-D-aspartate receptor. Clinically, hypomagnesemia can produce neurological symptoms as irritability, hallucinations, tremors or convulsions, but reports of hypomagnesemia and pain are unusual.

**Clinical cases:** We present four clinical cases of excruciating pain and hypomagnesemia. All patients were hospitalised, with advanced cancer, recent chemotherapy and under opioids. A patient was also with ketamine as adjuvant. The pain was presented in crisis of top intensity with fluctuation and anarchic response to opioids. We show the evolution of pain intensity and the blood levels of Mg. Excruciating pain was associated with Mg in the range of 1.2-1.5 mg/dl. Intravenous Mg replacement (12 mEq diluted in saline in 30 minutes) follow by same daily dose to cover requirements was indicated in all of them. Mg levels of 1.9 to 2.2 mg/dl were associated with relief pain.

**Conclusion:** Correction of hypomagnesemia can be associated with pain relief in concreted situations.

**Founding:** None

Abstract number: P1-023

Abstract type: Poster

### To Be in Pain (or Not); A Computer Enables Outpatients to Inform their Physician

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**Aim:** In the outpatient oncology clinic, pain management is inadequate. Incorporating systematic pain management into visits to the clinic is likely to improve this. In 2009, we started an innovative program, including structured electronic assessment of outpatients' pain intensity, with the aim of improving pain management. In this study, we investigated whether the program improved pain control.

**Method:** At eight oncology outpatient clinics, patients were asked to register their pain intensity on a touch screen computer. These scores were immediately entered into their electronic medical record. Additionally, a hospital-wide multidimensional cancer-related pain treatment protocol and web-based patient education were developed. A data warehouse system enabled us to extract the patient data from the electronic medical record anonymously and to use it for analysis. The main outcome was the adequacy of pain management; analyzed by the percentage of patients with moderate to severe pain (current pain intensity, NRS>4) during the first two weeks and after six months.

**Results:** During the first six months after implementation, in 8,968 of the 20,071 visits (45%), patients registered their pain intensity on the touch screen computer. The mean age was 54 years (sd=14) and 53% was male. Forty-four percent reported to be in pain (NRS>0). During the first two weeks of the implementation, 14% scored their pain as NRS>4. After six months, the prevalence of moderate to severe pain decreased with 33% compared to the start (9% NRS>4).

**Conclusions:** Although it is difficult to convince patients to adhere, pain registration by patients themselves is feasible, provides insight into patients' pain and may serve as a basis for improved integration of pain treatment into daily oncology care. For both physicians and nurses, it will be clearer for which patient pain is a problem, so that pain treatment can be tailored individually.

Abstract number: P1-024

Abstract type: Poster

### Clinical Benefit and Failure Factors of Methadone Rotation as Second Line-opioid in Patients with Advanced Cancer: Preliminary Results

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**Methods:** The group meets every two months. Incidents are discussed using the group's "Model for Safety Improvement". Causes of errors are explored so that system weaknesses can be identified and rectified.

**Results:** Safety initiatives led by the group have contributed to the downgrading of opioid medication risk status from 'red' to 'green' locally. Improvements have been made in key areas including:

- Syringe drivers - a supplementary chart has improved safety at the prescribing, set-up and monitoring stages. The process for discharging patients with injectable medicines from hospital has improved via an electronic solution.
- Opioid patches - a range of solutions highlighting the need to monitor, prescribe, administer and dispose of patches correctly has improved safety.
- Opioid safety across care settings - this is addressed by a network risk management programme focusing on improving medicines access, reconciliation of syringe driver contents and a redesign of the documents used to record these medicines.

**Conclusions:** We have demonstrated the benefits of a collaborative approach in improving opioid safety. This work has implications for all clinicians involved in palliative care, pain and oncology. There is potential transferability to clinical situations involving other high-risk medications. Dissemination of this work will allow the group to build on progress with colleagues across clinical and organisational boundaries.

Abstract number: P1-019

Abstract type: Poster

### Family Caregivers' Beliefs and Barriers to Effective Pain Management of Cancer Patients in Greece

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**Introduction:** Pain is a common symptom in cancer patients. Nowadays, there is a shift of care from hospital to home that increases the extent to which family caregivers (FC) are involved in pain management (PM). Identifying their beliefs and barriers to pain control can improve quality of PM at home care setting and patients' quality of life.

**Aims:** Perform a reliability and validity study of the Barriers Questionnaire II (BQ-II) in Greece and describe FC beliefs and barriers to effective PM of cancer patients.

**Methods:** The study planned as a descriptive and cross-sectional survey of a cohort of FC meeting the eligibility criteria. They recruited from two regional hospitals and completed BQ-II. Descriptive statistics and frequency distributions were generated for responses to all items and Cronbach- $\alpha$  value for the total scale and subscales (Physiological Effects, Fatalism, Communication, Harmful Effects). t-tests were conducted to assess relationships between demographic data, previous use of analgesics or patients health status and FC beliefs regarding PM.

**Results:** 82 questionnaires were included in the study. Cronbach- $\alpha$  for BQ-II is >0.9. Most of the participants reported worries on analgesics' side effects that often are assumed as irreversible. They agree on the effectiveness of medicine and analgesics in treating cancer pain and on addition to them. They disagree on the communication of pain as a factor that distracts doctors from the treatment of the cancer.

**Conclusions:** BQ-II is a valid and reliable scale for defining FC attitudes and barriers to cancer PM in Greece. Most of their beliefs can act as potential barriers in effective PM in home care settings. Further education and training of health professionals, interventions targeted to caregivers, establishment of pain centres, recruitment of hospitals with pain management specialists, development of home care teams and a national palliative care plan can change current practices and improve quality of cancer care.

Abstract number: P1-020

Abstract type: Poster

### Usefulness of Neurolytic Saddle Block with Intrathecal Combined Phenol and Dexamethasone for Intractable Sacral Pain due to Bone Metastasis of Rectal Cancer

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**Aims:** Neurolytic saddle block with intrathecal phenol can

provide excellent pain relief of the perianal area in patients who have been refractory or intolerant of aggressive conventional management. However, pain due to pelvic recurrence including sacral invasion is severe and intractable, and phenol saddle block is ineffective for such a pain. We experienced two cases in which saddle block with intrathecal combined phenol and dexamethasone were effective for sacral pain caused by metastasis of rectal cancer.

#### Methods and results:

**Case 1:** A 73-year-old man, who was given abdominoperineal resection of the rectum three years ago, presented with severe perianal pain due to pelvic recurrence of rectal cancer. At first, intrathecal saddle block with 0.3mL of phenol 10% in glycerin was received. Although perianal pain was almost disappeared, he complained of buttock pain due to sacral metastasis and needed oxycodone 160mg/day with adjuvant analgesics. Since his pain progressed severely during one month, we performed the saddle block with combined 0.2mL of phenol and 2mg of dexamethasone intrathecally. After the second approach, his sacral pain was reduced and controlled well with oxycodone 40mg/day without supplemental analgesics.

**Case 2:** A 54-year-old man presented with pain of perianal area and buttocks due to destructive sacral metastasis of rectal cancer, and not controllable with intravenous fentanyl 250mcg/hour and oral pregabalin 300mg/day. We applied saddle block with combined 0.2mL of phenol and 2mg of dexamethasone intrathecally. Just after the block, he presented with somnolence which was considered the symptom of withdrawal from fentanyl and that lasted for approximately one day. Two days after the block, only intravenous fentanyl 10mcg/hour was needed for relieving his pain.

**Conclusion:** We can conclude that saddle block with intrathecal combined phenol and dexamethasone might be effective for severe sacral pain due to bone metastasis of rectal cancer.

Abstract number: P1-021

Abstract type: Poster

### The Systemic Inflammatory Response and its Relationship to Pain and Other Symptoms in Advanced Cancer Patients

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**Background:** Inflammation has been identified as the 7<sup>th</sup> hallmark of cancer and is necessary for tumorigenesis and maintenance of the cancer state. Symptoms are also common in cancer patients however little is known about the relationship between symptoms and inflammation in cancer. The aim of the present study was to examine symptoms and their relationship to the inflammation in a large multinational cohort of patients with advanced cancer.

**Patients and methods:** Data from an international biobank of advanced cancer patients were analysed. Symptoms and patient related outcomes were recorded using the EORTC QLQ-C-30. Systemic inflammation was assessed using C-reactive protein (CRP). The relationship between these symptoms and systemic inflammation were examined using Spearman's rho rank (p) correlations and the Mann-Whitney U test.

**Results:** Data were available on 1466 patients across eight European countries; 1215 patients (83%) had metastatic disease at study entry. The median survival was 3.83 months (IQR 1.33-12.17). The following were associated with increasing levels of inflammation; performance status (p=0.179), survival (p=0.347), increased pain (p=0.154), appetite loss (p=0.206) poorer cognitive function (p=0.137), increasing dyspnoea (p=0.150), increasing fatigue (p=0.197), worsening physical function (p=0.207), worsening role function (p=0.176), worsening social function (p=0.132), worsening quality of life (p=0.178). All were statistically significant at p<0.001. When CRP was dichotomised (below/above 11) we obtained almost identical number of highly significant factors.

**Conclusion:** The results show the majority of cancer symptoms are associated with inflammation. Further studies examining the attenuation of the inflammatory response and the effect on symptoms would be of interest.

Abstract number: P1-022

Abstract type: Poster

### Hypomagnesemia and Refractory Pain in Advanced Cancer Patients: Case Series

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**Aim:** To assess the clinical benefit of rotation (ROP) to methadone (MTD) as second-line opioid in patients (pts) with advanced cancer and to identify factors of early failure to MTD ROP (< 28 days post ROP).

**Material and methods:** Prospective study assessing pain on days 3,7,9,14,21 & 28 post ROP to MTD. Pts on MTD & average pain < 4 without opioid toxicity on day 28 were considered responders. Pain was assessed using BPI & opioid toxicity with (CTCAEv3.0).

**Results:** Until now it has been included 117 pts (80.7% sample size). Mean age 58 y-old, men 69%. The most frequent neoplasms were lung 25% & pancreas 14%. Using ECS-CP 89% pts had bad-prognostic factor for pain control. Before MTD ROP pts were on Fentanyl 56%, Oxycodone 18%, Morphine 18% & Buprenorphine 8%. The mean daily dose of oral morphine before ROP was 200 mg, and the mean after ROP daily dose of oral methadone was 25 mg. The causes of ROP were poor pain control 81%, opioid toxicity 3%, and both 16%. After ROP pts on the study day 3, 7, 9, 14, 21 & 28 were 96%, 83%, 72%, 61%, 46% y 38%, respectively. Drop-outs for pain re-assessment (not from MTD) before day 28 happen in 71 pts; 42% clinical worsening or death, 25% for analgesic radiotherapy or invasive analgesia & 33% other causes. MTD Responders (day 0 vs. 28) average pain 5.5 vs. 2.4 p< .0001; average breakthrough pain episodes 5.8 vs. 1.1 p=.036. Pain interference (0-70) 48.9 vs. 18.2 (p< .0001) and mean toxicity 3 vs. 2.7 (p=0.61). Only 12 pts (10%) failed to MTD.

**Conclusions:** Rotation to MTD had produced clinical benefit in a cohort of pts with bad prognostic pain (>90%). It was observed a significant improvement in average pain, breakthrough pain and pain interference without increasing toxicity. Ninety % pts were on MTD until ending follow-up . The small number of pts how failed to MTD avoids factor's failure analysis.

This study was granted by the Spanish Ministry of Health FIS EC08/00234

**Abstract number:** P1-025  
**Abstract type:** Poster

**"It's the Whole Thing, it's Not Just the Pain". Understanding Pain Control in the Outpatient Head and Neck Cancer Population: A Qualitative Study to Explore the Views of Patients Enrolled in a Proactive Pain Management Programme**

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**Background:** A proactive pain management programme for head and neck cancer patients in the outpatient setting is being evaluated in a large RCT. This qualitative study complements the RCT and aims to explore patients' views of this "screen and treat" protocol. Facilitators and barriers to pain control have been explicitly sought.

**Methods:** Patients' views of the pain management programme and barriers to pain control were explored using semi-structured in-depth interviews. Patients randomised to the intervention arm of the RCT were sequentially approached over a 3 month time period. Interviews were audio-recorded, field notes taken and transcribed verbatim. A thematic analysis of the data was conducted aided by the Framework method.

**Results:** 6 participants (4 female), from an intervention group of 13 over 3 months were interviewed. Key themes were: *views of the "Screen and Treat" system; physical pain is only one component of the cancer experience; significance of head and neck cancer as a visible cancer; societal values presenting a barrier to effective pain control; regaining control and normalisation as an important coping strategy.* Participants were positive about the programme and expressed that *being listened to* and having *additional contacts* outside of the outpatient setting, was valuable. Physical pain, although present, was often not prioritised as a symptom. This may be due to the context of pain secondary to potentially curative anti-cancer treatments and the presence of other distressing symptoms including physical disfigurement following surgery. Re-gaining control and normalisation were often prioritised at the expense of pain control through the development of personal management strategies of which pharmacological interventions were only one component.

**Conclusion:** A "total pain" model incorporating physical, psychological, social, emotional and spiritual elements is crucial in directing pain management for the head and neck cancer population.

**Abstract number:** P1-026  
**Abstract type:** Poster

**Intravenous Opiate and Ketamine Administration for Rapid Pain Relief in Outpatient Practice**

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**Background:** Detailed case history and physical examination provide a good opportunity to establish the main components of cancer pain generally. However, in a complex situation or in the case of collaboration problems, it may be very difficult to quantify the role of certain components. Tricyclic antidepressants and anticonvulsant drugs have delayed start of action and have many adverse effects, so in the case of diagnostic uncertainty, their ex juvantibus administration is unadvisable. The aim of the current study was to evaluate a method of rapid titration with intravenous morphine, fentanyl and ketamine to achieve rapid pain relief in outpatient settings.

**Methods:** During a one-year period rapid intravenous titration was performed in 35 cases in a prospective manner. Pain was evaluated on a numeric scale of 0-10. In severe pain situations 0,5 mg/ml morphine or 5 ug/ml fentanyl solution was titrated slowly at 1 mg/min or 10ug/min speed, respectively. Over 10 mg morphine, there was a waiting period up to 5 minutes. After diminishing the permanent, dull pain, an intravenous ketamine titration was performed with 0,5 mg/ml solution at 1 mg/min speed, if it was necessary.

**Results:** The rapid titration was performed on 28 cancer patients in 35 cases. Pain was totally stopped in 19, and was significantly diminished (<VAS3) in 11 cases. In 5 cases, the results were insufficient or uncertain, because of inadequate communication. Adverse effects were observed in 9 cases (somnolence, dizziness and nausea), which were all mild and short lasting. The intravenous tests helped to determine the ratio of nociceptive/neuropathic components and the measure of opioid dose escalation.

**Conclusions:** Intravenous opiate-ketamine test is a safe and effective method to relieve severe, complex cancer pain rapidly in outpatient settings. It may also help the pain analysis and the measuring of opioid dose escalation.

**Abstract number:** P1-027  
**Abstract type:** Poster

**Unsolved Problems of Pharmacotherapy of Chronic Pain in Cancer Patients in Kazakhstan**

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Every year more than 30 000 people are taken to the dispensary registration with newly diagnosed malignancies in Kazakhstan and more than 17 000 people die of cancer. The purpose of the study - to realize the right of incurable cancer patients anesthesia.

**Methods:** Analysis of needs in pain therapy, the development of optimal tactics treatment of chronic pain in cancer patients with the WHO recommendations.

**Results:** Kazakhstan has a legal and regulatory framework for effective treatment of cancer patients with chronic pain. Code of the Republic of Kazakhstan on the people's health and the health care system Article 91 "Patients' rights" states that patients have the right to "alleviate the suffering to the extent which is allowed with the current level of medical technology." The list of required narcotic analgesics and adequate standards for their distribution were developed and approved by the Ministry of the Republic of Kazakhstan. But the Republican drug formulary has only 5 kinds of 30 drugs used in Europe and North America. Of the most powerful analgesics short-only injectable drugs are available - morphine and fentanyl. Introduction of non-injection drugs appeared tramadol drops and tablets. Among sustained release formulations fentanyl transdermal therapeutic system is registered.

Kazakhstan has free provision of narcotic analgesics for cancer patients. But there is a very complex multi-system writing prescriptions for narcotic analgesics, so doctors do not want to make prescriptions and prescribe analgesics of line I for a long time.

**Conclusions:** In Kazakhstan there is a need for skilled care in the terminal stage of the disease for more than 21 000 people with cancer. More than half of them do not receive appropriate care and die in agony.

**Abstract number:** P1-028  
**Abstract type:** Poster

**Clinical Experience Using Sublingual Fentanyl Tabs (SLF) in Breakthrough Cancer Pain (BtCP)**

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**Aim of the study:** To reveal effectiveness of SLF in BtCP based on the titrated Opioid ATC or Around-the-Clock analgesia with Tramadol SR up to 200 mg daily, Morphine SR ranging from 60 to 240 mg/daily or TDS (Fentanyl patches) from 25 to 300 mcg/h. Titrated ATC pain analgesia in medium not exceeded 2-3 according to the Numeric Scale (NS 0-10).

**Study design:** 63 palliative care cancer patients (pts) in advanced stage of disease had the titrated Opioid ATC analgesia. 562 BtCP episodes were studied with pain ranging from 6-9 according to the NS and in medium it was 8. SLF dosage for BtCP was titrated as soon as ATC was adjusted to the pts.

**Results:** 20 pts (31.7%) received 100 mcg of SLF (23.1% in 130 episodes; 26 pts (41.2%) had 200 mcg (24.9%) in 140 episodes; 5 pts (7.9%) had 300 mcg (14.2%) in 80 episodes; 10 pts (15.8%) received 400 mcg (28.4%) in 160 episodes; 2 pts (3.1%) had 600 mcg (9.2%) in 52 episodes. BtCP ranged from 6-9, in medium 8 according NS. Significant pain relief (up to 80%) was observed in the first 3-4 minutes. In 2% of cases mild side effects were observed such as palpitation, slight fever, nausea, skin rash, fatigue.

**Conclusion:** Both ATC and SLF dosages should be titrated (adjusted) in pts with chronic cancer pain. SLF had rapid onset and was highly effective in BtCP. SLF were immediately used as BtCP started. In the case of "dry mouth" syndrome before taking SLF pts always rinsed their mouth with water. The most common dosage of SLF was 200 mcg (41.2%). In 98% of cases SLF tabs were well tolerated. In 2% mild side-effects were observed not influencing considerably the quality of life (QoL) and more linked with the concurrent diseases and general condition.

**Abstract number:** P1-029  
**Abstract type:** Poster

**Ketamine's Role in the Palliative Care Armamentarium: New Questions and Directions**

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**Objectives:**

1. Review current evidence for the use of ketamine as an analgesic agent in a variety of pain syndromes.
2. Discuss the practice implications of recent data casting doubt on the role of ketamine in the treatment of cancer pain
3. Identify future research directions regarding the use of ketamine in specific pain syndromes.

Ketamine is a dissociative anesthetic with unique analgesic properties. It has activity as an NMDA-receptor antagonist with associated effects on a variety of other receptors. Ketamine's effects at the NMDA receptor have generated intense interest as a way to reduce opioid tolerance and central sensitization. These features are commonly seen in patients with a variety of difficult to control pain syndromes, including neuropathic pain syndromes. Ketamine's highly lipophilic nature and multi-step metabolism allows it to be administered by parenteral, oral, topical and buccal routes.

Ketamine has shown clinical efficacy in a number of pain syndromes including acute pain, malignant bone pain, topically in severe mucositis and painful vascular ulcers, as well as an adjunct to opioids in variety of cancer and non-cancer clinical settings. High-quality randomized studies have been lacking. However, a research group recently reported on a placebo-controlled randomized trial that concluded that ketamine did not have a net clinical benefit, specifically in the treatment of cancer pain.

Conflicting evidence, questions with appropriate patient selection as well as practitioner experience have led to confusion about what role ketamine should play in a palliative care provider's armamentarium. Using interactive case studies with audience participation, this session will focus on equipping participants with the confidence to identify clinical scenarios where ketamine may provide clinical benefit to selected patients. Finally, we will discuss avenues for research to further clarifying ketamine's role as an analgesic agent.

Abstract number: P1-030  
Abstract type: Poster

### Ketamine and Uncontrolled Cancer Pain: Experience of a Palliative Care Unit

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**Introduction:** Almost 80% of patients with cancer experience moderate to severe pain and 80 to 90% of these have controlled pain with standard analgesic therapy following the analgesic ladder of the World Health Organization. Ketamine seems to have a significant impact as an analgesic adjuvant in this context especially with neuropathic pain syndromes that are poorly controlled by opioids.

**Objective:** To assess the effectiveness of ketamine use in this palliative care unit and discuss its limitations.

**Design:** Retrospective study including inpatients treated with ketamine for severe pain, over a 32-month period at a tertiary palliative care unit.

**Results:** We included 13 patients, 3 of them treated with ketamine more than once, corresponding to a total of 16 evaluations. All patients had uncontrolled severe pain, 75% had both nociceptive and neuropathic pain and 25% presented with opioid toxicity. Before starting treatment with ketamine, the medium of oral morphine equivalent daily dose (MEDD) was 440mg. Ketamine dosage ranged from 50 to 180mg/day and almost 1/3 of the patients experienced psychotomimetic side effects, despite the general use of prophylactic agents as haloperidol and/or benzodiazepine. Pain scores were reduced in all patients, the MEDD was reduced in 13% of them and the number of rescue doses decreased in 63% after 24 hours the ketamine was introduced. Mean time of survival after ketamine introduction was 38 days.

**Conclusion:** Ketamine showed some effectiveness as an analgesic adjuvant for patients with severe pain, although with little impact on opioid dose reduction and a significant rate of side effects. It may be considered using when standard analgesic options have failed.

Abstract number: P1-031  
Abstract type: Poster

### Barriers to Adequate Cancer Pain Control - A Survey among Nurses from Different Hospitals in Vratsa and Students and Teachers from Medical College - Vratsa

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As a part of a larger project aimed to explore under treatment of cancer pain in Northwest Bulgaria a multicenter study was conducted among nurses from different hospitals in Vratsa and teachers and students 6<sup>th</sup> semester of the Medical College - Vratsa. Exclusion criteria were work in surgical departments or pediatrics. A questionnaire of 24 questions was used. Respondents had to point their agreement using 0(not agree at all) to 5(completely agree) scale. Data were processed using SPSS®.

**Results:** 110 questionnaires were distributed and 97 were returned. In 4 questionnaires the demographic part was not filled. The respondents' places of work were - 22.7% Cancer center; 11, 3% - Emergency center; 20.6% General hospital; 30.9% students and 9.3% teachers. 32% agree that opioids cannot control cancer pain, 42.3% agree that opioids are very addictive, 31.2% agree that it is easier to stand pain than to treat opioids' side effects. 61.9% agree that strong opioids should be kept in case pain becomes worst and should be used only in terminal patients - 45.4%. 39.2% agree that analgesics should be taken only when pain is intensive. 63.9% agree that there are no objective criteria to assess pain although 79.4% of respondents regularly ask their patients about pain. 78.1% from the nurses working in cancer center disagree that painkillers should be taken only when patient experience pain against 33.0% of the teachers of the college. 59% from nurses working in cancer center disagree with the statement that opioids should be avoided because when the pain gets worse they will not be effective, against 30% of the nurses from General hospital and 9% of those from Emergency center.

**Conclusion:** Major differences in responses of nurses resulting from their place of work and incorrect answers given by the teachers and students of medical college show that special attention should be paid to the education and training of nurses in the assessment and treatment of cancer pain.

## Other Symptoms

Abstract number: P1-032  
Abstract type: Poster

### The Clinical and Social Dimensions of Prescribing Home Oxygen for the Relief of Refractory Dyspnoea

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Refractory breathlessness is a significant problem in palliative care and long term oxygen is commonly prescribed for use in the home setting. Frequently, this prescription falls outside the current international funding guidelines.

**Aim:** The aim of this qualitative study is to understand the factors that most influence Australian specialist palliative care nurses' initiation of home oxygen prescribing for their patients. Understanding why palliative care nurses initiate home oxygen prescriptions and the threshold for doing so, is important if equitable, needs-based care is to underpin oxygen management.

**Methods:** A series of focus groups were held across Australia in 2011, involving specialist palliative care nurses. Recorded and transcribed data were coded by the research team for themes and sub-themes. A summary, which included quotes, was provided to participants to confirm.

**Results:** A total of 51 experienced Australian palliative care nurses participated in nine focus groups held in three Australian capital cities during 2011. Two major themes were identified:

- 1) Logistic / health service issues, involving the local context of prescribing within the Australian setting, and
- 2) Clinical care issues which involved assessing the patients' need for home oxygen and ongoing monitoring concerns. The results of this study build upon our knowledge underpinning home oxygen prescribing and highlight areas for further research.

**Conclusion:** In Australia, the place of long term oxygen therapy is changing. Palliative care nurses involved in initiating or prescribing oxygen often reported using this therapy as a second line treatment after other interventions had been trialled and after these had not provided sufficient symptomatic benefit. Safety issues were a universal concern and a person living alone did not emerge as a specific issue amongst the nurses interviewed.

Abstract number: P1-033  
Abstract type: Poster

### Providing an Ultrasound Guided Paracentesis Service in the Community Setting

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**Background:** A significant number of patients with advanced cancer develop ascites. If drainage is needed (normally to palliate distressing symptoms) then admission to hospital is usually required. We have developed a community paracentesis service to avoid unnecessary hospital admissions and support choice in place of care. This is especially important to our patients due to the rural area in which we work. To ensure patient safety we use ultrasound guidance and have recently developed comprehensive guidelines and a care plan.

**Methods:** Electronic notes were examined for patients who had a community paracentesis over a 12 month period and data extracted.

**Results:** 8 patients (6 female) had at least 1 paracentesis performed, with a total number of 15 procedures. Average age was 73 (range 57-90). Malignant diagnoses were: 2 Bowel, 2 Ovarian, 1 Hepatocellular, 1 Breast, 1 Pancreatic and 1 Oesophageal. Average time to death after first drainage was 40 days (range 12-128, 1 patient still alive). There were no serious complications. 1 patient had IV Albumin replacement as a planned procedure. 100% of patients had an ultrasound scan performed by us at least for the first procedure. Preferred place of death was achieved for 6/7 (86%) of patients; 4 died at home and 2 in a care home. 1 patient died in an acute hospital following an unavoidable admission not related to the procedure.

**Conclusion:** Providing an effective community paracentesis service is possible. In total 15 hospital admissions were

avoided. This has significant implications for patient choice as well as potentially reducing costs. We would suggest that this also facilitated patients dying in their place of choice. There is increasing emphasis on providing specialist services in the community and this is supported by national policy. In addition we give IV bisphosphonates and blood transfusions in the community setting and we aim to continue to develop these services in the future.

Abstract number: P1-034  
Abstract type: Poster

### Hungry Bone Syndrome Related to Prostate Cancer. A Case Report

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**Introduction:** Hungry bone syndrome is clinically characterized by the persistent occurrence of bone uptake that produces hypocalcemia. It is a rare metabolic complication that can occur in osteoblastic metastases in prostate cancer, and can make it difficult the symptom management at the end of life.

**Aim:** The aim of presenting this case report is to reinforce the importance of treatment of hypocalcemia in patients with osteoblastic metastases of prostate cancer in order to improve their quality of life and to allow the control of symptoms.

**Method:** We report a patient who was admitted to the palliative care unit diagnosed with prostate cancer and osteoblastic metastasis. He was receiving chemotherapy and zoledronic acid treatment. The patient presented hungry bone syndrome due to disseminated osteoblastic metastases. Zoledronic treatment was removed. He was initially treated orally with calcium carbonate (1500mg per day) and calcitriol (1 mcg a day). As it was not effective, the patient was treated later with a permanent intravenous infusion pump of calcium gluconate (0,5mg/kg/h), during about one month.

**Results:** Hypocalcemia symptoms were prevented and calcium levels were improved, although it was unable to obtain normal serum calcium levels although treatment was continued. The patient died due to the progression of the disease achieving an adequate relief of symptoms.

**Conclusion:** It is important to take into account this metabolic complication with regards to the proper management of the relief of symptoms and the significance of the hypocalcemia and its relationship in the use of disphosphonates in patients with advanced prostate cancer.

Abstract number: P1-035  
Abstract type: Poster

### Palliative Management and Survival of Advanced Hepatocellular Carcinoma (HCC)

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**Background:** HCC is the fifth most common cancer worldwide, and its incidence will further increase. There is little information in the literature on the final stage of this neoplasm and its control by palliative care teams.

**Objective:** Our aim was to evaluate the clinical profile of terminal HCC and their survival.

**Patients and methods:** Retrospective and descriptive study of patients referred to our Palliative Care Service between January 2010 and April 2012 based on demographic, clinical and evolutive data registered in the medical record.

**Results:** A total of 45 patients were analyzed. 82.2% were men. Mean age was 70 years. All patients had liver cirrhosis. The most frequent aetiology was chronic hepatitis in 42.2%. 33.3% had metastases. The first treatment of choice was the best supportive care in 42.2%. When the patients were transferred from Liver Unit to Palliative Care Service (PCS), 77.8% were BCLC D stage and 51.1% had palliative performance status (PPS) between 50 and 60. 80% lived with any relative, 17.8% received psychological support and 48.9% had social assessment. The mean time between diagnoses to PCS evaluation was 17.31 months. Patients assessed at the time of diagnosis as BCLC D were derived faster to PCS (1.25 months) compared to patients than BCLC A stage (34.75 months). The time between PCS evaluation until death was 60.31 days. The most common symptoms upon admission to PCS were weakness in 93.3% and anorexia in 88.9%. The most frequent complication was delirium in 37.8%. During the monitoring in PCS, all patients received opioids. The morphine was used in 51.1% and fentanyl in 26.7%. The initial dose was equivalent to morphine dose less than 60 mg in 91.1% and between 60 and 120 mg in 8.9%.

**Conclusions:** All patients required opioid therapy, usually at low doses, to achieve adequate symptom control. Whether patients were referred before the palliative care service, tracking closely with your usual hepatologist, we could offer comprehensive care.

**Abstract number:** P1-036

**Abstract type:** Poster

## Effectiveness of Anticonvulsant Prophylaxis in People with Brain Neoplasms. A Limited Systematic Review

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**Aims:** Seizures occur in at least 30% of people with brain neoplasms, according to tumor type, location and size.

Antiepileptic drug (AED) prophylaxis has been proposed to prevent these events. However, little is known on its actual effectiveness in people with primary or metastatic brain neoplasms.

In 2000 the American Academy of Neurology (AAN) evidence-based guidelines discouraged routine AED prophylaxis in previously seizure-free patients because of lack of effectiveness and potential side-effects.

A 2009 Cochrane review found poor evidence on prophylactic AEDs use.

Despite of it, prophylactic anticonvulsive treatment is widely used, even in palliative care.

The aims of the study are to identify and appraise evidence of AED prophylaxis effectiveness on seizure occurrence in previously seizure-free adults with brain neoplasms.

**Methods:** Ovid MEDLINE, EMBASE, PUBMED, CENTRAL were searched from 2007 to March 2012 for randomized and non-randomized controlled trials and cohort studies comparing two AEDs or an AED versus placebo or nothing. Citing papers were searched by Google Scholar.

Papers were screened and data extracted to a predetermined form. Risk of bias was assessed. Level I (from randomized controlled trials) and Level II (from observational cohort studies) evidence were to be defined.

**Results:** 1759 records were identified, 18 underwent data extraction. 3 retrospective cohort studies were included to qualitative analysis.

AED prophylaxis could reduce seizure risk in melanoma brain metastases patients (level II evidence). In postoperative time no evidence of prophylactic AED effectiveness was found.

**Conclusions:** The role of AED prophylaxis in brain tumor patients is still unclear. AAN guidelines and Cochrane review found no significant evidence on its effectiveness. In the last five years no randomized controlled trials addressed this issue. Further research is needed to assess who, when and how can benefit of AEDs for preventing seizure occurrence.

**Abstract number:** P1-037

**Abstract type:** Poster

## A Feasibility Trial to Assess the Use of Physical Activity to Mitigate Cancer Related Fatigue and Improve the Quality of Life in Terminally Ill Advanced Cancer Patients in Brazil: A Preliminary Report

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**Objectives:** To pilot study to test feasibility and efficacy of physical activity for reducing fatigue and quality of life in patients with advanced cancer at the end of 4 weeks and evaluate patient satisfaction with the physical activity intervention.

**Methods:** In this ongoing clinical trial, all advanced cancer patients presenting with fatigue  $\geq 4/10$  in a 0-10 scale Edmonton Symptom Assessment Scale (ESAS) were eligible. As per protocol, all patients performed a 10-minute walk and exercises for the upper limbs with 1-lb dumbbells, five sessions a week, during 4 weeks. The quality of life questionnaire, EORTC QLQ-C30 and ESAS are filled out at the beginning, in the end of the 2 weeks and in the end of 4 weeks, the satisfaction scale PGIC (Patients' Global Impression of Change scale) was assessed at the end of the study.

**Results:** To date, 14/30 eligible patients were enrolled in the study, only four completed the study, 6 dropped out due to disease progression, there were a decrease performance status and they just held 6 days of exercises. Of those who completed, 3 patients were below 60 years, 2 had a head and neck cancer and 80% performance status. There was a 1

point improvement in the average ESAS fatigue item scores at D1 and D20 time points. The average EORTC QLQ-C30 showed an improvement of 12.5 points compared to the baseline. In terms of degree of satisfaction of the patient, 3 patients pointed the item "Better, and a definite improvement that has a real effect and worthwhile", in the PGIC questionnaire.

**Conclusion:** According to the preliminary results of the study, physical activity intervention resulted in improvement of fatigue and quality of life in patients who completed the study. Further feasibility studies of various types of exercise interventions are needed.

**Abstract number:** P1-038

**Abstract type:** Poster

## Compression Therapy without Manual Lymphatic Drainage Seems Sufficient in Postmastectomy More Severe Lymphedema - A Pilot Study

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Physiotherapy still remains the golden method of lymphedema management. However there is an urgent need of well controlled studies assessing the value of each component of this therapy. Particularly one of them - manual lymphatic drainage (MLD) - especially time consuming additionally requires well trained therapists.

We conducted a prospective randomized study comparing the early and late effects of two-weeks complex decongestive therapy, involving MLD with compression bandaging, remedial exercises and skin care (CDT group) with patients treated similarly except the MLD (CB group). Sixty breast cancer survivors having more than 20% upper limb lymphedema without previous physiotherapy were enrolled. Groups did not differ according to age, BMI, time since mastectomy and edema duration. Nine patients (5 within CDT group) dropped out due to therapy regime incompliance. We observed comparable edema decrease in both groups: 15% in mean affected limb volumes, 47% in mean edema volumes and 14% in mean relative volume change. During the maintenance phase of 6 months follow up of wearing compression garments a temporary, insignificant lymphedema progression was observed in both groups. A congruent improvement in lymphedema related quality of life (Lymphedema Questionnaire) was noted in both groups, more pronounced in CDT patients.

This preliminary study indicates that CDT without MLD seems to be a valuable, time consuming equivalent for standard lymphedema management.

**Abstract number:** P1-039

**Abstract type:** Poster

## Pain, Resilience and Psychological Comorbidities in Home Patients

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**Introduction:** Psychological risk factors and construct of resilience can have an influence on cognitive-behavioral responses to chronic pain. Investigation of resilience, capacity to adapt to psychosocial adversity in patients with chronic pain, may help to choose therapeutic intervention. Aims of study were to evaluate resilience in patients with chronic pain, identify potential psychiatric comorbidities, correlate patients' resilience and presence of comorbidities with pain intensity.

**Methods:** During visits at home, carried out by physician volunteers of local non-profit voluntary care association, pain intensity (vNRS) and patients' functional autonomy (Karnofsky-PS) were evaluated. Resilience Scale for Adult (RSA) questionnaire to evaluate patients level of resilience and SCL-90 self-assessment questionnaire to identify most common psychiatric comorbidities associated with painful conditions, were administered. The results obtained were correlated with age and pain intensity.

**Results:** The cohort consisted of 47 patients (26 women; 21 men) with an average age of 67.8  $\pm$  20.6, with chronic cancer and non-cancer pain (vNRS: 6.9  $\pm$  1.8). Anxiety and depression correlated positively with pain intensity and advanced age ( $p < 0.05$ ), hence the greater the intensity of pain, the more frequent the symptoms of anxiety and depression ( $p < 0.01$ ). Older age correlated negatively with resilience, hence the older the age the lower the resilience of the sample ( $p <$

0.01).

**Discussion and conclusions:** Our study found a strong association between severity of pain and older age. This relationship may have an impact on the limited capacities of this population to deal with intercurrent stressful events. This conclusion is confirmed by the mid levels of resilience observed in the sampled cohort, when patients were confronted with chronic pain. Depression and anxiety can be direct consequences of chronic pain. In order to interrupt vicious cycle between older age, pain and comorbidities, it's necessary to provide effective pain management.

**Abstract number:** P1-040

**Abstract type:** Poster

## Usefulness of KM-CART for Refractory Malignant Ascites in Advanced Cancer Patients

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**Aims:** Malignant ascites deteriorates the quality of life (QOL) in advanced cancer patients by causing abdominal distension, respiratory distress, appetite loss, so on. Cell-free and concentrated ascites reinfusion therapy (CART) was conducted for refractory ascites in those patients. Recently, a novel KM (Keisuke Matsusaki) -CART system has been developed, which has a membrane clearing function and is capable of processing larger volumes of ascites compared with a conventional system. We investigated the usefulness of the KM-CART.

**Methods:** The patients were 7 men and 16 women, aged 61  $\pm$  9 years, with malignant ascites treated in our hospital between January and September in 2012. After abdominal paracentesis under an ultrasonographic observation, as much of ascites as possible was collected by gravity. The ascites was filtrated and concentrated about tenfold with a KM-CART system and the concentrated fluid was infused back into the patients. Statistical analyses were conducted with paired-t test or ANOVA.

**Results:** All patients underwent KM-CART safely during the average time of 345  $\pm$  135 min. The average volume of ascites drawn off was 5979  $\pm$  2341 ml and that filtered and concentrated volume was 776  $\pm$  294 ml. The average albumin retrieval rate was 56  $\pm$  15%. All showed improvement of pain and appetite loss, and nine with respiratory distress were relieved. One showed fever transiently. Body weight measured in 16 decreased significantly from 56  $\pm$  11 kg to 51  $\pm$  11 kg ( $p < .0001$ ). Blood pressure decreased significantly from 118  $\pm$  15/75  $\pm$  10 mmHg to 109  $\pm$  12/67  $\pm$  9 mmHg ( $p < .05$ ) without clinical changes, which was recovered to 117  $\pm$  16/69  $\pm$  12 mmHg on the day next. Urinary output showed a significant increase from 520  $\pm$  385 ml/day to 946  $\pm$  464 ml/day ( $p < .001$ ).

**Conclusions:** The KM-CART is safe, easy to use, and possible to improve the QOL of advanced cancer patients. Thus ascites control with this system is worthy in palliative care of those patients if the indication is chosen appropriately.

**Abstract number:** P1-041

**Abstract type:** Poster

## Palliative Treatment in Lung Cancer Patients with Respiratory Symptoms

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Respiratory symptoms that may require palliation include those caused by the primary cancer itself (dyspnea, wheezing, cough, hemoptysis, chest pain), or locoregional metastases within the thorax (superior vena cava syndrome), tracheoesophageal fistula, pleural effusions, ribs, and pleura) and can also result from complications chemotherapy and radiotherapy. Comorbid conditions can cause or contribute to respiratory symptoms. For patients with dyspnea, it is recommended that they be evaluated for potentially correctable causes, such as localized obstruction of a major airway, a large pleural effusion, pulmonary emboli, or an exacerbation of coexisting COPD or congestive heart failure. If one of these problems is identified, treatment with appropriate methods is recommended. For patients whose dyspnea does not have a treatable cause, opioids are recommended. Also recommended are oxygen, bronchodilators, and corticosteroids. For patients who have cough, it is recommended that they be evaluated for treatable causes. For patients who have troublesome cough without a treatable cause, it is recommended that opioids be used to suppress the cough.

For patients with large-volume hemoptysis, bronchoscopy is recommended to identify the source of bleeding, followed by endobronchial treatment. In patients with symptomatic malignant pleural effusions,

thoracostomy is recommended as the first drainage procedure for symptom relief. In patients that recur after thoracostomy, chest tube drainage and pleurodesis are recommended. In patients with symptomatic SVCS obstruction due to SCLC, chemotherapy is recommended and in patients NSCLC, stent insertion and/or radiation therapy are recommended. Stents are also recommended for symptomatic patients obstruction who fail to respond to chemotherapy or radiation therapy. For patients with a malignant transesophageal fistula and bronchoesophageal fistula, stenting of esophagus, airway, or both should be considered for symptomatic relief.

Abstract number: P1-042

Abstract type: Poster

### Palliative Endobronchial Treatment in Patients with Endobronchial Growth of Malignancies and Respiratory Symptoms

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**Aim:** Patients with endobronchial growth of malignancies are more likely to have significant dyspnea, hemoptysis, cough and require urgent therapy. Palliative bronchoscopy plays a major role in such situations.

**Patients and methods:** 165 patients underwent 281 endobronchial therapeutic procedures. All procedures were performed in general anesthesia. We wedged videobronchoscope through rigid bronchoscope. According The American Society of Anesthesiologists (ASA) physical classification were 55% patients ASA III and 45% ASA IV. The therapeutic endobronchial procedure was done in 137 patients with endobronchial NSCLC, in 12 patients with endobronchial SCLC, in 6 patients with endobronchial metastases of melanoma, in 3 with endobronchial metastasis of renal carcinoma, in 7 patients we started with endobronchial treatment before the morphological diagnosis. We started with the endobronchial treatment because of dyspnea in 100% patients (in 55% patients was dyspnea at rest), in 57% patients was cough, in 12% hemoptysis, in 2% pneumonia. During and after procedure we controlled oxymetry, electrocardiography, blood pressure.

**Results:** During and after procedures we observed in 28% patients hypoxemia, in 23% hemorrhage >250 cm<sup>3</sup>, in 10% arrhythmias, in 5% patients we observed hypertension and in 2% patients developed after procedure respiratory failure and both patients were 24 hours on invasive ventilation. Two patients died due complications after procedure. Any complications we observed in 40% of all procedures. The procedure leads to improvement of symptoms in 80% patients. The difference in number of complications in patients with ASA III and with ASA IV was not statistically significant (p=0.009).

**Conclusions:** Endobronchial treatment (electrosurgery and laser bronchoscopy) is palliative therapeutic procedure with acceptable rate of complications in patients with endobronchial growth of malignancies and in patients with ASA classification III and IV.

Abstract number: P1-043

Abstract type: Poster

### Symptom Profile in the Last 7 Days of Life among Cancer Patients Admitted to Acute Palliative Care Units

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**Aims:** The symptom burden in the last week of life of cancer patients has not been well characterized. We documented the frequency, intensity and predictors for 25 symptoms in the last 7 days of life among patients admitted to acute palliative care units (APCUs).

**Methods:** We systematically documented the Edmonton Symptom Assessment Scale (ESAS) daily and 15 other symptoms twice daily on consecutive advanced cancer patients admitted to APCUs at 2 Tertiary Care Cancer Centers from admission to death in 2010/2011. Data were only obtained when patients were able to provide patient-reported outcomes. We examined the frequency and intensity of the symptoms from death backwards, and determined the predictors of ESAS scores  $\geq 4$  using a multivariate generalized estimating equation model.

**Results:** A total of 203 of 357 patients died. The proportion

of patients able to provide patient reported outcomes decreased from 80% to 40% over the last 7 days of life. ESAS anorexia (P=0.001 for longitudinal analyses), drowsiness (P<0.0001), fatigue (P<0.0001), poor well-being (P=0.01) and dyspnea (P<0.0001) increased in intensity closer to death. In contrast, depression (P=0.008) decreased overtime. Dysphagia to solids (P=0.01) and liquids (P=0.005) and urinary incontinence (P=0.0002) were also present in an increasing proportion of patients in the last few days of life. In multivariate analysis, female sex was associated with more nausea (odds ratio [OR], 95% confidence interval [CI]=2.9, 1.1-7.7), drowsiness (2.8, 1.4-5.6) and anorexia (2.1, 1.03-4.3); non-Hispanic race was associated with greater fatigue (6.3, 2.4-16.7), anxiety (6.3, 2.4-16.7), drowsiness (6.3, 2.4-16.7), poor well being (2.4, 1.2-5), dyspnea (2.6, 1.3-5) and insomnia (5.9, 2.9-12.5); and lung cancer was associated with higher expression of dyspnea (7.7, 2.5-25).

**Conclusion:** Despite intensive management in APCUs, cancer patients frequently experience high symptom burden as they approached death.

Abstract number: P1-044

Abstract type: Poster

### How Is Depression Classified, Assessed, and Reported in Clinical Studies of Palliative Care Cancer Patients? A Systematic Literature Review

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**Background:** Reported prevalence rates of depression in palliative care (PC) patients vary from 3-58%. This may be due to selection of patients to the study, study design, and lack of using standardised classification and assessment of depression. To understand the population, key variables need to be presented.

**Aims:** To examine how depression is classified and assessed, and which clinically relevant variables are reported in order to describe the patient population in clinical studies of depression in PC cancer patients.

**Methods:** A systematic search using the MeSH terms "depression" and "cancer" and terms covering "palliative care" was performed in Medline, PsychInfo, EMBASE, and CINAHL, covering 2007-2011. Clinical studies in PC cancer patients with depression as the primary outcome were included. Titles and abstracts were screened, and relevant full-text papers were evaluated for inclusion by two readers independently.

**Results:** After deletion of duplicates, 916 citations were screened and 65 papers included for further investigation. The term "depression" was used interchangeably as a diagnosis and to describe depressive symptoms. Depression was diagnosed according to a classification system in 17 papers (26%); the DSM-IV criteria in 15 studies, and ICD-10 in two. Clinical interviews were used for assessment in 15 of these 17 studies, while two provided no information on assessment method. Self-report questionnaires on depression were used in 62 studies. Use of antidepressants was reported in 11 studies (17%). Duration of the present depressive episode was assessed in three studies (4%), while information about prior depressive episodes was reported in 13 (20%).

**Conclusion:** Standardised classification systems for diagnosing depression in clinical studies were rarely used. Assessment methods varied considerably, and specific clinical information related to depression was seldom reported. This calls for a standardisation when investigating depression in PC.

Abstract number: P1-045

Abstract type: Poster

### Efficacy of Aromatherapy on the Sleep Disturbance of Terminally Ill Cancer Patients Hospitalized in Palliative Care Wards

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**Introduction:** Terminal cancer patients hospitalized in palliative care wards often develop sleep disturbance such as insomnia. In recent years there have been many reports that aromatherapy using essential oils is effective against sleep disturbance. On the other hand, there are reports that

this has been ineffective, and there is no consistent opinion regarding whether aromatherapy using essential oils is effective or not. In this study, we paid particular attention to the essential oil Cinnamomum camphora (CC) and examined whether it was effective in treating sleep disturbance in terminal cancer patients hospitalized in palliative care wards. **Subjects and method:** For this study we used 10 terminal cancer patients with sleep disturbance who were hospitalized in the palliative care ward of Keikoukai Hara hospital from September 2011 to January 2012. Subjects consisted of 5 men and 5 women with an average age of 74 years old (54-84 years old), with 3 patients with pancreatic cancer, 3 with lung cancer, 2 with gastric cancer, and 1 with colon cancer. At 9PM, 0.25ml of CC was dropped into a lidded diffuser with the lid removed. The lidded diffuser was set on the bedside cabinet. The lid was replaced on the lidded diffuser at 6AM. In order to maintain objectivity for the evaluation of somnogenic effect of CC, the number of times nurses were called and the number of times patients were seen to be awake during the three regular checks per night (0AM, 2AM, 4AM) were totaled for three nights (from 9PM to 6AM) before and after the aromatherapy for the evaluation.

**Results:** The total number of times that subjects of the aromatherapy study using CC were awake upon checking was 24 times for the three days before starting the aromatherapy, which decreased to 10 times. No side effects of the aromatherapy were observed.

**Conclusion:** It was made clear that aromatherapy using CC is effective toward sleep disturbance in terminally ill cancer patients hospitalized in palliative care wards.

Abstract number: P1-046

Abstract type: Poster

### Doctor Does your Patient Rattle? Respiratory Tract Secretion Prevalence and the Use of Clinically Assisted Hydration in Palliative Patients in an Acute Hospital Setting

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**Background:** Respiratory tract secretions (RTS), or the "death rattle", are one of the most common symptoms in terminal care, affecting a mean of 44% of patients in studies of predominantly cancer patients in hospices. Symptom control with anti-muscarinics is a goal in the Liverpool Care Pathway for the Dying Patient (LCP), the latest version of which put renewed focus on the role of clinically assisted hydration (CAH). Although the majority of patients die in hospitals there is limited evidence on the prevalence of RTS and current practice regarding CAH in palliative patients in a hospital setting compared to cancer patients in hospices.

**Aim:** To identify in a palliative patient cohort in an acute hospital setting: the prevalence of RTS and the use of CAH in the last 48 hours of life; the association of a number of risk factors identified in previous studies with development of RTS; local compliance with the LCP in managing RTS.

**Methods:** A retrospective case note review of 100 patients who died whilst on the LCP at a teaching hospital (July-September 2011).

**Results:** In a dying population with a range of diagnoses, 73% non-cancer, RTS were present in 56% and 32% received CAH. Male gender was the only factor significantly associated with the presence of RTS. Management of RTS with anti-muscarinics was fully compliant with the LCP in 84% of patients. Areas of non-compliance consisted of incorrectly escalating management (6%), incorrect dosing (5%), not prescribing anticipatorily (3%), prescribing as once only rather than as required (1%) and prescribing intravenous rather than subcutaneous (1%).

**Conclusions:** RTS are as common in an unselected dying population in a hospital as they are in a hospice with cancer patients therefore hospital doctors need to be familiar with its management, which this audit suggests they generally are. Despite insufficient good evidence on the risk/benefit of CAH in palliative patients this study suggests it is not routine hospital practice.

Abstract number: P1-047

Abstract type: Poster

### Palliative Care Professionals' Reluctance to Talk about Suicidal Ideation in Depression

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**Background:** Depression is a common problem in patients with life-limiting illness and is associated with a higher incidence of significant symptom control problems. Studies have suggested that depression and suicidal ideation are under-reported and under-recognised in palliative care populations. Quality standards, including the EAPC Clinical Guidelines on the Management of Depression, suggest all patients with depression should be assessed for suicidal ideation.

**Aim:** To examine palliative care professionals' management of depression and exploration of suicidal ideation.

**Methods:** The audit consisted of an evaluation of clinical practice through a survey and a prospective case review across a regional palliative care network in North West England. Data was collected over one month. The population included patients over the age of 18 in contact with specialist palliative care professionals in community, hospice and hospital settings. Data was evaluated against six standards published in previous regional guidelines agreed through literature review and expert consensus.

**Results:** 60 completed evaluations of clinical practice were analysed. 48 completed prospective case reviews were completed, consisting of 18 new diagnoses and 35 existing diagnoses of depression. In the evaluations of clinical practice professionals stated that they assessed suicidal ideation always (27%), mostly (28%), sometimes (32%), rarely (8%) or never (5%). However in case reviews only 44% of patients were asked about suicidal ideation.

**Conclusions:** Doctors and clinical nurse specialists in palliative care do not consistently explore suicidal ideation in patients with depression. This is the case even with self reported measures. We present updated guidance and a discussion of the reluctance to discuss suicide from the literature. This includes suggestions of communication skills that may facilitate discussion with patients of suicidal thoughts.

**Abstract number:** P1-048

**Abstract type:** Poster

### Self-reported Quality of Life and Psychological Well-being in Patients with Multiple Myeloma Receiving Disease Modifying Treatment

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**Background:** Myeloma is an incurable disease in the majority of patients. Despite having a significant symptom burden several studies have shown that patients with haematological malignancies are less likely to receive care from specialist palliative care (SPC) compared to other cancers. Literature is sparse with regards to symptom burden and quality of life in myeloma patients undergoing disease modifying treatments. This represents a unique group of patients who may benefit from SPC involvement.

**Objective:**

1. To determine symptom prevalence in myeloma patients on disease modifying treatment and to identify the range and nature of these symptoms.
2. To measure self-reported quality of life within the dimensions of physical, psychological, social and financial well-being.

**Methods:** Cross-sectional quantitative survey. Patients are being recruited from a cohort of 100 adult myeloma patients on disease modifying treatment drawn from a central register maintained by the regional haematology service. Consenting patients complete two validated questionnaires, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) supplemented by the myeloma specific module (EORTC QLQ-MY20) and the Hospital Anxiety Depression Score (HADS). Data entry is on an Excel spreadsheet and analysed using SPSS 12.0.

**Results:** Data collection ongoing.

**Conclusion:** Interim data analysis suggests that myeloma patients on disease modifying treatment present as a group with distinct symptom burden and quality of life issues. Depression and anxiety scores are greater than that of the general population. We would anticipate that timely screening, identification and management of unmet needs would lead to improved outcomes for patients. Specialist Palliative Care services may act as a resource to help address these unmet needs.

**Abstract number:** P1-049

**Abstract type:** Poster

### Quality of Life and Symptoms in Patients Admitted to a Comprehensive Cancer Centre

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**Introduction:** Quality of life (QoL) and symptomatology in patients with malignancies admitted to comprehensive cancer centres are rarely investigated. Thus, this study aimed to investigate QoL and symptoms of inpatients at the departments of haematology and oncology.

**Methods:** Cross-sectional study, in which 124 cancer inpatients were assessed in May/June 2011. Collecting data was conducted in eight wards in two rounds of five days. No patient was included twice. Inclusion criteria: Age ≥ 18 years. Exclusion criteria: absence at assessments, not able to complete the questionnaire or unwilling to give informed consent. Demographic data, diagnoses and health-related quality of life (EORTC QLQ-C30) were assessed. EORTC QLQ-C30 consists of 9 scales (functional, global and symptoms): physical, role, emotional, cognitive, social, global health status/quality of life, fatigue, nausea and vomiting, and pain. Scores were converted into 0-100. Comparisons were analyzed using Wilcoxon two-sample, rank tests, and Fisher's Exact test.

**Results:** 124 patients were analysed, mean age = 59y (SD=13.7), 42% admitted to haematology department (14% had allogeneic stem cell transplantation), lung cancer was the most frequent diagnosis (15%). Role functioning scale was the most severely impaired (mean score=35), whereas cognitive function showed the best score (mean=70). The mean overall QoL/global health score was 43 (SD=25.6). The symptom burden of the inpatients was strikingly severe and especially fatigue and appetite loss were pronounced. Role and social functions appeared to be more impaired in haematology patients than in those admitted to oncology (P=0.0372 and 0.0167, respectively). On the other hand, pain and constipation were more severely affected in oncology patients (P=0.0194 and 0.0064, respectively).

**Conclusion:** Inpatients in a comprehensive cancer centre had low quality of life and a severe symptom burden. Fatigue and appetite loss were the most severe symptoms reported.

**Abstract number:** P1-050

**Abstract type:** Poster

### The Influence of Distressing Symptoms to Levels of Depression in Cancer Patients

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**Research aims:** To identify the frequency of reported depression by using the MDASI among younger cancer and geriatric outpatients. Moreover, to assess the associated symptoms of cancer using the MDASI and to evaluate the screening performance of depression between MDASI and BDI for younger patients and GDI for the elderly.

**Study design and methods:** 162 advanced cancer patients (group A: patients ≤65, group B: patients >65) attending a palliative care unit, took part in this open-label prospective trial with two parallel groups. The instruments that have been used were the Greek Beck Depression Inventory (G-BDI) for younger patients, the Geriatric Depression Scale (GDS) for geriatric patients and the Greek M. D. Anderson Symptom Inventory (G-MDAISI) for the severity and impact of cancer-related symptoms.

**Results:** A significant correlation was found between the GDS and MDASI symptoms for nausea (p=0.058), for increased sadness (p=0.011), increased constipation (p=0.021), interference of symptoms in mood (p=0.012) and in relationship with people (p=0.007) while interference of symptoms in mood was the most important risk factor. For

younger patients, many statistically significant associations were found between distressing symptoms and depression; however, interference of symptoms in mood (p=0.045) was the only important risk factor.

**Conclusions:** With aging, functional status is affected and especially in patients with cancer the effects of the disease and its treatment may develop multiple symptoms and thus assessment and management of these symptoms is required and more research will be beneficial for the best care of the geriatric patients in advanced stages of cancer. Health-care professionals should take into consideration the risk factors for depressive symptoms suggesting a holistic care in advanced cancer patients.

**Abstract number:** P1-051

**Abstract type:** Poster

### The Effect of Artificial Hydration Therapy in Terminally Ill Cancer Patients with Overhydration Symptoms Based on the Guideline for the Use of Artificial Hydration Therapy in Terminally Ill Cancer Patients (Published by the Japanese Society for Palliative Medicine; JSPM)

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**Aims:** Recently, there has been a growing interest in the use of artificial hydration therapy (AHT) for terminally ill cancer patients. The guideline for the use of AHT in these patients (GL) was published by JSPM in 2007. However, there still remains some discrepancy over the use of AHT in this stage depending on the physicians and medical institutions, and an excessive dose of hydration is often provided.

This study aimed to conduct AHT which is used for these patients based on this GL, and clarify the effects on the alleviation of various symptoms and QOL.

**Methods:** Our hospital is certified as a specialized cancer center that has a 30-year history of providing palliative care. Of the terminally ill cancer patients who were transferred from other hospitals to undergo palliative care over the last 18 months, 74 patients presented with symptoms of overhydration (dyspnea, nausea/vomiting, abdominal pain, edema and whole body malaise) at the time of admission.

Of the 74 patients, 52 patients who were judged "inappropriate" were used as subjects. AHT based on the GL was performed, and we examined the effects on the alleviation of overhydration symptoms and QOL using MDASI and EORTC-Q30 to compare values measured before and after the treatment.

**Results:** These symptoms of overhydration except for dyspnea and general QOL scores significantly improved after performing AHT based on the GL (p<0.05). Concerning dyspnea, no significant difference was observed by the single use of AHT; however, the concomitant use of drugs, such as antibiotics and anticholinergic agents, was effective in alleviating symptoms.

**Conclusion:** The provision of appropriate AHT based on the GL can contribute to alleviating symptoms associated with overhydration and improving QOL in terminally ill cancer patients.

In the future, specialized palliative care physicians must strive to disseminate such standard therapy across Japan.

**Abstract number:** P1-052

**Abstract type:** Poster

### Lessons Learned from Recruiting Palliative Care Patients to a Clinical Trial

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**Aim:** To describe recruitment patterns to a palliative care randomised controlled trial (RCT), as this area of recruitment can be challenging.

**Methods:** A phase III pragmatic single-blind fast track RCT, of a new breathlessness support service (BSS) joint between palliative care and respiratory medicine aiming to support breathless people with advanced disease, who were often not referred to palliative care. Analysis of recruitment: patient identification, response rates and reasons for refusal.

**Results:** 212 patients were referred, of which 193 met the inclusion criteria, of these 101 consented (59 men). Diagnoses: COPD 124 referred (55 consented), Cancer 37 (18), Interstitial lung disease 33 (20), chronic heart failure 12 (6), Asthma 3 (1), other 3 (1). Attrition rate for the primary endpoint (6 weeks) is approximately 20%, less than 40% as anticipated. Of the 92 patients that were not consented 45

were uncontactable, 29 refused to participate, 18 were too unwell and 1 felt too overburdened. Referral was from many different services, and this affected recruitment and response rates. Most referrals were from respiratory medicine and physiotherapy services, but also came from general practice, heart failure nurses and local community palliative care. Recruitment was initially slow. Referrals and consenting rates were improved by: research nurse attending clinics, multidisciplinary meetings, supporting clinical staff in patient identification, familiarity with the study or caring for patients who experienced the service and networking at local meetings.

**Conclusion:** The uptake to the study was similar to that in pulmonary rehabilitation literature. Key to successful recruitment are additional staff present in various clinical settings to facilitate the referral of patients, promoting patient screening for appropriate studies as part of patient assessment and care, and having research nurses with palliative care expertise.

**Abstract number:** P1-053  
**Abstract type:** Poster

### Validation of the German Version of the ESAS (MIDOS): Survey of Control Cohorts with Patients and Healthy Proband

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**Background:** Careful symptom assessment is paramount to guarantee effective symptom control for palliative care patients. The German version of the ESAS, MIDOS, has been designed for self-assessment of palliative care patients. The validation studies of 2000 and 2010 confirmed that it is a useful and valid self-assessment instrument for evaluation of the symptom burden of patients. In this study patients not receiving palliative care as well as healthy probands were asked to answer the MIDOS questionnaire, allowing differentiation between these groups and palliative care patients and in order to complete the validation data.

**Methods:** Data was collected from December 2011 until June 2012. Four groups were recruited: chronic pain patients, oncological patients, patients treated by a general practitioner and medical students of University Bonn. These persons completed the MIDOS- and the quality of life questionnaire SF-12.

**Results:** Until June 105 medical students (65% women, 35% men; age: 22-40 years), 64 general practice patients (56,5% women, 43,3% men; age: 19-82 years), 60 oncological patients (37% women, 63% men; age: 22-86 years) and 59 chronic pain patients (52,5% women, 47,5% men; age: 27-74 years) took part in the survey. The highest symptom score was 30.

Mean symptom scores differed significantly between groups, with higher scores for chronic pain patients=7,54 (range 2-16) compared to oncological patients=4,60 (range 0-17) and G.-P. patients=4,19 (range 0-19).

Students scored lower with mean sum score of 1,70 (range 0-17).

**Conclusion:** Comparing the mean symptom scores of our probands to the palliative patients of the MIDOS<sup>®</sup> study 2010 (mean symptom score=9,02) all groups showed - as expected- a lower symptom burden. This confirms the ability of MIDOS as a self-assessment instrument to describe the specific burdens of palliative patients.

**Abstract number:** P1-054  
**Abstract type:** Poster

### Palliative Treatment of Patients with Dysphagia and Malignant Stenosis of the Esophagus

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**Introduction:** Lung cancer is the second most frequent cause of malignant esophageal stenosis, which is caused either by direct invasion of, or by extramural pressure against, the esophageal wall. Esophageal stenosis reflects an advanced, inoperable clinical stage of the oncological disease. It is associated with huge weight loss, a decrease in performance status and poor prognosis. Nasogastric probe, percutaneous endoscopic gastrostomy and stenting are palliative procedures improving patients' performance status, quality of life and food intake during palliative treatment (radiotherapy, symptomatic care).

**Background:** We present case reports of two patients with esophageal stenosis and dysphagia due to the expansion of a lung tumour. The patient No.1 developed swallowing disorder during chemotherapy. Esophageal stenting was

applied. The same problem occurred in patient No. 2 at the time when the tumour was first diagnosed. Nutrition was provided via percutaneous endoscopic gastrostomy. Both procedures improved performance status of the patients and their quality of life and enabled further palliative treatment.

**Conclusion:** Our study reflects the advantages of multidisciplinary co-operation in the field of palliative oncological care and presents the methods of treatment of dysphagia due to esophageal stenosis. These procedures enhance the quality of life and facilitate further palliative treatment.

**Abstract number:** P1-055  
**Abstract type:** Poster

### Benefits of Physiotherapy in Cancer Patients at the End-of-Life

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**Introduction and aim:** The physiotherapy seems to play the important role in advanced cancer patients however until now its efficacy has not been defined by the clinical trials. The aim of this pilot study was to evaluate the effect of physiotherapy program on the intensity of symptoms in cancer patients at the end of life.

**Methods:** Thirty advanced cancer patients receiving palliative care were included to the study. The therapy took place three times a week for two weeks. The program included: active exercises, Proprioceptive Neuromuscular Facilitation (PNF) and myofascial release (MFR) techniques. Outcomes included the Edmonton Symptom Assessment System (ESAS) and Satisfaction Scores.

**Result:** The physiotherapy program caused significant reduction in the intensity of pain, fatigue, depression, anxiety, drowsiness, lack of appetite, and wellbeing. The analysis of satisfaction scores showed that it was also positively assessed by patients.

**Conclusion:** The results of the pilot study suggest that physiotherapy implemented in palliative care patients for the activity improvement also diminished the intensity of some symptoms. This study gives the reasons for further trials assessing the role of physiotherapy in cancer patients at the end of life.

**Abstract number:** P1-056  
**Abstract type:** Poster

### Development and Implementation of a New Out-patient Breathlessness Support Service

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**Introduction:** Breathlessness is a common and devastating symptom affecting many patients with advanced disease. Management comprises non-pharmacological and pharmacological interventions best delivered by a multidisciplinary team.

**Aim:** To describe the development of a newly established Breathlessness Support Service (BSS).

**Methods:** The BSS was designed following the Medical Research Council (MRC) Guidance for the development and evaluation of complex interventions. The BSS builds on already completed pre-clinical/ theoretical, modelling and exploratory phases. This new service is being evaluated in a phase III fast track randomised controlled trial (RCT) comparing immediate or delayed (after 6 weeks) access to BSS.

**Results:** An innovative BSS with palliative care and respiratory medicine (consultant, nurse, physiotherapy, occupational therapy, and social work) input has been developed and offered since October 2010 to patients with refractory breathlessness due to advanced malignant and non-malignant disease and their carers. Patients are seen twice in the clinic and offered a home visit by both physiotherapy and occupational therapy. Interventions include: patient and carer education, crisis planning, a relaxation CD, a fan, exercise, breathlessness and energy conservation techniques and a medical management review. Until October 2012, 78 patients (50 male), median age 67 years (range 40-88), have been seen in the BSS. Referrals come from across hospital and community settings with respiratory medicine and physiotherapy as main referrers. Diagnoses: COPD 44, Cancer 13, ILD 13, CHF 5, other 3.

**Conclusion:** The fast track RCT provides a method, which is generally well accepted as all patients will have access to the

intervention. Main organisational problems relate to transport to the BSS and patients being unwell to attend the second clinic visit.

**Abstract number:** P1-057  
**Abstract type:** Poster

### Nutritive Support - The Inseparable Part of Complex Oncological Treatment

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A cachexia and an unintended loss of weight are mainly the result of metabolic changes in an oncological patient's body. The weight loss is used as an independent survival indicator. It is known that 5% loss of weight can already decrease the response to oncological treatment. There are 16 patients with metastatic and 15 patients with locoregionally advanced stomach tumours. Their weights when they were admitted was 77 kg (56-95) and their food intake was 60-70%. The loss of weight before oncological treatment was 8% (3-24). Patients already have digestion problems before being admitted to our hospital, the time period from making the diagnosis to being admitted to our department was 3 months. The set of 5 patients has been treated symptomatically. Only 4 patients in the entire set were treated by full planned oncology treatment, 22 patients had to reduce chemotherapy doses, postpone or stop the treatment prematurely. 6 patients died during the first 2 months, 4 more patients died during the next 4 months. It is necessary to give patients at nutritive risk a professional advice and nutritive support before they start the planned oncological treatment, preferably right after the diagnosis of their tumour disease is made. It is undesirable to focus on an indication of operation or on a chemotherapy and omit a nutritive support. Oncological treatment can not be fully applied to a patient in malnutrition. The objective of nutritive support is to maintain the present nutritive and functional state, possibly slow down an irreversible worsening of this state, improve or maintain the quality of life and respect patient's wishes simultaneously. The assessment of presumptive oncological patient's prognosis does not only depend on the natural progress of tumour disease. The quality of complex supporting care and especially the way how nutrition is ensured influences the assessment strongly.

**Abstract number:** P1-058  
**Abstract type:** Poster

### Pleurodesis as a Palliative Treatment for Malignant Pleural Effusion

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**Background:** Malignant pleural effusion is characterized by the presence of tumour cells in pleural fluid or by the evidence of tumour tissue obtained directly from the pleura. It is mostly associated with malignant tumours of lung and breast. About 15% of patients are asymptomatic at the time of diagnosis of malignant pleural effusion. Patients with a massive pleural effusion tend to suffer from dyspnea, chest pain, dry cough or nausea.

Pleurodesis is a palliative therapeutic procedure whose aim is to preclude the formation of fluid between parietal and visceral pleura in symptomatic patients where chemotherapy is not an option or has failed.

**Aim and methods:** A retrospective analysis was performed of 31 patients hospitalized with symptomatic pleural effusion at the Dept. of Pulmonary Dis. and TB between October 2011 and October 2012. Malignant lung tumour was diagnosed in 27 of them (87%). The malignant origin of pleural effusion was proved only in 13 patients (42%).

**Results:** Pleurodesis was performed in 4 patients; in the remaining patients, it was not indicated due to poor clinical status, short life expectancy, „air trapping lung“, or presumed chemosensitivity of the tumour. Case reports are presented of two patients with malignant pleural effusion managed (with different outcomes) by pleurodesis.

**Conclusion:** Pleurodesis is an option among palliative therapeutic modalities which can alleviate symptoms of malignant pleural effusion, particularly dyspnea.

## Poster sessions

Abstract number: P1-059  
Abstract type: Poster

### Effect of Goreisan (TJ-17) for Malignant Lymphedema in Advanced Cancer Patient

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**Background:** Advanced cancer patients often experience uncontrolled pain by malignant lymphedema. Diuretics, corticosteroid sometimes relieve malignant lymphedema but most cases are resistant. Gorei-san (TJ-17), Japanese traditional herbal medicine with *Alismatis rhizoma*, *Attractylodis lanceae rhizoma*, *Polyporus*, *Hoelen*, and *Cinnamomi cortex*, is used to treat edema, gastrointestinal symptom (nausea, dry mouth), headache, and dizziness in general practice.

**Aim and methods:** To examine lymphedema treated by Gorei-san (TJ-17). Male/female ratio is 4/1 52-81yo. Retrospective reviews of cancer patients with consulted by palliative care support teams in Osaka National Hospital from 2011 to 2012.

**Results:** We treated successfully five lymphedema patients with Gorei-san (TJ-17). Primary site of cancer is colorectal, breast, kidney, stomach and all are severe advanced disease clinically. All patients have lower extremities lymphedema with pain, mild lymph leakage, and difficult to move. All take diuretics before Gorei-san administration. Average period to relief leakage/distension is 2/4 week.

**Conclusion:** Gorei-san (TJ-17) may manage symptoms of malignant lymphedema in palliative care cancer patients. Further prospective study is required.

Abstract number: P1-060  
Abstract type: Poster

### A Qualitative Study to Explore the Experience of Patients Attending a Nurse Led Breathlessness Group

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**Aim:** To explore patient's experience of attending a nurse led breathlessness group and the effects of non pharmacological interventions.

**Method:** The programme was developed within a UK day hospice, using an multi-disciplinary team (MDT) approach, based on intervention strategies by Corner *et al.* (1996). Ethical approval was obtained. Semi structured, audiotaped interviews were conducted with a purposeful sample of 6 patients who had attended a 4 week breathlessness group. Colaizzi's method of phenomenological data analysis and interpretation were used for analysis of the data.

**Results:** The participants had a mix of malignant and non malignant disease, but no differences were identified. The central component of the findings was "the breathlessness group" itself, participants spoke about the benefit of knowing that others experienced similar difficulties. This sub divided into benefit gained from the group setting and each other; the sharing with others, the comradeship and the importance of peer and carer support. Participants were aware of the distress their breathlessness caused their families and appreciated the opportunity of support for them.

5 further subthemes emerged; key interventions, psychological gain, MDT input, learning aids and the future. Beneficial interventions included; "the calming hand", breathing and pacing techniques, relaxation, and the "huff". Participants described feelings relating to lessening of isolation, and living with disability and dependence. The MDT approach was beneficial for participants and they described important relationships between themselves and the facilitator. Learning strategies improved their management of breathlessness, increased understanding, and reduced anxiety. Increased confidence in managing their breathlessness enabled participants to "face" the future more readily.

**Conclusion:** This study demonstrates the physical and psychological benefit to patients attending a nurse led MDT breathlessness group.

Abstract number: P1-061  
Abstract type: Poster

### The Changes of Drug Therapy and Laboratory Data of Cancer Patients toward the End of Life

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**Research aims:** It is known that a various symptoms appear in terminal patients toward the End of Life. However, it has not been clearly studied the changes of drug therapy and laboratory data of cancer patients toward the End of Life. We tried to get clinical prediction of survival from a retrospective study of them.

**Methods:** The electric medical records of 121 cancer patients who died between January 1st and December 31st in 2008 at an acute hospital were reviewed, and the medication history and laboratory data once a week for 90 days before death were collected retrospectively.

**Results:** The patients were 55% male, aged 58.1±17.0 (male 59.4±18.1, female 56.4±15.5) years with no gender difference. The primary site of cancer is blood, breast, lung and pancreas in decreasing order. The average number of drugs was 7.3 at the 90th day, 8.2 at the 45th day, and 10.9 at the 4th day before death respectively. Contraindications for coadministration were recognized in medication for 2 patients at the 4th day before death. The mean value of WBC, CRP, s-Cr, UN, ALT and LDH increased, s-Alb and PLT decreased toward the End of Life. CRP was more than normal value in over 80% of patients 10 weeks before death and continued to increase toward the End of Life. Conversely, s-Alb was lower than normal value in about 60% of patients at the 90th day before death and continued to decrease toward the End of Life.

**Conclusion:** The laboratory data of cancer patients in their last few weeks before death might be said to reflect the systematic inflammatory response (SIRS) or the multi organ failure (MOF). Further studied are necessary in order to get clinical prediction of survival.

Abstract number: P1-062  
Abstract type: Poster

### Swallow Screen and Test by Nursing Staff in Advanced Cancer

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**Introduction:** Swallowing is a complex process with four phases. It initiates digestion and is essential for proper nutrition. Difficulty swallowing independently correlated with cancer survival. We retrospectively evaluated the prevalence and incidence of difficulty swallowing in an acute care palliative medicine unit. BMI and survival were also examined.

**Methods:** Electronic Medical Records (EMR) 2010-2012 was reviewed. Assessment comprised of 3 steps: nurse survey on patient condition (coma, intubation, PEG/feeding tube, respiratory distress), screening questionnaire and clinical swallowing test. Change in BMI from the day of admission to discharge calculated. Survival calculated from EMR and Social Security Death Index.

**Results:** N=261 with cancer identified; 47% known metastases. Age (Mean ± SD): 68 ± 13 years. 55% females. 71% Caucasians and 25% African Americans. Common in lung, gastrointestinal (GI) and genitourinary (GU) cancers. Clinical swallowing test indicated in 94%. Prevalence of difficulty swallowing = 6%. Incidence of difficulty swallowing = 21%. Change in Body Mass Index (BMI) from 26 ± 7 (Mean ± SD) to 26 ± 6 on admission to discharge respectively. Median (25<sup>th</sup>, 75<sup>th</sup> percentile) survival: 25(13, 62) days.

**Conclusions:**

1. Difficulty swallowing common in lung, GI and GU cancers
2. Incidence of difficulty swallowing in acute care palliative medicine unit 21% and prevalence 6%
3. 75% with difficulty swallowing identified by nurse's survey, 19% through screening questionnaires and 6% clinical swallowing test
4. Swallowing evaluation critical for comprehensive cancer care

Abstract number: P1-063  
Abstract type: Poster

### Cancer Body Weight and BMI Trajectory: A Population Based Study

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**Introduction:** Large cancer databases can provide valuable information about weight loss prevalence and severity. Weight loss (WL) trajectory in outpatient adults with solid tumors was examined. The impact of WL on clinical and biochemical prognostic parameters was also observed.

**Methods:** Electronic Medical Records (EMR) from a tertiary academic center were retrospectively reviewed. Weight changes, clinical and biochemical parameters from three face-to-face visits (V1: Visit 1, V2: Visit 2 & V3: Visit 3) were analyzed. The results were summarized by descriptive statistics and analyzed for the level of association.

**Results:** N=6801; Age: 61 ± 12; 58% males. 77% were Caucasians and 13% African Americans. The cancer types were prostate 17%; lung 13%; breast 12%; colorectal 5%. 18% had metastatic disease. 43% received radiotherapy and 38% chemotherapy as antitumor treatment. Median (25<sup>th</sup>, 75<sup>th</sup> percentiles) weight in kgs V2: 81 (68, 95); V3: 79 (66, 94). Weight Difference V1>V2: 0 (-0.24, 1); V2>V3: 1 (2, 4); V1>V3: 1 (2, 5). Median (25<sup>th</sup>, 75<sup>th</sup> percentiles) Body Mass Index (BMI) V2: 28 (24, 32); V3: 27 (24, 31). The median resting energy expenditure (REE) on V2 and V3: 1555 (1354, 1792). The mean systolic/diastolic blood pressure (BP) on V2 and V3 were 135 ± 19/76 ± 11 and 132 ± 20/75 ± 11 respectively.

**Conclusions:**

1. 25% lost >5% of their weight from V1 > V2
2. Prevalence of hypertension decreased from V2 > V3,
3. Autonomic dysfunction may have a role in both WL and > BP
4. No change in Resting Energy Expenditure (REE) V2 > V3
5. BMI not a good indicator for weight loss: >50% were either overweight or obese at V2

Abstract number: P1-064  
Abstract type: Poster

Abstract withdrawn

## Assessment & measurement tools

Abstract number: P1-065  
Abstract type: Poster

### Feasibility Study of the Sheffield Profile for Assessment and Referral for Care (SPARC): A Holistic Needs Questionnaire

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**Background:** SPARC is a multidimensional holistic screening tool which provides a profile of needs (i.e. physical, psychological, social, spiritual) to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease.

**Aims:** A feasibility study (randomised controlled trial) was undertaken to establish whether using SPARC improves care (impact on quality of life, interventions, consultations, and referrals within supportive and palliative care), and to compare experience between patient groups.

**Methods:** The study was carried out within in-patients, out-patients, day care and in community settings, in accordance with the Medical Research Council framework for developing and evaluating complex interventions. Patients were randomised to receive SPARC at baseline or after a period of two weeks (waiting list control). Care continued as normal; SPARC responses were communicated to the care team to ensure identified needs were addressed. Participants were asked to complete three short research questionnaires (MYCAW, EQ5D and PEI) as part of the study, repeated after two, four and six weeks. 33 patients and 20 health professionals were interviewed (semi-structured interviews), and case notes were reviewed.

**Results:** 771 invitations were sent out, 189 patients consented (24.5% response rate). The number of completed questionnaires returned at the following time points were as follows; baseline: n=151, 2 weeks: n=122, 4 weeks: n=103, and 6 weeks: n=96. There were no significant differences between the control and intervention groups in the scores for MYCAW, EQ5D and PEI at 2 weeks, suggesting that the intervention did not have a detectable effect.

**Conclusions:** This negative trial result calls into question the utility of SPARC in specialist palliative care services. A process evaluation of the trial is currently underway, findings and



methodological issues will be presented at the conference.

**Abstract number:** P1-066

**Abstract type:** Poster

### Do Physicians Underestimate Non-pain Symptoms in Advanced Cancer Patients? Referring Patients to Pain Clinic Helps to Identify Other Distressing Symptoms

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**Background:** Pain is one of the most common symptoms at advanced stages of cancer disease. Cancer related non-pain symptoms receives less attention from oncologists as compared with cancer pain, such symptoms can be easily underestimated if physicians missed the comprehensive assessment of physical and psychosocial aspects.

**Aim:** This study aims to identify the prevalence and intensity of the most common uncontrolled symptoms in advanced cancer patients and the role of referral to pain clinic in management of such symptoms.

**Method:** A prospective study surveys 140 patients with metastatic cancer disease referred to pain clinic due to uncontrolled cancer pain. Questionnaire based on ESAS (Edmonton symptom assessment scale) were distributed to patients in the first interview. Patients were asked to identify and rate the severity of the 10 most common distressing symptoms. Results considered positive if patients rates the severity > 6

**Results:** From 140 patients referred to our cancer pain clinic 18 were excluded. The remaining 122 patients 72 female and 50 male were eligible. 88% reported fatigue as the most distressing symptom followed by pain 86%, anorexia 61%, worse well being 57%, depression 51%, anxiety 48%, constipation 47%, nausea 41%, dyspnea 32% and drowsiness 21%

**Conclusion:** The data emphasize that many symptoms can be more distressing than pain and it is not sufficient for oncologists to simply address pain during the treatment of patients with advanced cancer, a more global approach to symptom management is necessary. Referring cancer patients to pain clinic may be an alternative option for comprehensive symptom management in the absence of well established palliative care service.

**Abstract number:** P1-067

**Abstract type:** Poster

### Implementing Patient Reported Outcome Measures (PROMs) in Palliative Care Clinical Practice: A Systematic Review of Facilitators and Barriers

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**Background:** Many patient reported outcome measures have been developed in the past two decades, and they play an increasingly important role in palliative care. However, their routine use in clinical practice has been slow and difficult to implement.

**Aim:** To identify facilitators and barriers to the implementation of patient reported outcome measures in the clinical care of patients with advanced or long term progressive physical illnesses.

**Design:** Systematic literature review and narrative synthesis  
**Data sources:** Medline, PsycInfo, CINAHL, Embase and British Nursing Index were searched limited to studies published after 1985. Hand searching of reference lists for all included articles and relevant review articles were performed.

**Results:** 3863 articles were screened. 31 articles met the inclusion criteria. Facilitators, barriers and lessons learned were categorised. Recommendations for implementation on outcome measures at management, healthcare professional and patient levels were drawn from findings within three different time points: preparation, implementation and assessment/improvement.

**Conclusions:** Identifying and addressing potential barriers to the implementation of patient reported outcome measures in clinical practice by using appropriate facilitators seems to be vital. The most important facilitator has to do with an educational component for healthcare professionals prior to the implementation, which will help insuring that clinicians are familiarised with the patient reported outcome measure selected for use, aiding the correct interpretation of results, potentially improving practice and the quality of care provided by assisting clinical decision making.

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**Abstract number:** P1-068

**Abstract type:** Poster

### Validation of the Palliative Performance Scale Version 2 (PPSv2) into Spanish for its Use in End of Life Oncological Patients

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**Aims:** Research has become a major challenge in recent years for professionals involved in palliative care (PC). Most of PC assessment tools have been primarily developed in English so it is mandatory its validation into different languages to provide effective tools and to facilitate researchers to compare results more scientifically. The main objective is to validate the Spanish version of the PPSv2 in patients assisted by PC teams

**Methods:** Validation of the PPSv2 into Spanish was carried out in three different steps: Initially, the translation was based on the conceptual equivalence of the terms used under linguistic supervision. Second, cultural and grammatical adaptation on a sample (n=15) of oncological palliative patients was carried out in order to test inter and intraobserver reliability (intraclass correlation coefficients) and internal consistency (Cronbach's  $\alpha$ ). The rest of the psychometric properties (correlation between the PPSv2 and the Barthel test and the Karnofsky Performance Scale) were studied on a transversal study including 250 patients from the outpatient clinic, emergency unit and medical oncology ward.

**Results:** Inter and intraobserver reliability was good with intraclass correlation coefficients of 0.753 (0.264 - 0.917,  $p=0.007$ ) and 0.894 (0.684 - 0.964,  $p>0.001$ ), respectively. Internal consistency analysis showed a Cronbach's  $\alpha$  of 0.990 (0.988 - 0.992,  $p<0.001$ ). The psychometric properties of the validation process tested with the Pearson's correlation coefficient showed values of 0.854 and 0.927 (both with  $p<0.001$ ), respectively.

**Conclusion:** Psychometric and qualitative properties of the Spanish version of the PPSv2 showed to have high validity and reliability. These results supports the use of the Spanish PPSv2 to test functional status in advanced oncological patients attended by PC teams in a hospital environment.

**Abstract number:** P1-069

**Abstract type:** Poster

### Development and Validation of a Checklist for Symptom Management (SyMPEc) in Patients Treated with Chemotherapy in Palliative Intention Using the Data Set of the Trial SAKK 95/06

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**Aim:** Patients with advanced cancer suffer from a variety of symptoms with fluctuating intensity. During chemotherapy oncologists perform a range of pharmacological and non-pharmacological interventions in order to manage these symptoms. We aim to develop and validate a symptom management checklist (SyMPEc) for medical chart review in the oncology outpatient clinic.

**Methods:** A consensus of the content of the check-list was undertaken. The parameters were extracted and quantified from a test data set (half of the data set). To assess the inter-rater reliability, three independent researchers used SyMPEc on a random sample (10% of the test data set) and Fleiss' Kappa was calculated. For validation a comparison of retrieved symptom-specific interventions with the nurse-led assessment of patient perceived oncologists' interventions was performed on the whole data set.

**Results:** 5 categories of symptoms emerged: pain, fatigue, anorexia/nausea, dyspnoea and depression/anxiety. 247 patients from 84 oncologists from 8 centers were in the data set. In the test data set (123 patients) 402 unspecific pharmacological interventions and 260 that could be assigned to specific symptoms were identified. Non pharmacological interventions could scarcely be assigned to symptoms. In the 12 patients analysed by three researchers Fleiss' Kappa for symptom detection was  $K = 0.7$  and for intervention detection  $K = 0.86$ . When compared with nurse led assessment in all 247 patients, there was a match in 1003 of 1220 visits (86%) and a mismatch in 164 visits (14%). If analysed per case (6 visits) 195 out 247 cases (79%) had one mismatch or less.

**Conclusion:** Chart review by SyMPEc seems reliable and valid for symptom management in oncology outpatient clinics. Non-pharmacological interventions were difficult to

assign to a specific symptom. A checklist for documentation could improve standardisation.

**Abstract number:** P1-070

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P1-071

**Abstract type:** Poster

### Finding Routines in Estimation of Pain in Dying Patients in a Specialized Palliative Care Unit

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**Background:** Pain relief in dying patients is one of the most important tasks in palliative care.

Even though estimating pain with a validated tool is one of the parameters in the National Register of Quality in Palliative Care, there is a lack of using such tool in a specialized Palliative Care Unit at a university hospital in Sweden.

**Aim:** Finding routines for using a validated tool to estimate pain in dying patients to ensure the quality in pain relief.

**Method:** In September 2012 started a pilot study with one nurse to find a routine to estimate pain in inpatients at the palliative care unit.

From November 2012 each nurse at the ward will receive training in how to use the Visual Analogue Scale-tool (VAS) and the Abbey Pain Scale-blanket (APS).

At least twice a day, an estimate of pain should be done with one of the validated tools, for every patient who has an ongoing pain relief. In addition, an estimate shall be done every time the patient suffers from breakthrough pain, just before an extra dose is administered as well as 20-30 minutes after the given dose.

The VAS should be used for patients who are able to participate and the APS for those who cannot.

The results of the estimates will be documented in the patients' journal.

**Result:** In February 2013 will an evaluation be done, for to find out if it has become a routine for the nurses to estimate pain in dying patients, with an validated tool. A comparison of statistics from the National Register of Quality in Palliative Care, before and after the intervention will be done.

**Conclusion:** Training and gradually introducing is one way for nurses to find routines for estimating pain with validated tools.

**Abstract number:** P1-072

**Abstract type:** Poster

### Evaluation of Serum Markers Cathepsin s, Cystatin c, Interleukin-6 and C-reactive Protein as Prognostic Parameters in Palliative Care Patients

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**Aims:** Lack of clarity about palliative patients' prognoses poses a huge burden on both patients and their family and friends. Surprisingly early deaths can be grievous when relatives cannot take leave of their beloved one, while unexpectedly prolonged survival can be excruciating for patients and relatives. Recent studies identified certain serum markers as valid predictors of life expectancy in elderly citizens. However, the significance of such markers in a palliative care setting is unknown. The aim of our study is to identify possible prognostic parameters of life expectancy in patients at a palliative care unit (PCU).

**Methods:** In this study, blood samples are collected from 100 patients in our PCU from 01.08.2012 to 30.03.2012 regardless of underlying disease. 46 samples were collected from 01.08.2012 to 20.10.2012. Serum cathepsin s and interleukin 6 (IL-6) levels are determined by ELISA. Cystatin c levels are measured by nephelometry. Further parameters include blood count, HDL, LDL and cholesterol. Clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history). Results are correlated with survival time and documented risk factors by means of statistical correlation analyses. This study was approved by a local IRB, written informed consent is obtained from all patients or their legal caregivers.

**Results:** Data from 23 already deceased patients indicate a correlation between the average survival time (average  $8.9 \pm 7.7$  days) and serum levels of cystatin c (Pearson's  $r = -0.54$ ), IL-6 ( $r = -0.37$ ), c-reactive protein ( $r = 0.41$ ) as well as

## Poster sessions

Karnofsky performance score ( $r=0.56$ ).

**Conclusion:** Our data identify potential prognostic parameters of survival time in a palliative care setting. A combination of such parameters may prove to be a valid predictor of life expectancy at PCUs in the future and warrant further validation.

This project did not receive external funding.

**Abstract number:** P1-073

**Abstract type:** Poster

### Responsiveness to Delirium Severity Variations, Neurobehavioral and Global Cognitive Factors of the Memorial Delirium Assessment Scale

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**Background:** The Memorial Delirium Assessment Scale (MDAS) is a reliable and validated instrument with which to assess delirium. Responsiveness to delirium changes detected by the MDAS has not been investigated. Two factor loads in the MDAS, neurobehavioral and global cognitive, have been previously defined. This study's primary objective was to evaluate the MDAS' responsiveness and analyze individual factors on this questionnaire.

**Methods:** Study subjects included 85 advanced cancer patients with delirium diagnoses who were admitted to 3 palliative care units. Delirium diagnosis was determined by clinical DSM IV TR criteria; the Confusion Assessment Method Instrument also was used. Patients were evaluated at baseline (0) and 72 hours with the Delirium Rating Scale-Revised-98 (DRS-R-98), Mini-Mental State Examination (MMSE), and MDAS.

**Results:** The variation in DRS-R-98 scores shows a correlation of  $r = 0.93$ , with variation in MDAS scores at  $P < .001$ . The variation in MMSE scores shows a correlation of  $r = -0.84$ , with variation in MDAS scores at  $P = .015$ . Factor I, neurobehavioral (reduced awareness, reduced attention, perceptual disturbance, delusions, altered psychomotor activity, and sleep-wake cycle disturbance) correlated moderately with MMSE at  $-0.56$ ; Factor II, global cognitive (disorientation, short-term memory impairment, impaired digit span, and disorganized thinking), correlated strongly with MMSE at  $-0.81$ . Factor II was significantly more reliable than I ( $\rho = 0.7$ ,  $P = .01$ ).

**Conclusions:** The high responsiveness confirms the value of the MDAS for ongoing delirium assessment. The existence of 2 differentiated factor loadings points to a potential future need for MDAS subscales.

**Abstract number:** P1-074

**Abstract type:** Poster

### Early Recognition at Home, a Pilot Study

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A proactive approach of palliative care problems ameliorates quality of life of patients and family caregivers. A study regarding early recognition nursing interventions in palliative home care patients was conducted.

**Aims:** To develop a feasible set of nursing interventions to optimize palliative care for patients and their caregivers at home.

**Method:** From February- June 2012 a longitudinal pilot study was conducted. Palliative care patients receiving nursing ambulatory coaching and their primary caregivers were included. Nurses received coaching to integrate early recognition in daily practice. Study outcomes: symptom intensity, quality of life, caregivers' burden, use of healthcare facilities, attrition rate and missing data, use of study tools in daily nursing practice. Data collection was performed by a nurse researcher during home visits and by self-assessments. Descriptive statistics were performed.

**Results:** Fifteen patients were selected, 12 patients were enrolled (5 men; m 60 years) during a mean of 53 days. Attrition rate was 33%, missing data 8% patients, 32% caregivers. In average patients experienced 6 symptoms. Fatigue, sleeping disorders and pain occurred most frequent and intense. Sleeping disorders and early satiety increased; quality of life decreased concurrently. Caregivers experienced burden increased. Patients consulted an average of four different healthcare professionals. Nurses barely used early recognition strategies in daily practice.

**Conclusion:** The patient journey of palliative home care patients shows an increase of symptom intensity, a decrease of quality of life and increase of caregivers' burden. Nurses recognize the importance of early recognition interventions without integration in daily practice. Lessons learned for

future studies: create several data collection strategies related to patients preferences; focus on nursing training/coaching on the job to empower nurses to integrate early recognition in daily practice.

**Abstract number:** P1-075

**Abstract type:** Poster

### An Audit of the Use of the Distress Thermometer Problem List in a Hospice Day Therapy Unit: What Is the Added Value?

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The Distress Thermometer (DT) is a patient led, subjective scale recommended by the National Cancer Collaborative Network, USA (2007) as a tool designed to screen distress. In the UK, a Problem Checklist has been added to enable patients to identify and rank their top 4 concerns.

The Day Therapy Unit Multidisciplinary Team were seeking to extend their holistic needs assessments to focus more clearly and consistently on the patients' own identified concerns, by introducing the DT, Problem Checklist and Action Plan. The aims of this audit were to:

1. Collate the spread of problems identified by patients in the Problem Checklists and actions taken following the assessment.
2. Evaluate whether introduction of the DT added to the quality of initial holistic assessments.
3. Recommend whether the DT would be introduced to other aspects of the hospice service.

**Methods:** The Patients Forum was consulted on their views about the DT, staff were trained in how to use the DT and the Problem Checklist tool effectively, then the tool was introduced for a four month pilot period for all new assessments in the Day Therapy Unit. All staff members completed a questionnaire on their experience of the use of the DT. Data was collated from all the completed assessments.

**Results:** 24 assessments were completed during the pilot period. The range of patients' concerns identified and actions taken will be presented. Staff feedback reported that the tool enhanced holistic assessment by structuring collaborative discussion between staff and patients, supported patient self-management and ensured appropriate onward referrals through shared action planning by keyworker and patient.

**Conclusion:** The Problem Checklist is the most highly valued aspect of the tool reported by patients to staff, and its use has added to the consistency, quality and documentation of holistic assessments in this setting. The tool will be extended next to the Hospice at Home Service and then evaluated.

**Abstract number:** P1-076

**Abstract type:** Poster

### Applicability of the Swedish Version of the Frommelt Attitude Toward Care of the Dying Scale (FATCOD) among Nurses and Nursing Students and Factors Influencing the Attitudes

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**Background:** To improve quality of life of patients with life-limiting illness is important in palliative care, and to this quality nursing care for dying patients is essential. Nurses need to be prepared to meet dying patients, therefore, nurses' attitudes toward caring for dying persons and factors influencing such attitudes need to be explored. One instrument investigating these attitudes is the Frommelt Attitudes Toward Care of the Dying (FATCOD) scale, which has not previously been used in Swedish language.

**Objectives:** To compare FATCOD scores among Swedish nurses and nursing students with those from other languages, to explore the existence of subscales and evaluate influences of earlier experiences on attitudes toward care of dying patients.

**Methods:** The FATCOD is a 30-item questionnaire concerning attitudes toward caring for dying persons. FATCOD scores of 113 Swedish nurses from hospice, oncology, surgery clinics, palliative home care and 100 nursing students were compared with published scores in similar populations from the USA, Israel and Japan. Descriptive statistics, t-tests, factor and regression analyses were used.

**Results:** Swedish FATCOD mean scores did not differ from published means from the USA and Israel; but were significantly more positive than Japanese means. Factor

analysis yielded a two-factor solution. Total FATCOD and subscales had low Cronbach's alphas. Hospice and palliative team nurses had more positive attitudes to care of the dying than did oncology and surgery nurses.

**Conclusions:** Although our results suggest that the Swedish FATCOD may comprise two distinct scales, the total scale may be the most adequate and applicable for use in Sweden. Nurses' professional experience and the workplace care culture affect their attitudes toward giving care to dying patients. Factors influencing student nurses' attitudes and the benefit from education need to be further explored.

**Abstract number:** P1-077

**Abstract type:** Poster

### Palliative Prognostic Index: Further Validation in Hospice Cancer Patients with a Multi-center Prospective Study

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**Background:** Predicting prognosis is important for patients and clinicians, potentially helping in decision making about treatments, referral to appropriate services and preparing and planning for a patient's remaining time. The Palliative Prognostic Index (PPI), a prognostic tool calculated using clinical indices alone (oral intake, oedema, dyspnoea at rest, delirium and palliative performance scale) was first formulated by Morita in Japan and validated by Stone in 2008 and Subramaniam in 2010. This study aims to further test the accuracy of the PPI in hospice patients with advanced cancer, using a larger sample drawn from multiple sites.

**Methods:** A multi-centre prospective study aiming for a sample of 1000 adult hospice inpatients with advanced cancer. Statistical advice sought from a local university and ethical approval granted. Sequential start of data collection from 10 UK hospice sites between August 2012 and November 2012. The PPI score is recorded by the patients' usual medical team on admission to the hospice and also between day 3 and 5 where relevant. Patient status at 6 weeks [alive or deceased] is documented. Anonymised data collated and analysed. Analysis looking at

- Accuracy of prognosis prediction by PPI score at admission
- Accuracy of prognosis prediction by second PPI score
- Any effect of rate of change in score on accuracy of prognosis prediction
- Presence/absence of inter center variability
- It is planned to calculate calibration and discrimination ability of the tool.

**Results:** Data collection is ongoing and to be completed April 2013.

**Conclusion:** Results and conclusions will be presented at the Conference.

**Abstract number:** P1-078

**Abstract type:** Poster

### Development of a Pain Body Map for Tablet Computer for Use in Patients with Advanced Cancer

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**Background:** Computerized assessment tools ease documentation and facilitate integration of self-report data into electronic patient record systems. However, advanced cancer patients have special needs regarding usability of computer programs. We have previously tested a computerized pain body map (CPBM) for pain location in advanced cancer patients. The aim of the present work was to develop an improved version of the CPBM for a tablet computer.

**Material and method:** A stepwise, user-centered approach was performed. This included repeated testing (iterations) of a prototype of the program in patients from the target

group. During four iterations patients were observed and instructed to "think aloud"; audio and video recordings were made, and each participant interviewed after each round. The first iteration presented a paper sketch, while the subsequent iterations were performed on a tablet. Based on responses and feedback, the prototype was improved and/or new functionality added.

**Results:** The program was tested in 23 advanced cancer patients; mean KPS 75 (40-90) and mean age 64 years (42-92), and six health care workers. Design and functionalities were based on the patients' preferences and ability to use the application. The final CPBM for iPad includes pain location and intensity, and was preferred by all test patients except one. All found it easy to use.

**Conclusion:** We have developed a user-friendly, functional CPBM iPad application for patients with advanced cancer. The user-centered approach enabled us to create a program with a high usability for target patients. The application will be further developed to include pain qualities.

**Funding:** Central Norway Regional Health Authority and the Cancer Fund, St Olavs Hospital, Trondheim, Norway.

**Abstract number:** P1-079

**Abstract type:** Poster

### Measuring Capacity at the End of Life

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Cognitive impairment (CI) and delirium have been reported in up to 90% of palliative care patients in the weeks before death. Given the importance of decision-making at the end of life, being able to give informed consent to treatment or other decisions (e.g., advanced directives) is critical. CI may limit patient capacity to make decisions, but is often only assessed globally with instruments such as the Mini Mental Status Exam (MMSE), if at all. The present examination explored the relationship between the MacArthur Competence Assessment Tool (MacCAT) dimensions (understanding, appreciation, reasoning, choice) and the MMSE.

Subjects were recruited from an inpatient hospice facility and from the community as part of a larger study on medical decision-making at the end of life. Subjects were included if they were over the age of 50 and had no known dementia or CI ( $n=95$ ). Mean age of the sample was 67, and mean MMSE score was 26.4.

Multiple regressions were calculated including MMSE score, education, and age as predictors for each of the four dimensions of the MacCAT. These regressions indicated that MMSE score was a significant predictor for all four dimensions of the MacCAT: Understanding ( $R^2 = .43$ ,  $F(3,91) = 22.84$ ,  $p < .001$ ), Appreciation ( $R^2 = .12$ ,  $F(3,91) = 3.97$ ,  $p < .01$ ), Reasoning ( $R^2 = .25$ ,  $F(3,91) = 10.03$ ,  $p < .001$ ), and Choice ( $R^2 = .16$ ,  $F(3,91) = 5.89$ ,  $p < .001$ ).

These findings indicate that the MMSE and MacCAT demonstrate concurrent validity. Although all dimensions were significantly predicted by MMSE scores, there was still a large proportion of unaccounted for variability in MacCAT scores. Therefore, clinicians in hospice care who are determining patient capacity to provide informed consent to treatment may wish to evaluate capacity in a more multifaceted way with instruments such as the MacCAT. Additional analyses will explore differences between inpatient and community subjects.

**Abstract number:** P1-080

**Abstract type:** Poster

### Do Patients Want to Tolerate Unrelieved Pain? Nurses' and Patients' Experiences with Pain Management in Hospices

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**Background and aims:** Pain management is an essential aspect of caring in hospices. A substantial number of people with cancer experience pain during their affection. Suffering from severe pain at the time of death is one of patients' greatest fears. As one consequence, advanced cancer patients often frequent a hospice in the hope of the possibility to control pain.

A health services research project in the city of Muenster (Germany) aimed to optimize pain management in different health care facilities. The objective of the here presented substudy was to investigate the needs and requests of hospice patients regarding pain management. Another objective was to identify barriers to pain management labelled by hospice nurses.

**Methods:** The study used a qualitative design. Data were collected during two group discussions with 12 hospice

nurses and six individual semi-structured interviews with hospice patients with cancer from two different hospices. Audiotapes were transcribed and analyzed using content analysis.

**Results:** Hospice nurses describe that many patients suffer from pain during their stay and psycho-social aspects play a major role how pain is experienced and coped. Nurses point out the importance of an assessment but experience standardized tools as not useful to meet this demand. They also depict the challenge, when patients prefer to tolerate unrelieved pain.

Hospice patients describe that they feel comfortable in the hospice due to the nurses respecting their wishes. They emphasize the autonomy which they enjoy in the hospice and the possibility to be in charge of their own decisions at end of life.

**Conclusion:** Current pain assessment tools are not capable of describing the hospice patient's pain experiences in a comprehensive way. Hospice nurses evaluate them as insufficient. Multidimensional tools that also cover the psycho-social aspects of pain in a systematic way have to be developed. Furthermore, the wishes of the hospice patients have to be considered.

**Abstract number:** P1-081

**Abstract type:** Poster

### Does the End-of-Life Patient-reported Outcome Measure (EOLPRO) Plug the Quality of Life Assessment Gap?

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It's over ten years since 'preparation for death' was identified as one of the most important quality of life (QOL) attributes for patients at the end of life, yet this primary domain is still rarely captured in health services research. Suboptimal measurement of QOL could lead to missed funding opportunities for valuable palliative care programs.

Consequently, this research aimed to develop and validate a new, supplementary, single-item EOLPRO to measure changes in this patient-valued domain. 9 cognitive interviews were conducted with purposively sampled Australian palliative care patients to evaluate content validity. Construct validity, test-retest reliability and responsiveness were assessed using data from the multi-site, double-blind, parallel arm, dose titrated, Phase III Australian Palliative Care Clinical Studies Collaborative randomised controlled trial comparing subcutaneous ketamine and placebo for the management of cancer pain ( $n=184$ ).

Analysis of cognitive interviews provisionally supported the content validity of the EOLPRO. The significant correlation between baseline performance status and EOLPRO scores demonstrated convergent validity ( $n=137$ , correlation coefficient= $0.41$ ,  $p < 0.001$ ). Correlations between baseline EOLPRO and MMSE scores and proximity to death were in the expected direction but not statistically significant. Pre- and post-treatment EOLPRO scores moderately agreed ( $n=14$ ,  $\kappa=0.52$  [95% CI 0.19, 0.84]). The EOLPRO's apparent lack of sensitivity to discriminate between those who did/did not respond to pain management may have been confounded by other factors ( $n=104$ ,  $\chi^2=0.43$ , unadjusted  $p=0.98$ ).

Very few palliative care QOL questionnaires measure the ability of patients with a life limiting illness to finalise their affairs at the end of life. Within this context, the EOLPRO has promising psychometric properties as a tool to add to existing questionnaires, plugging the QOL assessment gap.

**Funding:** Australian Government & Flinders University

**Abstract number:** P1-082

**Abstract type:** Poster

### A Study of the Palliative Prognostic (PaP) Score in a Comprehensive Cancer Centre

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The PaP score is a prognostic tool that uses clinical and

laboratory parameters to classify patients with advanced cancer into three risk categories predictive of 30-day survival. The PaP score is calculated based on clinical prediction of survival (CPS), performance status, anorexia, dyspnoea, white blood cell count and lymphocyte ratio. Although extensively validated in inpatients, limited studies evaluate its use in outpatients. The CPS which is commonly determined by a single clinician tends to overestimate survival by a factor of approximately three to five. At our institution, the CPS is determined by a palliative care multidisciplinary team (MDT). This is a retrospective study of the PaP score in a series of cancer patients referred to the Pain and Palliative Care (PPC) Department.

The aims of this study are to evaluate the accuracy of prognostication by the PaP score in inpatients and outpatients, assess the accuracy of prognostication by a palliative care MDT and to identify other factors that may impact prognosis in cancer patients.

A total of 645pts (224 outpts) referred over 2 years excluding haematological and renal malignancies were included in this study. Data was sourced from the PPC Database which routinely collects patient data including demographics, PaP score and CPS predicted by a palliative care MDT. Standard statistical tests were used to analyze data.

The PaP score was found to accurately predict survival among inpatients although in outpatients the PaP C group was limited by small numbers. A CPS by a palliative care MDT was more accurate than a single clinician CPS; overestimating survival by a factor of 1.5 in inpts and 1.2 in outpts. The PaP score was more accurate in predicting survival compared to MDT- CPS on its own (Spearman correlation). Age was found to impact survival in outpatients. The palliative care MDT needs to be defined and standardized and prospective studies are needed to validate the PaP score for use in outpatients.

**Abstract number:** P1-083

**Abstract type:** Poster

### Expert Panel on Eliciting a Spiritual History for Research Purposes

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Taking a spiritual history is an assessment designed for therapeutic use. To validate the semi-structured assessment tool SPIR (German adaption of FICA) spiritual histories were elicited for research purposes in two PCUs. Later, following the Delphi method, an international group of spiritual care experts was invited to join a hermeneutic circle to establish the complexity of taking spiritual histories.

Two participants were asked to read out loud a transcript of a pre-selected research interview. Experts were asked to communicate their expertise regarding the content and methodical issues. The discussion was recorded on discussants' permission. The transcript was analyzed using the thematic content analysis (TCA).

The discussion revealed that taking a spiritual history for research purposes is a complex and challenging task, which requires from a researcher certain qualities that transcend his/her usual competences and role. The qualities connected to eliciting a spiritual history are "being present"; "not only hearing, but listening"; "understanding the message beyond the words uttered" and "picking up linguistically suitable register to respond". In order to "establish a link of sharing" the interviewer is expected "to go beyond the ethical stance of neutrality", which may cause several ethical and moral dilemmas, such as "fear of causing more problems"; "not daring to take it further"; and above all, "being ambivalent about one's role". While taking a spiritual history, one has to be extremely careful in terms of patient's vulnerability. To avoid "causing more violations" it is essential to propose "a follow-up contract" that allows responding to "patient's yearning for genuine care".

Taking a spiritual history is an intervention that needs a systematic follow up under any circumstances. This is to assure that emerging spiritual needs of the patient are taken care of and to grant the researcher with a primary right of acting as a human being.

**Abstract number:** P1-084

**Abstract type:** Poster

### Nursing Diagnosis in Palliative Care: The Case of a Palliative Care Hospital Support Team

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**Introduction:** Nursing documentation in palliative care

provides relevant information about the critical thinking and clinical judgment used in nursing process (assessment, diagnosis, care plan, interventions and evaluation). The International Council of Nurses published the Catalogue "Palliative care for a dignified dying"; ICNP Catalogue, which includes a set of nursing diagnosis in palliative care.

**Aim:** To identify nursing diagnosis exhibited by palliative patients supported by a hospital support team.

**Methods:** A longitudinal study was conducted in a Portuguese hospital support team during one month. Data were collected using the nursing diagnosis' identification instrument, developed upon the Catalogue "Palliative care for a dignified dying". Nursing diagnosis were identified in 11 patients.

**Results:** Nursing diagnosis identified in this study were: suffering (present in 9 out of 11 patients at the first moment of evaluation and in 4 patients at the last one); spiritual distress (identified in 8 out of 11 patients in the first moment and in 2 patients at the last one); impaired ability to bathe (present in 7 out of 11 patients at the first moment and in 6 patients at the last moment of assessment), to clean the house (notorious in 6 out of 11 patients at the first assessment and in 5 patients at the last moment), to get dressed / undressed (identified in 5 out of 11 patients from the first until the last moment of evaluation).

**Conclusions:** The most common nursing diagnosis identified in the patients who participated in this study were suffering and spiritual distress. Impairment related to the ability to bathe, to dress/undress, and to clean the house were also notorious. Furthermore, there was a decrease in the presence of almost all diagnosis over time. Findings reinforce nurses' role in palliative care; particularly promoting suffering relief and spiritual support, and helping patients to fulfill their needs of self-care.

**Abstract number:** P1-085  
**Abstract type:** Poster

## Development of an Instrument to Assess the Capacity for Families to Provide Home Care in Portugal

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Some studies shows the importance of adequate family supports if palliative patients are to be cared for at home. Assessing their capacity to provide support is therefore an essential component of a home-based care plan. A Portuguese instrument, called the "Escala de Capacidade para Cuidar em Paliativos" (ECCP), has been developed to assess this capacity, taking into local culture and realities.

**Aim:** Explore the initial face and content validity of the instrument.  
**Method:** Instrument development occurred in phases. Items were based on a literature review and a framework emanating from previous work at a large Portuguese Centre by one of the investigators. The initial instrument was then reviewed by a panel of palliative care professionals (4 physicians, 5 nurses and a psychologist) as well as 10 family caregivers (Phase 1). Modifications were made to the instrument based on their input. The modified instrument was then reviewed by the panel using a mixed methods approach: a) "think aloud" qualitative method (cognitive debriefing) and b) a survey with a Likert Scale (1-5) in which the panel indicated their level of agreement with each item (Phase 2). A Content Validity Index (CVI) was used to assess the level of agreement between panel members on the items. After further modifications, the instrument was reviewed again by the same panel.

**Results:** Of the initial 58 items, 39 (67%) required further modifications. In phase 2 there was a high level of agreement between panel members; agreement on 47 items (I-CVI  $\geq 80\%$ ). This level of agreement increased with subsequent modifications. Some of the more challenging items included the role of the care (obligation or love) and the role of finances.

**Conclusion:** The results demonstrate early face validity of this new instrument. A large study with family caregivers is underway to provide data for further psychometric testing of the instrument; including internal consistency, item correlations, and exploratory factor analysis.

**Abstract number:** P1-086  
**Abstract type:** Poster

## Employing an Outcome Measurement Tool in a Palliative Care Unit of a Cancer Hospital in Brazil

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**Background:** Brazil has been classified, according to the International Observatory for End of Life Care (UK), as level 3b, which means there is isolated provision of Palliative Care. It was ranked 38th out of 40 countries in the Quality of Death Index, published by The Economist - Intelligence Unit (Singapore). Brazil has many developing Palliative Care teams but there is little knowledge about how to measure outcomes of care.

**Service Development:** The Palliative Care Unit at Barretos' Cancer Hospital is 7 years old and has 50 palliative care beds for cancer patients. Currently no outcome measure is used. The authors have begun searching for information about outcomes in Palliative care in order to apply them in our unit. Evidence from the PRISMA project supports the use of a validated scale to evaluate outcomes in palliative care. Following its suggestion, we have chosen POS which was recently been translated into Brazilian Portuguese.

**Methodology:** All patients referred to the Palliative Care Unit were considered eligible for evaluation, except patients exhibiting cognitive impairment. The POS was used at admission (time 1) and every week thereafter. For the evaluation, the first and the last measurement before discharge were used. Then, we have compared the average POS at time 1 (POS 1) and at discharge or death (time 2) (POS 2).

**Results:** There were 17 patients, 53% men; Lung 35%, Colon 17%. Analysis of POS 1 - at admission was: mean 16,41 Median 16. POS at discharge - mean 12,24 Median 12. This demonstrated a reduction of 25%,  $p=0,023$  (Paired Sample Test) and  $p=0,021$  (Wilcoxon).

**Discussion:** This evaluation raises questions about the meaning of the POS in this context and the interpretation of these findings across other centres.

**Abstract number:** P1-087  
**Abstract type:** Poster

## Health-related Quality of Life among Breast, Prostate and Colorectal Cancer Patients Receiving Palliative Care

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**Aims:** To explore health-related quality of life (HRQoL) in breast (BC), prostate (PCa), and colorectal cancer (CRC) patients receiving palliative care, to compare the results of different HRQoL instruments, and to explore predictors of poor HRQoL.

**Methods:** Patients for this cross-sectional observational study were recruited from the Helsinki University Hospital palliative units and from a hospice in the Helsinki area. HRQoL was assessed using two generic instruments, the 15D and the EQ-5D-3L including its visual analogue scale (VAS), and the cancer-specific EORTC QLQ-C30. In addition, clinical and demographic information was collected. A linear stepwise regression model, including clinical and demographic factors, and EORTC symptoms as explanatory variables, was used to assess predictors of poor HRQoL.

**Results:** 138 palliative care patients were included in the analysis. Of them 27 had BC, 39 PCa, and 73 CRC. The mean age was 70 (range 35-87), PCa patients being eldest. 47 of the patients died within three months after having answered to the questionnaire and 46 within three to six months after the response. The mean HRQoL scores varied widely depending on the instrument used. The mean score (SD) measured with 15D, was 0.73 (0.14) with EQ-5D 0.56 (0.33), and with VAS 53.2 (20.9), respectively. Fatigue was the most common symptom, closely followed by pain and insomnia. Closer to death, the role of fatigue, dyspnoea, appetite loss, and constipation increased. In the regression model the most important factors predicting deteriorated HRQoL of life turned out to be fatigue and financial difficulties, which was associated with depression.

**Conclusion:** All instruments used in the study are applicable to evaluate palliative care patients' HRQoL, but the values they provide differ substantially. In addition to cancer symptoms also financial difficulties had a clear negative impact on HRQoL which needs to be taken into account when supporting palliative patients' HRQoL.

**Abstract number:** P1-088  
**Abstract type:** Poster

## Development of a New Screening Tool for Delirium, Depression and Dementia

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**Background:** The improvement of quality of life is a predominant destination in palliative care. To achieve this goal, management of physical and psychological distress is required. Delirium, depression, and dementia (the 3Ds) are major psychiatric problems in the elderly. These problems are frequently underdiagnosed or misdiagnosed. Our purpose is to develop a tool screening for the 3Ds (3DST). The pilot study were presented at 17th congress of Japanese Society of Palliative Medicine. We will present the data with more patients.

**Method:** A cross-sectional survey was conducted of adult cancer patients who were admitted to the palliative care unit, St. Luke's International Hospital, Tokyo. Nurses evaluated patients using the newly developed tool. The diagnosis of a psycho-oncologist based on DSM-IV was used as a gold standard to calculate sensitivity and specificity.

**Results:** Fifty seven patients out of 97 admitted participated in the study. Forty patients were excluded because of illness or no consent. The sensitivity and specificity were 0.53 (95%CI: 0.30-0.75), 0.95 (0.84-0.99) for delirium, 0.50 (0.28-0.70), 0.93 (0.80-0.98) for depression, and 0.67 (0.35-0.88), 0.98 (0.89-1.0) for dementia, respectively. The positive and negative predictive value were 0.80 (95%CI: 0.49-0.94), 0.85 (0.72-0.93) for delirium, 0.73 (0.43-0.90), 0.83 (0.69-0.91) for depression, 0.86 (0.49-0.97), 0.94 (0.84-0.98) for dementia.

**Discussion:** This tool, to our knowledge, is the first tool screening for the 3Ds simply and concurrently. Because it has a sensitivity of over 50% for the 3Ds, routine use of the tool facilitates capturing more than half of patients with any of the 3Ds. Because it has a high specificity, the tool can be useful to distinguish between the 3Ds.

**Conclusion:** We developed a new, simple screening tool, 3DST, to assess delirium, depression, and dementia in palliative care setting. Further investigations to test reliability and validity are needed.

**Abstract number:** P1-089  
**Abstract type:** Poster

## Application of Single-items for Measuring Quality of Life in Children with Life-limiting Conditions - At which Age Does it Work?

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**Introduction:** Preserving the highest possible quality of life (QOL) is of major importance in pediatric palliative care (PPC). For the evaluation of different therapies or procedures methods are needed, that are able to assess ones quality of life efficient and accurate. Multiple-item indices are time-consuming and have other disadvantages like high complexity, hampering them from regular application in PPC. Single-items (SI) have the advantage of simplicity and time-effectiveness, and can be therefore used in longitudinal studies. On the other hand abstract thinking is required for some SI, which makes it difficult to use in young children. For evaluation of SI in measuring QOL in children 8 years or older with life-limiting conditions three different SI were used and analyzed for different age-groups.

**Materials and methods:** Three different SI were used (visualized as visual analogue scale) to assess quality of life, in a group of 101 children (age range: 8-18 years) with life-limiting conditions, defined according to ACT (Association for Children with Life-threatening or Terminal Conditions and their Families 2003). For comparison two validated and widespread multiple-item indices have been used (KINDL, Kidscreen-27).

**Results:** There were significant variations of correlation-coefficients between all three SI and the multiple-item indices for the different age groups. An age dependent increase of correlations was not observed. Mean correlations varied between 0,3 - 0,47, age specific correlations varied between 0,05 - 0,74.

**Discussion:** We could observe significant differences between the age-specific correlation-coefficients of the different SI and the multiple-item indices, although there was no general tendency related to the correlation coefficients and age. Therefore we conclude that the used SI are applicable from 8 years of age. Further studies are needed to determine the value of a SI in measurement quality of life in pediatric palliative care.

Abstract number: P1-090  
Abstract type: Poster

### Validation of the Palliative Prognostic Index and the Palliative Prognostic Score in an Inpatient Palliative Care Team Setting

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**Aim:** This study aims to clarify the predictive value of two prognostic prediction tools, the palliative prognostic index (PPI) and the palliative prognostic score (PaPS), in an inpatient palliative care team setting.

**Methods:** This prospective cohort study, conducted from July 10, 2009 to December 12, 2011, includes all patients older than 18 years, hospitalized with an advanced cancer, and referred to the palliative care team in an acute hospital in Japan; two hundred forty-seven patients are included in the PPI study, and 187 patients are included in the PaPS study.

**Results:** For PPI validation, the sensitivity (Sn) and specificity (Sp) of predicting survival for less than 3 weeks with a cut off PPI > 6 are 63% (95% CI: 50-75) and 91% (95% CI: 86-94), respectively; the positive predictive value (PPV) and negative predictive value (NPP) are 0.89 (95% CI: 0.83-0.93) and 0.69 (95% CI: 0.55-0.80). The Sn and Sp of predicting survival for less than 6 weeks with a cut off PPI > 4 are 80% (95% CI: 73-85) and 64% (95% CI: 54-73); the PPV and NPP are 0.76 (95% CI: 0.68-0.82) and 0.71 (95% CI: 0.60-0.79). The difference in survival is highly significant ( $p < 0.001$ ).

For PaPS validation, 30-day survival rates are 88.1% in group A (PaPS: 0 to 5.5), 55.2% in group B (PaPS: 5.6 to 11), and 5% in group C (PaPS: 11.1 to 17.5). The median survival is 94 days (95% CI: 76.6-111.4) for group A, 38 days (95% CI: 12.9-63.0) for group B, and 14 (95% CI: 6.2-21.8) for group C. Again, the difference in survival was highly significant ( $p < 0.001$ ).

**Conclusion:** The results suggest that although PPI and PaPS successfully divide patients into three groups with significantly different survival times, discrepancies exist between the original studies done in a hospice setting and the current study in predicting the actual length of survival.

Abstract number: P1-091  
Abstract type: Poster

### Measuring Pain and Comfort in Dementia at the End of Life

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**Aims:** To map and compare items and domains covered by tools to assess pain and comfort in severe dementia or dementia at the end of life.

**Methods:** We examined each individual item and descriptors if available in thoroughly tested tools to assess pain (PAINAD, PACSLAC, Doloplus) and comfort (including discomfort and quality of life; DS-DAT, DisDAT, EOLD-CAD, QUALID). Three independent raters, a nurse, psychologist and epidemiologist undertook a conceptual analysis, classifying all items into domains, without referring to pre-existing frameworks.

**Results:** All raters identified physical, social, behavioural, and ADL domains. However, there was less agreement on a psychological domain; on distinguishing between "affect" and "mood," and on the categorizing as "behavioural," "social," or "spiritual." Further, it was difficult to classify items that referred to different levels of observation: those requiring exact observation of vocalisation, facial expression or body language (e.g., frowning, leans to side) versus items indicating changes, or broader concepts requiring some interpretation (e.g., angry, peace).

Studying the specific tools, the differences between pain instruments (e.g., PACSLAC and Doloplus in addressing facial expressions) may be larger than between a pain tool and a comfort tool (PAINAD and DS-DAT). Regarding items, "guarding" was only included in a pain tool. The largest differences concerned additional items in comfort tools, such as "positive" items (eye contact, content facial expression, relaxed body language), and items indicating other concepts (sadness and fear).

**Conclusion:** Pain and comfort tools cover almost identical

domains. Comfort tools include a broader item pool. Some items (lack of positive indicator) may be tested for additional value to pain instruments. Further concurrent testing of pain and comfort tools is needed to assess validity of each item for measuring pain or (dis)comfort.

Abstract number: P1-092  
Abstract type: Poster

### C - Reactive Protein (CRP): An Important Prognostic Indicator in Solid Tumors

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**Introduction:** CRP, a non-specific marker of inflammation, may help cancer prognostication. We observed if solid tumors were related to high CRP. Clinical predictors if correlated with CRP were evaluated. We retrospectively examined associations between CRP levels and survival.

**Methods:** Review of electronic medical records (EMR) was conducted. Data included multiple CRP measurements at a tertiary cancer center (2006-2011). Hematological cancer diagnoses excluded. Survival defined as day from highest CRP level to date of death. CRP reported as median (25<sup>th</sup>, 75<sup>th</sup> percentile). CRP reference range 0-10 mg/L.

**Results:** N=6809 with solid tumors were identified. 56% were males. 83% were Caucasian and 15% African American. Cancer types were genitourinary (GU) 29%, breast 14%, gastrointestinal (GI) 14%, and lung 7%.  $\geq 1$  CRP and survival data available for 462. The highest median CRP = 5.1 (1.3, 12.1). Highest CRP for GI, GU, lung, breast = 7.7 (2.4, 15.2); 5.7 (1.8, 14.8); 3.2 (0.6, 8.1); 2.1 (0.7, 4.8). The median survival = 13.1 (7.9, 30.1); 18.4 (10.7, 33.2); 15.9 (8.0, 27.2) and 25.3 (14.9, 40.9) months respectively.

**Conclusions:**

1. Highest CRP levels (within the reference range) were for GI, GU, lung, breast cancers
2. Inverse relationship between absolute CRP value and survival
3. High CRP level associated with shorter prognosis across primary sites
4. (High) normal CRP value may be an adverse prognostic indicator in solid tumors

Abstract number: P1-093  
Abstract type: Poster

### Daily Assessment of Seven Important Cancer Symptoms: Challenges and Opportunities

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**Background:** Symptom assessment is a challenge, as cancer patients are often polysymptomatic. Symptom assessment tools should be practical and acceptable for patients particularly in repeated assessments.

**Objectives:**

- 1) Focus regular assessment on 7 identified clinically important symptoms
- 2) Examine the completion rate of daily systematic symptom assessments in advanced cancer
- 3) Assess the prevalence and severity of 7 important cancer symptoms

**Methods:** All admissions to an acute care palliative medicine unit were screened for eligibility. A 7-item categorical symptom survey was conducted consecutively throughout their stay. Symptom survey included

- 1) confusion
- 2) constipation
- 3) loss of appetite
- 4) nausea/vomiting
- 5) pain
- 6) shortness of breath
- 7) trouble sleeping.

Symptom severity was graded as mild, moderate, severe. **Results:** 47 cancer patients were screened; 31 were eligible. Reasons for ineligibility: 7 declined, 5 too ill, 2 language barrier, 1 readmission, and 1 dying. Among study participants, 52% female; median age 57 (52, 64) years; 77% Caucasian, 23% African-American. Most common cancers: respiratory 9 (29%); gastrointestinal 7 (23%). 251 assessments were conducted in 26 days; complete 203 (81%); partial 34 (14%); 14 (5%) not done (for various reasons e.g., procedures). Overall symptom prevalence: pain (79%); loss of appetite (40%); trouble sleeping (32%); shortness of breath (29%); confusion (23%); nausea or vomiting (19%); constipation (16%). Intensity was predominantly severe for nausea/vomiting; moderate for constipation, loss of appetite, pain, trouble sleeping; mild for confusion,

shortness of breath.

**Conclusions:**

- 1) Pain was the commonest symptom; nausea/vomiting most severe
- 2) Complete/partial completion rate was 95% for a daily repeated 7-item categorical systematic cancer symptom assessment
- 3) A categorical scale focused on clinically important symptoms was practical and acceptable even in very ill patients.

Abstract number: P1-094  
Abstract type: Poster

### Palliative Care Index - A Measurement Tool

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There is a need for a scoring system palliative care (PC) programs can use to track their adherence to national guidelines. In order to provide a quantitative measure, and longitudinal tracking system, of structure and process indicators for PC programs, we developed a novel instrument, the Palliative Care Index (PCI). The PCI was constructed by integrating the following consensus recommendations. CAPC: Crosswalk of National Quality Forum Preferred Practices, National Palliative Care Registry, Consensus recommendations-consultation service metrics; VHA: ICU Palliative Care Quality Measures. The PCI was reviewed by a national team of PC experts. The PCI consists of 16 dimensions (10 points each). Eight domains assess structure: interdisciplinary team, availability, care coordination, record availability, committee, training, certification, and team wellness. Eight domains measure process: symptom assessment, expired patients receiving consult, usage of PC screens, follow-up, post-discharge services, bereavement contacts, marketing, and family-centeredness. To represent the program's score, a "flowergram" is created, consisting of 16 petals, each representing one domain. Petal length represents the amount of points earned in the domain. The PCI was piloted in nationwide. Hospitals (n=17) had totals ranging from 19 to 107 (160 points possible; median=70; mean=59). Scores related to number of PC consultations performed ( $r = .51, p < .05$ ).

Abstract number: P1-095  
Abstract type: Poster

### To Transfuse or Not to Transfuse? - That Is the Question

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**Background:** Patients with advanced disease may require blood transfusion as part of on-going symptom management. To evaluate the effectiveness of this intervention an audit was undertaken with a specialist palliative care unit, reviewing documentation & recording of pre & post transfusion symptoms & initial haemoglobin concentration. Comprehensive symptom assessment both before & after transfusion is essential to assess response to transfusion. Disease related fatigue is often significant in this patient group thus it is important to monitor the clinical impact of this intervention to ensure benefits of transfusion outweigh burdens. Does the recording of symptoms prior to & following transfusion improve patient care & allow for treatment only when benefit is likely?

**Method:** Initial audit to determine recording of symptoms present both prior to & following transfusion against standards of pre-transfusion symptom recording, benefit vs burdens conversation prior to transfusion recording & post transfusion symptom relief recording. A random sample retrospective case note review of clinical details were reviewed in 10 patients who received blood transfusions. Re-audit was carried out following staff education & discussion to complete the audit cycle.

**Results:** An improvement in symptom recording alongside a slight improvement in burdens benefits conversations recorded & post transfusion follow up was shown on the second cycle. Documentation was adapted to allow for specific recording of symptoms & for benefits/burdens of procedure discussions & post transfusion follow up appointments are now given at the time of transfusion. **Conclusion:** This audit has enabled an improvement in hospice procedure around recording & documentation of symptom change enabling easier identification of benefit & facilitating discussion around blood transfusions.

**Audit & quality control**

Abstract number: P1-096  
Abstract type: Poster

**Factors Affecting Continuity of Care from Mulago Hospital Palliative Care Unit**

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**Aim:** The study explored factors affecting continuity of care following discharge from the hospital by the palliative care unit at Mulago Hospital, Kampala. The study objectives were to find out the factors that affect continuity of care and to what extent these factors affect the continuity of care. Our secondary objective was to understand the patient and carer experience following referrals.

**Methodology:** This was a qualitative study using semi structured interviews for (13) patients and carers based on the phenomenological approach. Data was collected using telephone interviews for both patients and the carers which were recorded, transcribed and thematic evaluation undertaken.

**Results:** The findings of the study indicate the following factors; referral pathways and expectations, patient and carers' understanding of illness, health seeking behaviour, unrealistic promises, communication about practical issues on discharge, infrastructure, poverty and transport costs, pain relief, discharge planning, age, spiritual and cultural issues, family support. The results also indicated that these factors were interrelated with one complicating the other.

**Discussion:** Important issues which affect the experience of patients and carers include; the patient's general condition on discharge, the lack of available financial and family support with high expectations which are unrealistic affected continuity of care. Further more, patient and carer understanding of illness, spiritual and cultural issues and identified practical issues during discharge planning will all affect continuity of care.

**Recommendations:** There is need for proper communication, documentation and established functional referral system and community sensitization.

Abstract number: P1-097  
Abstract type: Poster

**Successful Recognition of Patients Entering the Terminal Phase and Use of the LCP - Retrospective Audit of All Adult Ward-based Deaths within an Inner City Teaching Hospital**

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**Aims:** As part of the UK initiative in improving end of life care our local target is that 25% of expected deaths within the hospital should be supported with the LCP (Liverpool Care Pathway). The aim of this audit was to ensure the hospital was achieving the target and whether involvement of the palliative care team affected rates of deaths of the LCP.

**Methods:** Retrospective audit conducted quarterly looking at all adult deaths occurring within the hospital setting over a one month period. Eligible deaths were identified through examining the medical records held in the bereavement service.

**Results:** A series of five months was audited. 277 eligible deaths were identified, cancer was the primary cause of death for 77 (27.8%) of patients, with 41 (14.8%) of patients dying from either end stage chronic obstructive pulmonary disease or heart failure. Over 60% of patients were appropriately recognised as entering the dying phase and commenced on the LCP, clinicians were better at recognising patients dying from cancer with almost 85% of eligible deaths occurring with the patient on the LCP. All adult medical and surgical wards within the hospital achieved over 50% of eligible patients dying whilst supported by the LCP. 126 (45.5%) patients were known to the palliative care team of which 82% were eligible to be on the LCP and 83% (85/103) were placed on the pathway. Palliative care was involved in 90% of deaths where cancer was the primary cause and only just over a quarter of all other deaths.

**Conclusions:** The results reported here show that hospital teams are still not recognising when patients are dying from a non-malignant condition. It was also noted teams would recognise someone was deteriorating however, fail to make the final step and place a patient on the LCP. This could be due to a lack of confidence in diagnosing dying or a lack of understanding about when to use the pathway. This highlights the need for ongoing education.

Abstract number: P1-098  
Abstract type: Poster

**Permission Granted**

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**Aims:** Hospice at Home service works with community services to fill gaps in end of life care for patients whose preferred place of care is home. Care is provided predominantly by health care assistants, and a small number of registered nurses (RNs). RNs receive consent training in their nursing studies.

The aim was to achieve a standard of 100% that all hospice at home care plans should clearly state 'consent status documented for all care interventions given.'

Consent to valid treatment and care is central in all forms of healthcare: patients have a fundamental, legal and ethical right to determine what happens to them.

Many patients are unconscious and unresponsive when care interventions occur. Hospice policy states 'Consent status must be documented for all personal and invasive procedures.' It was difficult to see at a glance if consent status was recorded in the care plan.

**Method:** A retrospective (random) audit of 204 care plans was performed to determine if consent status for personal care was documented. Confidentiality was maintained at all times. 77% records completed by HCAs and 23% by RNs

**Result:**  
**Cycle 1** -74% of care plans had consent status recorded. 26% records had no evidence of consent status documented. Further analysis identified only 37% of RNs had recorded consent status.

Training needs were identified and implemented in various ways to include Consent, Mental Capacity Act (2005), and Record keeping.

**Cycle 2** Re-audited 6 months later using same criteria and data collection tools.

-93% of care plans had consent status recorded for personal care, improvement in the number of RNs recording consent status- 77%.

**Results:** Care plans now checked daily to identify staff not adhering to policy.

The need to replicate audit in other areas of the Palliative Care Services was highlighted.

Induction and in-service training now includes education on consent and good record keeping for all grades of staff. Re-audit in 12 months to ensure improvement continues

Abstract number: P1-099  
Abstract type: Poster

**An Audit of the Provision of Anticipatory Medications in the Community for End of Life Care**

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**Background:** Many patients approaching the end of life express a wish to die at home. As health professionals, it is important to support and facilitate this through anticipatory prescribing of medications which are commonly needed at the end of life, as this can then alleviate distressing symptoms readily. Therefore, the prompt and timely acquiring of these medications is vital to support patient's to die in their preferred place of care, home.

**Methods:** Retrospective case note review of all hospice patients who died within the community team's caseload during a 6 week period.

**Results:** 38 patients were identified with 21 having confirmation that anticipatory medications were in the home prior to death. Of the remaining 17 patients, documentation did not support their provision. 52% (11/21) of those prescriptions were initiated by the hospice, with an interval between day requested and patient death of 1 to 287 days. For 7 of the 11 patients, a community prescription form was also requested by the hospice team. Interestingly, of the 38 patients, 6 (16%) of them had non-malignant diagnoses, and 3/6 (50%) had anticipatory medicines in the home.

**Conclusions:** 45% of patients did not have anticipatory medications in the home according to hospice records. The reasons for this varied, with clear evidence for the need to improve practice. Requesting a community prescription form is fundamental in the delivery of adequate symptom control, but was not done in every case. Diagnosis (malignant vs. non-malignant) made no difference in the prescribing of anticipatory medications. 4 (10%) patients whom did not have anticipatory medications in the home needed interventions from the out of hours community teams. Recommendations for practice need to be communicated with the wider teams, in particular community and hospital settings, as this would significantly impact on the importance of appropriate and timely prescribing of anticipatory medications.

Abstract number: P1-100  
Abstract type: Poster

**Basic Quality Indicators for Palliative Care Services in Portugal: Ethical and Legal Aspects of Care**

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Ethical and Legal Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study.
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.
- The criteria to determine the agreement and consensus were:
  - Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0.
  - High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
  - Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
  - Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- To define the standard we use the median rating on the 10-point scale (10-100%)
  - Only the indicators that obtained the classification of very-High or High were chosen

**Results:**

- A total of 11 from 11 quality indicators were defined.
- These indicators 3 are of structure, 7 of process and 1 of outcomes (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 11 basic quality indicators which belong to the domain of "Ethical and Legal Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

Abstract number: P1-101  
Abstract type: Poster

**Basic Quality Indicators for Palliative Care Services in Portugal**

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- Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
- High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
- Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
- Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- Only the indicators that obtained the classification of very-High or High were chosen
- To define the standard we use the median rating on the 10-point scale (10-100%)

**Results:** A total of 101 from 120 quality indicators were defined (22 of structure, 63 of process and 16 of outcomes). 33 quality indicators belong to the domain "Structure and Process of Care"; 16 to the domain "Physical Aspects of Care"; 14 to the "Psychological and Psychiatric Aspects of Care"; 9 to the "Social Aspects of Care"; 3 to the "Spiritual, Religious and Existential Aspects of Care"; 2 to the "Cultural Aspects of Care"; 13 to the "Care of the Imminently Dying

Patient" and 11 to the "Ethical and Legal Aspects of Care".  
**Conclusions:** We found a total of 101 basic quality indicators which must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered.

**Abstract number:** P1-102  
**Abstract type:** Poster

**Basic Quality Indicators for Palliative Care Services in Portugal: Social Aspects of Care**

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Social Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI), and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively
- The criteria to determine the agreement and consensus were:
  - Very high:  $\geq 80\%$  of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
  - High:  $\geq 80\%$  of agreement + Median rating  $\geq 4$  on the 5-point agreement scale + IQR = 1
  - Moderate: Median rating  $\geq 4$  on the 5-point agreement scale +  $60\% - 79\%$  of agreement + IQR = 1
  - Low: Median rating  $< 4$  on the 5-point agreement +  $< 60\%$  of agreement + IQR  $> 1$
- To define the standard we use the median rating on the 10-point scale (10-100%)
  - Only the indicators that obtained the classification of very-high or High were chosen

**Results:**

- A total of 9 from 11 quality indicators were defined.
  - These indicators 1 are of structure and 9 of process (their description and standard will be done in the presentation).
- Conclusions:** We found a total of 9 basic quality indicators which belong to the domain of "Social Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P1-103  
**Abstract type:** Poster

**Evaluating and Developing End of Life Care Across Central and Eastern Cheshire for People with Dementia and Carers**

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Dementia is now recognised as a life limiting illness. Palliative and end of life care for this group is high on the national agenda in the UK. Dementia is predominantly a disease of older age with Central and Eastern Cheshire having one of the largest and fastest growing older populations within the UK. As a result it is anticipated large numbers of older people with dementia will require support in this geographical area in the future. This project is exploring current service provision with a view to developing a specialist service. This paper will outline early, interim results and recommendations.

**Aims:** Explore current service provision. Develop a new specialised service.

**Methods:** Interviews, questionnaires and focus groups with a range of formal and informal carers who care for people with dementia in the last year of life and time surrounding death.

**Results:** This project is ongoing until July 2013. Early and interim results indicate there are several initiatives, in a variety of care environments considering palliative and end of life care for this group within the geographical area. However, problems exist with current systems that will require addressing.

**Conclusion:** There is currently no specialist service provision within Central and Easter Cheshire for people with dementia and their carers. Early results indicate a specialist palliative

and end of life care service for people with dementia is required. This would facilitate the provision of improved care at this difficult time for people with dementia and the range of carers who support them.

**Abstract number:** P1-104  
**Abstract type:** Poster

**Characteristics, Outcomes and Symptom Prevalence of Patients Referred to a Community Based Palliative Care Consult Team**

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**Aim:** Our community based palliative care consult team, part of a comprehensive integrated Palliative Care service delivery model, provides consultation to patients in their homes, smaller community based hospitals, long term care facilities and hospices, in an urban and rural area with an estimated population of 1,15 million inhabitants. We use standardized assessments, with the referral and assessment data entered into a program-wide electronic database; the data is used to enhance clinical practice and inform administrative reporting and decision making. The aim of this study was to examine referral and patient demographics, symptom prevalence and acuity, as well as referral outcomes, over a three-year period.

**Method:** Anonymized data was reviewed for all referrals to the Palliative Community Consult Team for a period of three years.

**Results:** Referral numbers have increased steadily over three years. Referrals for patients with non-cancer diagnoses have increased consistently during the study period. Patients at home have a lower symptom burden as measured by the Edmonton Symptom Assessment System and less complex pain syndromes as reflected by incidence of neuropathic pain, incident pain and psychosocial factors, when compared to patients in community hospitals. The number of follow-up visits has shown wide variation, with an increase in telephone follow-ups noted. The number of patients admitted to hospice units has increased.

**Conclusion:** Demonstrating the increase in workload and patient acuity as shown by these results which are based on standardized assessments and systematic data, is useful to ensure that the appropriate resources are available for the care of patients with life-limiting illnesses, both with cancer and non-cancer diagnoses. The existence of a rich, well-maintained data base is essential to the provision and evaluation of palliative care services.

**Abstract number:** P1-105  
**Abstract type:** Poster

**Dying Peacefully in Residents with Dementia in Long-term Care Facilities: A Good Quality Indicator?**

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**Background:** Little is known about whether people with dementia die peacefully. This may be influenced by the (palliative) care provided. If so, dying peacefully may serve as a quality indicator for palliative care in dementia.

**Aims:**

- (1) To describe the proportion of residents with dementia in long-term care facilities that dies peacefully.
- (2) To explore whether the available quality indicator "the percentage of relatives who indicate that the patient died peacefully" captures quality differences between different care facilities and hence is a discriminative and useful indicator.

**Methods:** We used written questionnaires about quality of dying completed by families and physicians in the Dutch End of Life in Dementia study, performed in 34 long-term care facilities in the Netherlands between January 2007 and July 2010.

The percentage of residents dying peacefully was

calculated for each facility and Generalized Estimating Equation models were used to explore associations between long-term care facility characteristics and the proportion of peaceful deaths.

**Results:** Relatives of 233 residents with dementia indicated that the resident died peacefully in 56% of cases. This percentage ranged from 33-85% across facilities. This range points to the discriminative power of this quality indicator, enabling a comparison of care provided by long-term care facilities to residents with dementia. Residents were more likely to have died peacefully in facilities with a moderate (versus no) "perceived influence of religious affiliation on end-of-life decision making", and when "family finds staffing sufficient".

**Conclusion:** According to their relatives, about half of Dutch people with dementia die peacefully. This proportion varies between care facilities. Differences in scores appeared to be related to characteristics of the long-term care facilities, which suggests that the percentage of residents with dementia dying peacefully is an indicator of the quality of care in this setting.

**Abstract number:** P1-106  
**Abstract type:** Poster

**An Audit of Opioid Prescribing at a Large Teaching Hospital**

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**Introduction:** In 2008, the National Patient Safety Agency (NPSA) issued guidance on the prescribing, dispensing and administration of opioids. The report was prompted by reports of 5 deaths and over 4,200 safety incidents.

**Aims and objectives:** To undertake an audit to assess whether prescribing of opioids (schedule 2 or 3 controlled drugs) in patients with malignant disease is consistent with the NPSA alert and the new guidance set out by National Institute of Clinical Excellence (NICE) CG140.

**Method:** This was prospective audit which took place over a four week period. All medical and surgical wards were covered. Suitable patients were identified by ward pharmacists.

**Results:** Data was collected for 30 patients. The majority 21 (70%) of patients were prescribed opioids prior to admission. Of these, 80.9% were prescribed the same opioid as they were taking prior to admission. Only 66.7% of the 30 patients were prescribed an opioid for rescue medication and one third of these received inappropriate doses. In 53.3% (n=16), regular laxatives were prescribed; in contrast, 73.3% (n=22) received anti-emetics, either regular or on a 'when required' basis.

Of the patients initiated on an opioid at admission (n=9), 66.7% were commenced on regular sustained release morphine, with the majority (83.3%) prescribed a daily dose of 20-30mg. All these patients were offered an appropriate opioid at an appropriate dose for rescue medication. The results showed 70% of the initial prescribing was undertaken by FY1 doctors at the trust.

**Discussion:** Two fundamental issues were highlighted by the audit. Firstly, the audit identified a concern relating to the prescribing of an opioid for rescue medication. Secondly, the audit highlighted the need to address one of the most common adverse effects of opioid therapy - constipation. Since initial prescribing of opioids was undertaken mainly by junior doctors, the audit emphasises the need for further education and training.

**Abstract number:** P1-107  
**Abstract type:** Poster

**"Please Describe a Typical Case of an Error in Palliative Care" - Qualitative Results of a Survey in Palliative Care Professionals**

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**Context:** Patient safety is a relevant concern in medicine and handling of medical errors poses a challenge. In palliative care, the definition and understanding of an error is particularly difficult, and there is only scarce empirical evidence about the special nature and causes of medical errors in this discipline.

**Objectives:** We aimed to explore palliative care professionals understanding of what constitutes an error and what possible areas and consequences of errors in palliative care might be.

**Methods:** In the context of a mixed-methods survey among

all palliative care institutions in the region of Bavaria, Germany (n=168), we asked various professionals to describe a typical case of error in palliative care. One item of the questionnaire offered free text answering. This data was qualitatively analysed according to the summarizing content analysis of P. Mayring, and categories for areas and causes of errors were extracted.

**Results:** The questionnaire was returned by 42% (n=70) of professionals. One third of the respondents (n= 42) described typical errors in palliative care. Seven different potential areas for errors were identified: drug treatment, palliative sedation, communication, care organisation, treatment plan, end-of-life care, and history taking. Six categories emerged as causes of errors: miscommunication, system failure, dysfunctional attitudes, lack of knowledge, wrong use of technology and misjudgement.

**Conclusion:** Our data shows the broad diversity of errors and their causes in palliative care. The importance and mentioning of errors other than pharmacological symptom control, in particular errors in communication, may be characteristic for the understanding of "error" within palliative care. Further qualitative research, including the perspective of patients and families on the topic, is warranted in order to be able to prevent those errors and enhance patient safety.

**Abstract number:** P1-108  
**Abstract type:** Poster

**Audit of Steroid Prescribing and Monitoring in an Inpatient Specialist Palliative Care Unit (SPCU)**

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**Aims:** Steroids are frequently prescribed in palliative care for a variety of indications. They can provide significant benefits however they are associated with undesirable effects and drug interactions. It is important to:

- 1) consider potential benefit versus risk;
- 2) use the lowest effective dose for the least possible time;
- 3) discontinue if no clinical benefit. Inconsistencies in steroid prescribing and documentation were noted in our SPCU and therefore an audit was done to assess adherence to network and national guidelines.

**Methods:** Retrospective case note review of admissions to a SPCU over 3 months using a data collection proforma in patients identified as taking steroids

**Results:** 74 admissions, 69 case notes reviewed of which 61% were taking steroids (76% admitted on steroids, 24% started during admission). Indication and duration of steroids not documented in 26% and 31% respectively. 79% had steroids reviewed within 7 days and in 12% steroids stopped or weaned as no benefit. 79% patients were taking PPIs. 26% were on concomitant NSAIDs, 1 patient not on a PPI. 4 patients on enzyme inducing anti-epileptics, none of whom had steroid doses adjusted. 50% had blood glucose monitoring, 1 developed hyperglycaemia. 16 patients in the end of life situation, 8 of whom did not have benefit/burden of continuing steroids clearly documented. 20 patients discharged on steroids, 18 of whom had a documented plan for ongoing steroid management. No steroid cards issued.

**Conclusion:** The audit demonstrated that steroids were reviewed appropriately in most cases but documentation in certain areas was lacking. Recommendations are: a weekly drug chart review with the pharmacist to identify appropriate dose adjustments; written prompts on the drug chart; blood glucose monitoring at least weekly on all patients on steroids; steroid cards for patients taking corticosteroids for >3 weeks. The plan is to develop local guidelines for steroid prescribing and monitoring to improve practice.

**Abstract number:** P1-109  
**Abstract type:** Poster

**Successful Implementation of a National Research and Quality Assurance Database: The Danish Palliative Care Database (DPD)**

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**Aims:** The Danish Palliative Care Database (DPD) was launched in 2010, and is one of the few national registries aiming to include ALL patients referred to specialised palliative care (hospice and palliative care teams/units), irrespective of whether they are admitted or not. The aims were to analyze the feasibility, data completeness, and the results of the DPD for the first two years, 2010-11.

**Methods:** A web-based data reporting system was established for the specialised palliative care units. Additional data were extracted from the Danish Patient Register. These data form the basis for five quality indicators. The completeness of DPD was determined by comparing these databases.

**Results:** In 2010, all 36 units in Denmark reported their patients; totally N=6,041 cancer patients were referred (3.8% had other diagnoses). DPD patient completeness was > 95.7%. Completeness of reported data was 98.6%. Results for the five quality indicators:

- (1) 76.5% of the referred patients were admitted (Standard (S)=75%);
- (2) 81.5% were admitted within 10 days from referral (S=90%);
- (3) 27.6% of all patients dying from cancer were admitted (S=35%);
- (4) 38.1% were screened with QLQ-C15-PAL (S=50%);
- (5) 39.8% were discussed at a multidisciplinary conference (S=80%).

There were very large regional and inter-institutional differences. Results for 2011 showed increased activity (7,891 patients referred), and small improvements in 4 of the 5 quality indicators. Survival from referral to death was median 31 days (hospice 18; palliative teams 41), mean 67 days (hospice 43, teams 80).

**Conclusion:** A national database with exceptionally high data completeness was established. Standards were met for 1 of 5 indicators. Results are clinically meaningful, showing marked variations in quality according to the five indicators between regions and units, and small improvements over time. It is expected that DPD will contribute to securing Danish patients equal access to high quality palliative care.

**Abstract number:** P1-110  
**Abstract type:** Poster

**Care Home Sweet Care Home: An Audit of Hospital Attendances from Care Homes**

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**Aim:** 1.5% of the population in this retirement area, reside in 109 care homes. Nationally, the proportion of deaths occurring in care homes is increasing (22% in 2010), but it is unclear why the number of local people transferred from care home to hospital appeared not to be reducing. Local Clinical Commissioning Groups (CCG) commissioned an audit to understand the reasons for, & identify whether measures could be put in place to reduce, the number of hospital admissions.

**Design:** The agreement & assistance of all care homes, hospital departments & GP practices were obtained. All acute hospital, care home attendances, during October/November 2011 were identified & data collected from review of admission notes & a telephone interview with the care home.

**Results:** Of 366 identified attendances, 1/3 had resided in a care home for more than one year, over half had dementia & 1/3 had ≥3 co-morbidities. Despite the initial call for help being "in hours" the majority were assessed in hospital "out of hours". In over half, the initial call was directly for an emergency ambulance, yet 51% returned home in less than 24 hours suggesting community management may have been possible.

Since then, 29 care homes have participated in the Six Steps to Success programme. A care homes conference enabled staff to meet with hospital staff, CCG leads & other health & social care professionals & was well received. A supportive care register is embedded within the acute hospital & advance care planning training continued across the locality. The re-audit of some elements after 1 year will be available for this poster.

**Conclusion:** Understanding the circumstances of many short, acute hospital, attendances from care homes, has resulted in collaborative projects between care homes, primary, secondary & specialist palliative care, improved communication & guided Advance Care Planning promotion. Anticipating care needs & collaborative working should improve experience of care home residents.

**Abstract number:** P1-111  
**Abstract type:** Poster

**Regional Re-audit of the Management of Hypercalcaemia of Malignancy on behalf of the North West Audit Group (Palliative Medicine NWAG)**

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**Aims:** To assess the management of patients with hypercalcaemia of malignancy including fluid rehydration; checking and recording of renal function; medication review; timing, dose, dilution and rate of bisphosphonate treatment; timing of repeat blood calcium after treatment and to compare the results to those of the original NWAG audit carried out three years previously.

**Methods:** A multi-centred, cross-regional retrospective audit of case notes from patients with cancer and hypercalcaemia as defined by their local biochemistry laboratory. The original proforma was revised slightly in line with the latest evidence and disseminated to palliative care services in the region. The data was analysed centrally by NWAG and a combined and individual reports were disseminated to participating organisations.

**Results:** A total of 79 proformas were returned from ten organisations comprising four hospital sites and six hospice sites. Of the eight audit standards, there was an improvement in adherence to seven when compared to the original audit. The most significant change pertained to the correct dilution and rate of bisphosphonate infusion. The only lower standard was recording of a patient's eGFR prior to treatment. This may be because the standard was amended from the original audit to specify 'eGFR' rather than 'renal function'.

**Conclusion:** This re-audit demonstrates an improvement in the management of hypercalcaemia of malignancy across the region in the three years since the original audit. The results were disseminated to organisations for local action plans to be developed.

**Abstract number:** P1-112  
**Abstract type:** Poster

**Audit of Regional Metastatic Spinal Cord Compression Clinical Guidelines and Pathway**

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**Aims:** Metastatic spinal cord compression (MSCC) occurs in 10-15% of patients with vertebral metastases. It may cause paraplegia and loss of bladder and bowel function. Early investigation and treatment may limit or prevent irreversible neurological damage. Regional guidelines were introduced in May 2012 to support healthcare professionals in identifying and managing patients with suspected MSCC appropriately and urgently. The guidance also outlines the action that should be taken when MSCC is confirmed. This audit aims to assess adherence to these guidelines within an acute hospital.

**Methods:** A retrospective audit will be conducted to assess compliance with regional guidelines over a five-month period. Patients who have had Magnetic Resonance Imaging (MRI) of the spine for suspected MSCC, as well as those who have had an incidental finding of cord compression on MRI, will be identified. Their clinical notes will then be reviewed to assess whether the guidance and care pathway were followed.

**Results:** This audit is currently in progress and results are awaited.

**Conclusion:** It is intended to use the results of the audit to improve clinical practice and as the basis for education of health professionals in this area.

**Abstract number:** P1-113  
**Abstract type:** Poster

**Overcoming the Chaos: Terminology and Definition of Outcome Quality in Palliative Care**

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**Background:** In the intense discussion on outcome indicators in palliative care (PC) neither the terminology nor the definition of outcome quality (OQ) are applied



uniformly. The conception of a consistent terminology and a definition of OQ in PC that considers its multidimensional approach was the goal of this project.

**Methodology:** The theoretical foundation for the quality evaluation is the differentiation between constructs (latent variable), criteria (observable dimension) and indicators (measures).

Three preceding publications of the project team on aims and tasks of PC were analysed. Some aspects referred to constructs, and others described criteria for a high quality. Constructs were critically examined and items categorized as criteria were examined regarding their applicability to the already identified constructs.

**Results:** Constructs mentioned directly were "dignity", "autonomy", "spirituality and personality" as well as "quality of life". The criteria led to the identification of two additional constructs: "physical wellbeing" (symptom control, general physical wellbeing) as well as "social trust and care" (social interactions of the patient).

**Conclusion:** The evaluation showed that constructs are multidimensional and cannot be differentiated clearly from each other. Especially "quality of life" might not be an independent construct, and further evaluation is needed to describe how far it is included in other constructs or whether it might even be synonymous with the outcome quality of palliative care as such.

The next step in the project will be an investigation of the individual constructs and the identification of adequate criteria for each construct.

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**Abstract number:** P1-114

**Abstract type:** Poster

### Audit of Empirical First Line Antibiotic Therapy for In-patients at St. Andrews Hospice, Airdrie

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**Introduction:** Antibiotic usage within the hospice setting is increasing with the rise in elective admissions for symptom control, this is the first audit to review adherence to the regional policy in NHS Lanarkshire in the hospice setting. An antibiotic prescribing policy exists because antimicrobial resistance is increasing and this causes a threat to patient safety and increases risk of antibiotic associated infection.

**Aim:** The NHS Lanarkshire antibiotic prescribing policy is standard care for patients with infection at St. Andrew's Hospice, Airdrie. The purpose of the audit is to review first line antibiotic prescribing for in-patients at St. Andrew's Hospice, Airdrie to ensure prescribing meets the current standard.

**Method:** Retrospective analysis of patient kardex and notes, for admissions in months - August 2010 and October 2011. Results of cycle 1 were reviewed at a medical management meeting and practice re-evaluated. Changes were implemented and practise reviewed in cycle 2 October 2011.

**Results:**

1st cycle

60 patient admissions August 2010  
19 (32%) patients administered with antibiotic therapy  
• 22 courses of antibiotics in total administered - 6/22 (27%)  
• antibiotic prescriptions adhered to prescribing policy

2nd cycle

60 patient admissions October 2011  
15 (25%) patients administered with antibiotic therapy  
• 15 courses of antibiotics - 13/15 (87%) antibiotic prescriptions adhered to prescribing policy + 2/15 (13%) prescriptions not adhering to prescribing policy  
• 60% improvement in overall antibiotic prescriptions adhering to prescribing policy.

**Conclusion:** Antibiotic prescribing policy is practised in St. Andrew's Hospice and results of cycle 1 demonstrated an improvement was needed in compliance with antibiotic prescribing policy. After full implementation and distribution of policy to all wards and staff members, cycle 2 demonstrated an improvement in antibiotic prescribing.

**Abstract number:** P1-115

**Abstract type:** Poster

### Has the Liverpool Care Pathway Improved the Care of the Dying Patient in NHS Lanarkshire?

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The Liverpool Care Pathway ensures a high standard of care

for the patient in their last days of life.

**Aim:** Five years after its initial introduction this review provides an insight into the extent and standard of use of the LCP within NHS Lanarkshire.

**Method:** A retrospective analysis of deaths in the three acute NHS Lanarkshire Hospitals - Hairmyres Hospital, Monklands Hospital and Wishaw General Hospital during February 2012. Case records were reviewed for patients who had died.

**Results:**

166 patients died across the 3 hospitals in February 2012. 56 (34%) Patients were cared for on the LCP. The percentage of patients from each speciality cared for on the LCP was:

- 54 % of patients in medical wards
- 50 % of patients in surgical specialities
- 45 % of general surgical patients
- 41 % of patients in care of the elderly wards

The LCP was used mainly in patients with malignant disease:

- 45 % of patients with malignant disease were on the LCP.
- 28 % of patients with non-malignant disease were cared for on the LCP.

110 patients died not cared for using the LCP.

For the 56 patients on the LCP version 11:

- 73% of patients had non essential medications discontinued

As required medications for symptom control prescribed for:

- Pain in 91% of patients
- Agitation in 91%
- Dyspnoea in 82%
- Respiratory Tract Secretions in 82%
- Nausea and Vomiting in 79%

**Conclusion:**

In NHS Lanarkshire the LCP was used to care for less than 50% of patients who died in February 2012.

The LCP was mainly used for the palliation of patients with malignant disease. Less than a third of patients with non-malignant disease were cared for using the LCP.

This is disappointing as it has been shown worldwide that patients managed on the LCP receive a higher quality of care in their last hours and days of life.

When the LCP is used in NHS Lanarkshire it has been used appropriately and medications for relief of symptoms are prescribed in the majority of patients.

**Abstract number:** P1-116

**Abstract type:** Poster

### Blood Transfusions in Palliative Care: A Retrospective Audit

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Blood is a valuable resource. It is good practice to consider the clinical context and not just the patient's haemoglobin (Hb) level when considering transfusion. This is particularly true in the palliative setting. Accurate documentation of the process is an important aide to safe transfusion.

**Aims:** To assess:

1. Is blood being prescribed for an appropriate indication, as per national standards?
2. Are transfusions being documented appropriately?
3. Are transfusions achieving the desired outcomes?

**Methods:** The audit population were hospice in-patients who received transfusions of one or more units of blood over an 8 month period. There were a total of 41 units transfused to 15 patients over the designated time. An audit proforma was completed for each patient; results were compiled and compared to audit standards.

**Results:** The indication for the transfusion was documented in all patients, with more than one reason being given in 14 out of 15 patients. The most common reason cited was low Hb, with the range being 3.4 to 9.1. The most common symptoms cited as an indication were shortness of breath and fatigue. The outcome following transfusion was documented in 7 out of 15 patients and varied from clear symptomatic improvement to none. Out of the 15 patients, 9 died during the same admission. The range of time between blood transfusion and death was 5 to 32 days. The standard of documentation overall was good, with some areas highlighted for improvement.

**Conclusions:** Physicians are practicing holistically by using more than one indication for transfusion in the majority of patients. The short survival times post transfusion may raise questions over whether some of these were indeed justified. However, the most important outcome for palliative patients is symptomatic improvement. Recording outcome is an often forgotten part of the process. Routine addition of this may help guide decisions on further transfusions, and prevent inappropriate use of a valuable resource.

**Abstract number:** P1-117

**Abstract type:** Poster

### Audit of Usage of Short Acting Fentanyl (Oral and Nasal) in a Tertiary Oncology Center in UK

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**Background:** Fast acting fentanyl preparations are sometimes used for break through pain and particularly incident pain, where conventional IR opioids are ineffective. They are licensed for opioid tolerant cancer patients ( $\geq 60$  mg morphine equivalent daily dose MEDD). Starting dose does not equate to background opioid dose and must be individually titrated. These medications are strong opioids with potential risk of toxicity. They are also expensive; hence usage should be appropriate, monitored with clear outcomes recorded.

**Methodology:** Retrospective case notes review of patients identified from pharmacy data January to December 2011. Case notes, Electronic Patient Records, Drug charts and Nursing notes were reviewed against clear audit standards using a specifically designed proforma.

**Results:** 81/91 patient notes were available and 75 included data on adult patients commenced on abstral (73) or effentora (2) in the clinical setting (69/75 inpatients). 68% of doses were prescribed by the palliative care team, 17% by the pain team and 15% by other teams. Assessment: There was poor documentation of rationale of use over conventional IR opioids (60%), 8/75 (11%) were on  $\leq 60$ mg MEDD. Background opioids included morphine (29%) oxycodone (33%) and fentanyl (29%). Dose/titration/review: 46/75 (61%) patients started on the recommended dose of 100 mcg. However, 21 started at 200 mcg, 3 at 400 mcg, and 4 at 200-400 mcg. Where effect could have been assessed/documentated, 25 patients had benefit, 15 had no benefit and 27 had no documentation of assessment of benefit. Of the 34 patients who were titrated and discharged, 28% used 200mcg, 5% 300mcg, 8% 400mcg and 8%  $\geq 600$ mcg.

**Conclusion:** Use of fast acting fentanyl warrants clearer guidelines, documentation re rationale, assessment of benefit and follow-up plans. Guidelines have been drafted and clinical practice will be re-audited following implementation. This baseline data will aid monitoring of prescribing trends within the Trust.

**Abstract number:** P1-118

**Abstract type:** Poster

### Beneficial Effect of Jellied Elemental Diet in Patients with Head and Neck Cancer

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**Aims:** Either combination or monotherapy of radiation and chemotherapy in patients with head and neck cancer results in worse nutritional status, because unfavorable incidence occurs followed by eating and swallowing disturbance. We supplied jellied elemental diet in cancer patients and examined to see the persistency and the effects on the nutritional status.

**Study design:** Prospective interventional study.

**Methods:** Participants were 57 patients with various cancers who were hospitalized in Shimane University Hospital (2010.4.-2012.2.). Elental<sup>®</sup> (Ajinomoto Pharma Co., Ltd) of 300kcal/day was jellied with a flavor at patient's choice and supplied for each meal in 100ml or 200ml (diluted with water). Nurses and dietitians coached and encouraged them to eat. Eating rate of each patient was recorded. Statistical difference was determined by Mann-Whitney U-test.

**Results:** Patients with head and neck cancer (n:19, group A) had taken jellied Elental<sup>®</sup> significantly longer time than patients with other cancer (n:38, group B). The ratio of patients who kept taking Elental<sup>®</sup> at 14 days was 74% (14/19) in A and 47% (18/38) in B. In this population, serum albumin (Alb) level was significantly increased at 14 days in A ( $3.1 \pm 0.6$  to  $3.6 \pm 0.6$  g/dl,  $p < 0.001$ ; mean  $\pm$  SD) whereas no change was found in B. In addition, Alb was not changed in 5 patients in A who stopped the diet within 14 days ( $3.6 \pm 0.3$  to  $3.6 \pm 0.9$  g/dl), suggesting that at least 14 days are needed to show the potential benefit of elemental diet. Main causes of the cessation were stomatitis and appetite loss.

**Conclusion:** Jellied elemental diet may be beneficial in patients with head and neck cancer when persistently taken for 14 days or more.

## Poster sessions

Abstract number: P1-119  
Abstract type: Poster

### Inpatient Palliative Care - Is there a Role for Medical Process Management? A Qualitative Approach

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**Introduction:** Patients in Palliative Care (PC) have individual and often changing needs. Multiprofessional and patient centered care is crucial to achieve the objective, but at the same time this can be challenging as it involves many interfaces. Furthermore, the Inpatient PC Unit (IPCU) is part of a hospital - a strongly process oriented system. The possible role of medical process management (MPM) - often referred to as a tool to optimize efficacy and efficiency - is unclear in PC. Therefore we conducted a first study to describe processes and learn about the role of MPM in PC.

**Materials and methods:** A five step approach was performed.

- (1) Participant observation;
- (2) Expert interviews to detect processes, the individual person responsible for a single process and the main interfaces on IPCU;
- (3) Discussion of the results in expert-rounds;
- (4) Visualization of detected processes and
- (5) Analysis of current procedures and proposed optimization.

**Results:** Four key processes have been identified and examined in detail: Transfer / admission, diagnosing, therapy and discharge. Emerging uncertainties as to responsibilities for the key processes as well as the importance of systematic documentation and the appointment of process owners have been shown (1-4). During this study, the interface between the referring service and the PC service has been restructured to optimize admission and to provide the staff with the information necessary to quickly address the needs of newly admitted patients (5).

**Conclusions:** To our knowledge this is the first study on MPM in PC. The systematic analysis of processes and structures helped to optimize the workflow, to detect obstacles in the treatment process and to provide a secure and reliable service for the patient. MPM was of key importance to clarify responsibilities within the team. So, MPM in PC can help to reduce administrative workload and thereby gain resources for what the palliative care team stands for: best possible patient care.

Abstract number: P1-120  
Abstract type: Poster

### Have Changed the Prejudices against Opioid Therapy in the Last 10 Years?

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**Research aims:** The majority of terminal ill patients in Germany are treated by general practitioners and other physicians in private practices as part of the general outpatient palliative care (AAPV = Allgemeine ambulante Palliativversorgung), most of them without training in palliative care. The newly established specialized palliative home care (SAPV = Spezialisierte ambulante Palliativversorgung) was implemented as a right for every patient in need beginning in the end of the year 2008.

The results of our survey can help to improve SAPV and AAPV.

**Methods:** We sent out 600 questionnaires to randomly selected physicians in Mecklenburg-Western Pomerania/Germany in April 2008 (response rate: 34.5%; n=207). They consisted of 46 questions about palliative care and cancer pain therapy. We compared our data collected in 2008 with those of the earlier survey conducted in 1999 (t-Test).

**Results:** 74% of the physicians would prescribe no higher doses than 200 mg of oral morphine at any time in the course of the disease to cancer patients in pain. 19.4% of all physicians feel that you must be very careful when prescribing narcotics because of the danger of addiction; in the subgroup of physicians treating cancer pain patients this fear is significantly lower than in those not treating cancer pain patients ( $p < 0,001$ ), also in group of general practitioners this fear is lower than in other physicians ( $p=0,022$ ); also professional training ( $p=0,01$ ) and personal experience ( $p=0,038$ ) reduce this possible impediment to opioid prescription.

Compared to 1999 there is no significant change.

**Conclusion:** Based on our survey the treatment of cancer

pain patients by their physicians has not improved much in the last ten years. More than one quarter of the physicians (26,0%) would generally limit the daily morphine dose. General practitioners do a good job, but there are still deficits. Training of all active physicians and medical students in palliative medicine should be compulsory.

Abstract number: P1-121  
Abstract type: Poster

### Communication: The Interface between Community Specialist Palliative Care and Primary Care

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**Aims:** An approachable, responsive specialist palliative care team (SPCT) is crucial in supporting primary care, with SPC commonly being the link between hospital specialties and the community. We were keen to ascertain what primary care consider the best way to communicate to them as well as determining how effectively we currently communicate. This was explored via a primary care survey. Alongside this we were keen to investigate how effectively we document our communication to primary care in our case notes. This was explored via a retrospective case note audit.

**Methods:** The survey was sent to all General Practitioners (GPs) within our locality and we asked the following questions:

- How primary care would like us to respond to the urgent/non-urgent referrals sent from primary care
- How primary care think we perform with regard to specific communication domains
- The audit was a retrospective review of nurse case notes over a period of 6 months following an urgent referral from primary care, looking principally at:
  - Following our review whether the patient was placed on the GP palliative care register
  - How the SPCT responded to the referral

**Results:** Only half of respondents had referred a patient to the SPCT in the last 12 months  
Urgent reviews - faxed document  
Non-urgent reviews - written letter  
Satisfaction scores - majority rated as good  
Out of a total of 59 case notes records:  
56% of patients were on the GP palliative care register  
Over half of all clinical encounters were not communicated to primary care

**Conclusion:** Since this piece of work we have now developed a communication pro-forma to fax to primary care following any patient review by the SPCT. The pro-forma has been designed to ensure it is easy to complete and easy to read quickly.

Following agreement with the health-board this has been approved for use across the region (this encompasses three SPCTs) with a plan to reassess GP satisfaction and to re-audit early 2013.

Abstract number: P1-122  
Abstract type: Poster

### Quality Measures for End-of-Life Care - A Review of Swedish Policy Documents

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**Background:** All patients with palliative care needs should be guaranteed equal and safe treatment and care regardless of their disease or site of care. This accords with the general aim of Swedish law. The inclusion of quality indicators in national guidelines and other guiding documents supports quality assurance and improvement in provision of care. In connection to the work on National Clinical Practice Guidelines for palliative care in Sweden, we decided to review existing quality indicators in national Swedish policy documents relevant to end-of-life care.

**Methods:** We reviewed existing guidelines for diseases expected to require palliative care issued by the National Board of Health and Welfare (NBHW), existing regional clinical practice guidelines and the annual report of Swedish Register of Palliative Care (SRPC) until 2010.

**Results:** The total number of quality indicators was 240 and

of these we found 11 indicators pertinent to palliative care, seven general in the guidelines for oncology and care of the elderly and four specific indicators in the lung- and prostate cancer guidelines. The indicators included assessment and treatment of pain, communication with the patient and the family, documentation in the patient record and registration in the SRPC. In the national guidelines for cardiology, pulmonary diseases, stroke, diabetes and dementia there were no indicators relevant for end-of-life care.

**Conclusion:** In the existing Swedish national guidelines for many different diseases, there is still a great need to define clinically relevant and feasible outcome measures of quality of palliative care. To increase the quality of care in a patient as well as caregiver and organizational perspective, it is important to continue the work to develop and define general, as well as specific, quality indicators. National and international consensus would support the opportunity to benchmark and exchange experience.

Abstract number: P1-123  
Abstract type: Poster

### A Review of Paracentesis in a Specialist Palliative Care Unit in Northern Ireland

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**Background:** Paracentesis can improve symptoms caused by malignant ascites. The Northern Trust developed a paracentesis protocol to standardise practice and reduce risk. This study reviewed practice against the protocol in a specialist palliative care unit (SPCU) in Northern Ireland.

**Method:** A retrospective chart review of inpatient and outpatient paracenteses performed from September 2011 to September 2012 was undertaken.

**Results:** 13 paracenteses were performed. All patients had advanced malignancy and had no further oncology treatment planned. In 8 cases there were no documented pre-procedure blood results and no pre-procedure ultrasound marking. There was documentation of written consent for 10 cases. 6 paracenteses were performed using a pigtail catheter, 4 using an intravenous cannula and three-way tap, and there was no documentation of the specific method in 3 cases. There was documentation of the volume of fluid drained for 11 cases and of these, the average was 4 litres (range 1.4 to 6 litres). The length of time the drainage device was in situ was not documented in 10 cases. All patients had baseline observations but there were no regular peri-procedure observations documented in 8 cases. No patients required albumin. There were no post procedure complications. All patients died within 3 months of the procedure.

**Conclusion:** Paracentesis is a commonly required procedure in a SPCU. Large volumes of ascites were drained and there were no associated complications, however, documentation relating to the procedure was lacking despite the protocol being easily accessible. This review has prompted the development of a paracentesis proforma which addresses pre-procedure risk assessment, peri-procedure monitoring and post procedure review, in line with the protocol. This is currently in use and a reaudit is planned in 2013.

Additionally, this study implies that the development of clinically significant malignant ascites is a poor prognosticator.

Abstract number: P1-124  
Abstract type: Poster

### DNACPR: The End or the Beginning of the Story? An Audit of Do-not-Attempt-cardiopulmonary-Resuscitation Orders in a District General Hospital

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**Background:** Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders are made in hospitals where clinically necessary. They may be based on patients' wishes, likelihood of an unsuccessful outcome or a decision based on balancing the benefits and the burdens of this treatment. Some patients with DNACPR orders die in hospital but some patients leave hospital and may have increasing health needs due to advancing disease and frailty. Advance care planning and the use of supportive care registers may be indicated for these patients.

**Methods:** Over a 3 month period all hospital inpatient DNACPR orders were analysed to assess the standard of

documentation against national guidelines and the local hospital policy. Patient records were reviewed again at 6 months following the DNACPR decision, and date of death and/or entry on the local supportive care register was recorded.

**Results:** 87 decisions were analysed. Most DNACPR decisions were made in the last 2 weeks of life (median time 3.5 days before death). 23.6% of all the patients who had DNACPR orders were still alive at 6 months. Of the patients who were discharged from hospital following a DNACPR order, 36.7% died subsequently. 12 patients were listed on the local supportive care register (14%).

**Discussion:** Whilst this does not prove that patients with a DNACPR order will die in the next 6 months, DNACPR status may indicate a poor prognosis. Where patients who have had inpatient DNACPR orders are discharged from hospital, realistic discussions about the state of their health should follow and entry on a supportive care register and advance care planning may be appropriate.

**Abstract number:** P1-125

**Abstract type:** Poster

### Malignant Bowel Obstruction in Patients with Advanced Ovarian Cancer Admitted to a Regional Oncology Centre

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**Aims:** The management of malignant bowel obstruction (MBO) in patients with advanced ovarian cancer (AOC) is challenging. This baseline audit aimed to determine the number of AOC patients with MBO at a regional oncology centre (ROC), their baseline characteristics, management and outcomes.

**Methods:** Retrospective review of all AOC patients with MBO admitted to the ROC from January to October 2011. Management was audited against standards derived from new local guidelines.

**Results:** 78 consecutive AOC admissions were screened. 8 patients had MBO (mean age 58), 7 of whom were diagnosed radiologically. In the first 24 hours, all patients had blood and radiological investigations as per guidelines. 7 received IV fluids, 2 had a rectal examination. All 8 patients had nausea or vomiting and 7 were given antiemetic via continuous subcutaneous infusion (CSCI). 3 patients without colic received Metoclopramide via CSCI. Of 5 patients with colic, 3 received Hyoscine butylbromide via CSCI. All 6 with other pain received opioid via CSCI. 2 patients were given Dexamethasone at 72 hours for refractory vomiting. 5 patients had a surgical referral (1 underwent surgery). 3 required nasogastric tube drainage. The average duration of admission was 18 days (range 8-36). 3 patients had complete resolution of MBO and were discharged home; 3 patients had ongoing MBO at discharge (1 discharged home, 2 to a hospice); 2 patients died during admission. Of the 6 discharged, 3 died within 30 days and 2 more died within 6 months.

**Conclusion:** Fewer AOC inpatients had MBO than was anticipated. They were polysymptomatic and their management was complex. Management strengths included initial assessment, use of CSCI medications and discharge planning. Weaknesses were inclusion of rectal examination at assessment and poor documentation of vomiting. As a result, local guidelines have been updated and included in junior doctor induction. This review also highlights MBO as a signifier of poor outcome in AOC.

**Abstract number:** P1-126

**Abstract type:** Poster

### Provision of General (Non-specialist) Palliative Care in an Urban Setting

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**Introduction:** It is government policy in Ireland to provide general level (non-specialist) palliative care in non-acute hospitals for palliative care patients requiring ongoing rather than specialist palliative care. These beds are available mainly in rural areas. A new facility incorporating both specialist palliative care and long term care of the elderly was recently opened in an urban area. Six beds became available on care of the elderly wards for patients in need of general palliative care. Patients can be transferred to these beds from the specialist palliative care unit, from the acute

hospital or from home.

**Aims and objectives:** The aim of the study is to analyse the use of this resource in order to improve efficiencies and to inform further development of the service.

**Methodology:** A retrospective mixed methods review from 1/03/11 to 1/03/12 will be carried out. Quantitative data will include patient information such as primary diagnosis, length of stay, place of death, funding arrangements, and bed occupancy. The qualitative aspect will involve 3 focus groups to elicit opinions of multidisciplinary team members from specialist palliative care, care of the older person service and specialist palliative teams in the acute hospitals and community.

Focus group discussion will be recorded, themes identified and information collated to inform future development of the service. A confidential chart review will be undertaken to collect data. Consent will be sought from the participants in the focus groups. Ethical approval is being sought from the local research ethics committee. Results will be reported and discussed.

**Discussion:** As this is a relatively new model of care, there is little published research in this area. This information will inform resource allocation and service delivery and it may be of benefit to other services as the findings will be disseminated.

**Abstract number:** P1-127

**Abstract type:** Poster

### VTE (Venous Thromboembolism) Prophylaxis in a Palliative Inpatient Unit: To Administer or Not, that Is the Question

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**Aims:** The National Institute for Health and Clinical Excellence has rolled out guidelines for VTE prevention for England and Wales which all NHS trusts have adopted. They aim to reduce preventable VTE in hospitals, causing 25,000 deaths per year. There is strong evidence that VTE is preventable in a general hospitalised population; this is less evident in the palliative inpatient population. The guidelines dichotomises terminal care for palliative patients, recommending only to treat the potentially reversible acute pathology patient. VTE prophylaxis can also increase the risk of bleeding. We assessed the suitability of VTE prophylaxis for our hospice population.

**Methods:** Audit of palliative inpatients from January to March 2012 in a 10-bed hospice using the Oxford Radcliffe NHS Trust online VTE risk assessment tool.

**Results:** Over the 3 months, 37 patients were admitted to our inpatient unit. 56% (n=21) males and 44% (n=16) females. Their average age was 72 years. 11% (n=4) were in for respite. 43% (n=16) admitted for terminal care were not suitable for VTE prophylaxis. 92% (n=34) died. 46% (n=17) were in for symptom control but only 24% (n=4) met the criteria for VTE prophylaxis. Eventually all 4 died. 41% (n=7) had increased bleeding risk which negated the VTE prophylaxis. 24% (n=4) were already being treated for confirmed VTE. 12% (n=2) were mobile and not at risk. None had a VTE event.

**Conclusion:** Generally, cancer patients have higher risks of thromboembolism and bleeding. With palliative inpatients, it is difficult to determine if initial symptom control has transitioned to terminal care and hence whether VTE prophylaxis should have been started. From our cohort of symptom control patients, only 26% (10% of all patients admitted) met the criteria for VTE prophylaxis but all eventually died. We conclude that the benefit of VTE prophylaxis as prescribed by the guidelines is questionable for our study. Bigger studies like the CLOTS trial (Lancet 2009) are required.

**Abstract number:** P1-128

**Abstract type:** Poster

### Patient Involvement in Care & Treatment - An Audit

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**Introduction:** The Care Quality Commission states that patients should be involved in decision-making about care and treatment; however evidencing this, or that patient expectations are met, can be a challenge.

To demonstrate this, admission objectives were introduced the hospice inpatient unit (IPU) in June 2009. Admitted patients are asked what they hope the admission will achieve; these are identified as objectives. SMART (Specific, Measurable, Achievable, Realistic and Time-framed) objectives are agreed with the hospice team and documented in the notes. During admission, these are regularly reviewed and modified, appropriate to current circumstances. Objectives are signed off when completed,

or commented on if unachievable.

**Aim:** To assess documentation and achievement of patient objectives.

**Method:** Thirty objectives forms from December 2010 were reviewed following discharge/death. The audit examined the number of objectives set on admission, if these were SMART, if there was evidence of achievement/review during admission and if new objectives were set as circumstances changed. Re-audit was carried out in March 2012 following recommendations.

**Results:** The initial audit showed 80% of patients had SMART objectives set on admission, 30% of patients achieved some/all of these, 53% had inadequate comments to support evidence of achievement, and 13% had evidence of new objectives being set. Recommendations included staff training, revising documentation and timing of reviews. Re-audit showed improved practice: 87% of patients had SMART objectives set on admission, 60% of patients achieved some/all of these, 30% had inadequate comments to support evidence of achievement and 27% had evidence of new objectives being set.

**Conclusions:** Most patients were able to identify and achieve some or all of their objectives during admission. The objectives form is a useful way of evidencing patient-centred care, and helping to meet patient expectations.

**Abstract number:** P1-129

**Abstract type:** Poster

### Improving Compliance to Symptom Monitoring Using the Edmonton Symptom Assessment System in a Multicultural Tertiary Setting

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An audit of 470 patient episodes in which the Edmonton Symptom Assessment System (ESAS) was used revealed that less than 80% of patients self rated symptoms and there was a lack of standardization among surrogate raters in the assessment and record of patient's symptoms. Depression, anxiety and nausea were also found to be most difficult to describe. The aims are to improve compliance to ESAS recording by studying challenges faced by patients, healthcare providers and other surrogate raters and to implement changes based on an understanding of the challenges faced.

A focus group of 10 healthcare providers with at least one year of palliative care experience gathered to share their experiences. Challenges were discussed and thematic analysis was conducted on transcribed results. Solutions based on the results were offered and implemented.

Patient challenges cited included difficulty understanding the numerical rating scale (NRS) in relation to symptom intensity, even when the visual analogue scale was substituted, with some preferring qualitative descriptors ('mild', 'moderate', 'severe') over the NRS. Another patient factor was being "too tired" to self rate symptoms. Healthcare providers (HCP) identified a lack of understanding of the purpose of the ESAS as a tool to screen and to chart symptom response, and language differences between patients and HCPs in a multicultural setting which made translation of symptoms, particularly those of the qualitative nature, for example, depression particularly challenging. A lack of standardization in the way the symptoms are understood poses difficulty from both patient and HCP perspectives.

Clarifying the purpose of the ESAS in patient care management, standardizing the use of the ESAS amongst HCPs with training in the administration of questions, and integration of the ESAS into routine workflow for the orientation of new doctors and nurses were identified to overcome these challenges.

**Abstract number:** P1-130

**Abstract type:** Poster

### "As Needed" Psychotropic Medications in a Long Term Hospital

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**Introduction:** Pro Re Nata (PRN) or as needed psychotropic medications associated with routine medication is a common practice in mental health centers and nursing homes. However, it has highlighted the absence of specific guidelines governing this practice. The aim of the study is to describe its use in a long-term hospital including four welfare programs: hospice patients, chronic diseases, brain damage and convalescence.

**Materials and methods:** A retrospective review of PRN medications in patients admitted from April 2009 until August 2012 was performed. Pharmacy medication records

## Poster sessions

were reviewed to analyze the number of patients who are prescribed psychotropic PRN, the main drugs involved and the condition for its administration.

**Results:** During the study period 774 patients were admitted to hospital, initially assigned to one of the four welfare programs. Nine out of ten patients were prescribed one or more PRN medication. A total of 1,338 PRN psychotropic medications were prescribed. More than half of the patients received one of the 23 drugs recorded (364 patients hypnotics or anxiolytics as need, 212 neuroleptics, 8 antidepressants and 18 antiepileptics). The main drugs were lorazepam, midazolam, risperidone and haloperidol. Regarding the condition for administration, "as needed", "insomnia", "agitation", "anxiety" and titration accumulated 79% of PRN prescriptions. The remaining were ambiguous or combined conditions.

**Conclusions:** Just as in other hospitals, psychotropic drug prescription "as need", is very common in our hospital. The conditions for administration expressed by the prescriber are in many cases inaccurate to interpret correctly. Although all administered doses are recorded in the nursing chart and discussed by the health care team, this inaccuracy may lead to different interpretations by nurses and an overuse of these drugs unnecessarily. Developing best practice consensus would reduce discretion in decision-making.

**Abstract number:** P1-131  
**Abstract type:** Poster

### First Quality Manual for Hospice and Palliative Care Services in Europe

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**Aims:** Aim of this project was a quality manual assisting hospice and palliative care institutions in the designing and processing of their daily activities.

**Methods:** For each of the six types of hospice and palliative care services (palliative care units, in patient hospices, day hospices, mobile palliative care teams, palliative care hospital support teams, volunteer hospice teams) a model process was developed for the following situations:

- Start of Care
- Care
- End of Care

These processes were developed by the joint effort of GÖG/ÖBIG (Austrian Federal Institute for Health Care), Hospice Austria and the Austrian Palliative Care Association (OPG). All 260 hospice and palliative care institutions in Austria were invited to participate in this quality management project. About 60 of them became partners in the project thus ensuring an outcome meaningful for the daily practice. The project group started by assessing the actual present situation (How do people work now?) and then created the model process (What is the best way of working?). A multiprofessional group of experts functioning as a quality board had developed the design of the project, monitored the project and provided support in creating the manual.

**Results:** The quality manual for hospice and palliative care services provides model processes consisting of flow charts, comments and key performance indicators for evaluation relevant for the daily routine. It was rolled out during a festive event hosted by GÖG/ÖBIG and the Ministry of Health. All hospice and palliative care institutions in Austria were invited.

**Conclusion:** Two aspects make the manual unique: the first is the involvement of all services working in the field of hospice and palliative care resulting in a great alignment with regards to basic structures of processes. The second is that one manual was created for all types of hospice and palliative care services.

The project was funded by public funds.

**Abstract number:** P1-132  
**Abstract type:** Poster

### Adherence to the Resuscitation Guidelines on DNAR Form Completion at Queens Hospital, Romford

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Whilst working as SHOs in Queens Hospital we recognised the large number of cardio-respiratory arrest calls. We found DNAR forms were often incomplete and therefore invalid. Poor awareness and accessibility of forms had resulted in patients receiving CPR inappropriately.

**Aims:** To audit the accuracy, completeness and awareness of DNAR form documentation  
To educate and raise awareness.

**Method:** Using local trust guidelines as a standard we designed a proforma to measure current practice. We reviewed 307 notes across medical wards; 71 had DNAR forms. We assessed form completion by section as outlined in the results.

**Results:** Handwriting was considered legible if 2 auditors were able to read all information on the form. Patient ID was considered complete if the 2 identifiers, name & hospital number, were documented. 88.7% were legible, 93% had complete patient ID.

Discussion and communication of a DNAR with patient, nursing and medical respectively was 38%, 59% and 33%.

Consultant countersigning was deemed as complete when signed, printed, dated and timed within 24 hours of the initial decision. The outcome of the form not being signed was either for a period of time the DNAR had not been valid or remained invalid at the date of audit. 74.6% of forms were countersigned.

Indication for the DNAR was completed in 91.5% of forms. Indications varied from being patient specific and appropriate to vague and insignificant causing the suitability of the form to be questioned.

Location of the form should be secured at the front of notes and nursing/medical staff should be made aware of its existence. 82% of forms met this criteria.

Only 1 form of the 71 forms was entirely complete!  
**Conclusions:** We highlighted numerous concerns and shortfalls in the decision process and completion of forms. The documentation of what is literally 'life or death' should be impeccable and entirely appropriate. We recommended the need for an improved DNAR form which guides and encourages valid decisions.

**Abstract number:** P1-133  
**Abstract type:** Poster

**Abstract withdrawn**

## Basic & translational research

**Abstract number:** P1-134  
**Abstract type:** Poster

### A Cost-effectiveness Analysis of a Rehabilitation Service for Survivors of Cancer

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**Aim:** To evaluate the cost-effectiveness of a rehabilitation service for people living with and beyond cancer, delivered in a hospice day care unit.

**Methods:** Clinical and economic data were collected as part of a wait-list randomised controlled trial of a complex rehabilitation intervention delivered by a hospice-based multi-disciplinary team versus usual care. Out-patients with active, progressive, recurrent haematological and breast malignancies were recruited from 2 hospitals forming a joint cancer centre in London (UK), and followed-up for 3 months. A cost-effectiveness analysis was undertaken using Monte-Carlo simulation. The main outcome measure for the economic evaluation was quality adjusted life years (QALYs). Costs were measured from the perspective of the National Health Service (UK). Uncertainty in the observed data was captured through probabilistic sensitivity analysis. Scenario analysis was conducted to explore the effects of treatment being maintained beyond the observed trial period.

**Results:** Forty-one patients entered the study. Preliminary results show an incremental cost-effectiveness ratio for the base-case analysis around £19,500 per QALY. At a societal willingness to pay of £20,000 per QALY the intervention is likely to be cost-effective in 55% of simulations when compared with usual care. The likelihood that the intervention is cost-effective increases with the length of time after the intervention improvements in quality of life are maintained.

**Conclusion:** This rehabilitation intervention may offer a cost-effective use of resources for the benefit of cancer survivors, especially if benefits are sustained long term. There is significant uncertainty in the results; we recommend collection of further evidence to evaluate cost-effectiveness over longer time periods and in different settings.

**Abstract number:** P1-135  
**Abstract type:** Poster

### Prospective Evaluation of Specialized Palliative Home Care in Germany - Comparison of an Adult and a Pediatric Sample

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**Objective:** In Germany, since 2007 patients with advanced life-limiting diseases are eligible for Specialized Outpatient Palliative Care (SOPC). The goal of this study was to compare SOPC for adults and children provided by the adult and the pediatric specialized Palliative Home Care Team (PHCT) based at a German University Hospital.

**Methods:** All patients treated by the two PHCTs and their primary caregivers were eligible for the prospective non-randomized study. We compared the underlying diseases, the duration and the impact of SOPC on symptom control and quality of life (QoL) in patients, as well as the caregivers' distress, burden of patient care and QoL.

**Results:** Between April 2011 and June 2012, 60 adult (median age 67.5 y, 55% male) and 40 pediatric patients (median age 6 y, 57% male) were included in the study. In 38% of adult and 93% of pediatric pts., only the caregivers could be interviewed. Non-oncologic diseases were predominant in children (75% vs. 13%). 57 adult (95%) but only 17 pediatric patients (43%) died until the end of data acquisition. The median period of care was 4 weeks in the adult and 11 weeks in the pediatric sample. Patient-perceived improvement of symptom control (NRS median 5 to 9.5) and QoL (NRS 4.4 to 6.0) could be assessed only in adult pts. In both patient groups, the caregivers reported a significant improvement in both the patients' (NRS 1 to 2 and 2.5 to 4) and their own QoL (QOLTI-F 6.1 to 7.3 in spouses vs. 5.8 to 7.1 in parents), while their psychological distress and burden significantly decreased (HADS 22 to 16 vs. 28 to 19; HPS 13 to 9 vs. 20 to 14.5).

**Conclusions:** SOPC can lead to a substantial improvement of the QoL in patients and caregivers in the adult as well as in the pediatric setting. SOPC can also lower distress and the burden of home care for the caregivers. In the pediatric sample, non-oncologic diseases were predominant, the median period of care was longer and the number of deaths in the study period was lower.

**Abstract number:** P1-136  
**Abstract type:** Poster

### A Study to Predict Serum Concentration of Transdermal Fentanyl in Cancer Patients by SKIN-CAD®

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**Aims:** Serum concentration of fentanyl patch (FP) may have wide variation among cancer patients because absorption ratio via skin might be affected by skin condition. Therefore, we conducted a prospective study to predict serum concentration of FP by using SKIN-CAD® (CAD).

**Methods:** Patients applied reservoir type (FP-R) were 35 and those of matrix type (FP-M) were 9, respectively. Blood samples were collected at 24, 48, and 72 hr after application of FP. Thereafter we calculated predictive serum concentration by CAD and the method (INFU) that hypothesized transdermal administration as continuous intravenous infusion, and compared the results by both methods. Mean absolute prediction error (MAE), mean prediction error (ME), and root mean squared error (RMSE) of each serum concentration at 24, 48, 72 hr after application were computed, and probability of prediction was evaluated.

**Results:** MAE, ME and RMSE of FP-R calculated by CAD were 4.063, -1.864, and 1.596 at 24hr, 3.471, -1.161, and 1.306 at 48hr, and 1.194, 0.682 and 0.433 at 72 hr, and those calculated by INFU were 4.487, -3.860 and 1.732 at 24 hr, 3.775, -3.045 and 1.459 at 48hr, and 1.176, -0.295, and 0.540 at 72 hr. In contrast, MAE, ME and RMSE of FP-M calculated by CAD were 0.811, 0.019, and 0.367 at 24 hr, 1.203, -0.498, and 0.626 at 48 hr, and 1.008, -0.558, and 0.608 at 72hr, and those calculated by INFU were 1.336, -1.336 and 0.676 at 24 hr, 1.498, -1.498 and 0.837 at 48hr, and 1.215, -1.215, and 0.750 at 72 hr.

**Conclusion:** The numerical values of MAE, ME and RMSE calculated by CAD were smaller than those by INFU, and it was indicated CAD was more predictable. However, values of FP at 24hr were unpredictable, and it was considered serum concentration of FP had wide variation until 24 hours after application. Therefore careful monitoring is essential during 24 hours when FP is administered. This is the first clinical trial used by CAD, and it is suggested CAD could be predictable to some extent.

Abstract number: P1-137  
Abstract type: Poster

### Understanding how Cancer Patients Actualise, Relinquish and Reject Advance Care Planning: Implications for Practice

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**Purpose:** Although advance care planning (ACP) is recognised as integral to quality cancer care, it remains poorly integrated in many settings. Given cancer patients' unpredictable disease trajectories and equivocal treatment options, a disease specific ACP model may be necessary. This study examines how Australian cancer patients consider ACP. Responses will inform development of an Australian Cancer Centre's ACP programme.

**Methods:** A constructivist research approach with grounded theory design was applied. Eighteen adults from lung and gastro-intestinal tumour streams participated. Participants first described their initial understanding of ACP, then received ACP information, and finally completed a semi-structured interview assisted by the vignette technique. Qualitative inter-rater reliability was integrated.

**Results:** Participants initially had scant knowledge of ACP. On obtaining further information on ACP, their responses indicated that: For cancer patients, ACP is an individualised, yet dynamic and shared process characterised by myriad variations in choices to actualise, relinquish, and/or reject its individual components (medical enduring power of attorney, statement of choices, refusal of treatment certificate, and advanced directive). Actualisation of each component involves considering, possibly conversing about, planning, and communicating a decision, usually iteratively. Reactions can change over time and are informed by values, memories, personalities, health perceptions, and trust or doubts in carers.

**Conclusion:** ACP may be acceptable to patients who initially reject them if sensitively approached. Policy makers may need to broaden criteria for ACP outcomes to include the choice not to discuss care plans, and discourage ACP facilitators from offering ongoing ACP opportunities which offend patients' collectivist values or personality styles.

Abstract number: P1-138  
Abstract type: Poster

### Developing a Culture of Practitioner Research

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Very often research is seen as the preserve of academic institutions and practitioners may find it difficult to see their role in both undertaking research and translating findings into practice. This session will explore the development of practitioner research capacity in the Children's Hospice Association Scotland (CHAS) across all disciplines, from care to fundraising, through the establishment of a project to support audit, evaluation and research.

CHAS is a charity that provides the only hospice services in Scotland for children and young people with life-shortening conditions. CHAS offers care in two children's hospices, Rachel House in Kinross and Robin House in Balloch. CHAS also provides a home care service, called CHAS at Home, staffed from both hospices and with dedicated teams in the North of Scotland.

The aims of the project are to:

- Raise awareness of the role of practitioner research in developing evidence-informed practice
- Encourage staff from all areas to become involved in audit, evaluation and research
- Implement findings to improve and develop practice
- Share learning from projects beyond CHAS

**Results:** The project has now been established for one year and already capacity has increased. More staff are engaged in the processes of audit, evaluation and research than previously, in areas such as care, human resources, voluntary services and learning and development. Staff with no previous experience have been supported to develop projects, submit abstracts to conferences, develop poster presentations and present their work publicly. This has generated interest and excitement in practitioner research as staff begin to recognize the difference which their work makes to practice in CHAS, in addition to contributing new knowledge to the field. It has also led to partnerships with academic institutions in scoping and developing joint

research projects in which CHAS staff will have an opportunity to further develop practitioner research capacity.

Abstract number: P1-139  
Abstract type: Poster

### Subcutaneous Application of Medication in Palliative Care - Preliminary Results of a Systematic Evaluation

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**Background:** In palliative care, a safe and easy application of medication is essential. Due to different reasons oral intake can be hampered, so that the subcutaneous (SC) route is preferred in many patients. However, evidence for this method is rare. This study explores the clinical practice focussing on local reactions or complications and the subjective patient perception.

**Methods:** Since January 2012, patients treated with SC medications (SCM) in our institution are invited to participate. All SCM including dosage and volume of injection, type of needles and injection site are documented. Additionally, the objective evaluation of injection sites and the subjective perception of patients are systematically assessed. T-Tests of these variables for group differences between needles with vs. without complications were calculated ( $p < 0.05$ ).

**Preliminary results:** To date, 60 patients could be included. Overall 207 needles were used and 2751 applications analysed. The needles were placed predominantly in the thigh (36%) or upper arm (22%). Hydromorphone (76%), haloperidol (11%) and midazolam (5%) were used most frequently. In 22 needles (11%) complications such as reddening, swelling, pain or reflux of blood and liquid occurred. Factors influencing the occurrence of complications were number of applications (mean 18.4 vs. 9.3 applications;  $p < 0.01$ ), length of time in situ (4.4 vs. 3.0 days;  $p < 0.05$ ) and by trend the number of medications combined in one application (1.28 vs. 1.17 preparations;  $p < 0.10$ ). More complications occurred in women, in older patient and with higher volume of injections in sum. No influence was found for injection site.

**Conclusions:** Preliminary data indicates that SCM is safe but not complication free. More evidence base is needed to calculate regression models. This study aims to draft a recommendation for clinical practice defining critical limits and risk factors for SCM.

### Bereavement

Abstract number: P1-140  
Abstract type: Poster

#### Support for Bereaved and pre Bereaved Siblings within a Palliative Care Context

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Children's Hospice Association Scotland (CHAS) provides the sole children's hospice services in Scotland to children, young people with life-limiting conditions and their families. CHAS provides vital care and support through its two hospices Rachel House and Robin House and a home care service.

Having a brother or sister that has complex care needs and fragile health, impacts not only on the lifestyle of a well sibling but on their emotional wellbeing. Over a number of years we have developed a variety of strategies in support of the well sibling, helping them understand and manage the challenges and tough realities they face. A new initiative in 2012 saw us team up with an organisation that works with young people in identifying leadership qualities within themselves. Recognising that both organisations held a similar philosophy of care and support and a commitment to invest in the lives of children and young people in need, we embarked on a remarkable partnership.

**Aim:** Our aim was to enhance the resilience and emotional strength of the young people in our care, so they can make the most of the present and have the courage to face the future with hope.

**Design:** A week long residency programme of self-discovery which explored inner values and qualities, where the young people and staff set their own personal goals and support and share with others in realising their own potential.

**Results:** We would like to share with the conference this inspirational and dynamic journey that gave a group of young people the chance to discover the strength and courage to find their own unique voice and purpose and to use that voice to inspire others within their community.

**Conclusion:** This group of young people now have the knowledge that despite the difficult times that may lie ahead they have the confidence and inner greatness to face the future and make positive choices that will transform their lives.

Abstract number: P1-141  
Abstract type: Poster

### Bereavement. The Bright and Dark Side of Online Discussion Forums

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**Introduction:** This explorative work commenced with a literature search on how the internet impacts on the bereavement experience. Four themes emerged: 1) bereavement counselling and cognitive therapy online 2) memorial websites, 3) information on bereavement and 4) bereavement support online (eg internet online discussion forums).

This presentation presents the findings of the last theme- the benefits and difficulties of online support.

**Methods:** A literature review on Medline, CINAHL and PsyhInfo has been conducted using the thesaurus term "bereavement" in each database as it is a subject heading in all of them. Subject heading and free text searches were combined with bereavement using the terms "internet", "social media" and "online" to ascertain what has been researched and written on the subject and, most importantly, as there is no definitive research, on how health professionals have developed good practice in this area.

**Results:** Initial results found 23 relevant results from Medline, 25 from PsyhInfo and 22 from CINAHL. There are few resources that focus on good practice on the use of discussion forums and bereavement. Although they provide some useful material, the search has been extended to retrieve records using the term "moderated online" aiming to capture how these forums are conducted in other health-related subjects. This is because a key area of discussion around online support is how these groups are moderated (eg peer versus professional support). Similar issues may arise in other health care environments.

**Conclusion:** This literature search provides some guidelines on whether and how health professionals could host online discussion forums as a part of their work with bereaved people, in the future. The final presentation will also incorporate findings from a survey of bereavement organisations, mainly in the UK, to ascertain the opportunities and challenges of this area of work.

Abstract number: P1-142  
Abstract type: Poster

### Relatives' Satisfaction with Care of Terminally-ill Patients at Different Places of Care

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**Research aims:** The aim of the study was to assess relatives' satisfaction with care of terminally ill patients at different inpatient places of care in the federal state of Rhineland-Palatinate, Germany.

**Study design and methods:** The cross-sectional survey was based on a random sample of 5,000 inhabitants of Rhineland-Palatinate that had died between 25 May and 24 August 2008. Relatives of these randomly drawn deceased persons were interviewed by means of a written survey. Of the 1,378 relatives who responded, 753 evaluated the quality of inpatient care during the last four weeks before death. Since every person was allowed to evaluate two different inpatient facilities, 1,049 ratings were made. Chi-square test was used for the comparison of the quality of different inpatient care settings.

**Results:** 34.3% rated only a standard hospital ward, 7.1% only an intensive care unit of a hospital, 5.8% a palliative care unit of a hospital and 13.4% a nursing home. All other relatives rated two different places of care.

Palliative care facilities were rated best, with 88.3% of the relatives (totally) agreeing of having been satisfied with care, followed by nursing home (69.4%), intensive care unit of a hospital (68.1%) and standard hospital ward (59.0%). Deficits were especially notable with respect to physicians' communicative and supportive skills in standard hospital wards: 34.5% of the relatives were unsatisfied with and 17.1% were partly unsatisfied.

For almost all items, physicians on palliative care units were

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evaluated better than in other care settings. Relatives were also highly or mostly satisfied with pain treatment in palliative care units.

**Conclusions:** The majority of the relatives were satisfied with professional inpatient care, particularly in palliative care units, nevertheless there was a high degree of variation. Physicians' communicative and supportive skills deficits in standard hospital wards could be tackled by appropriate training programmes.

**Abstract number:** P1-143

**Abstract type:** Poster

### Recording Voices in Palliative Care: How Does Providing an Oral History at the End of Life Influence Well-being of the Individual and the Bereaved?

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**Aims:** This research is assessing the impact of creating an oral history with palliative care patients and seeks to understand how family and friends regard audio recording in bereavement.

**Background:** An oral history and photography service for patients has run successfully in the Sheffield Macmillan Unit for Palliative Care (UK) since 2007. The British charity Macmillan Cancer Support is working with the Sheffield team in developing further services in the UK, with a focus on the impact of audio recordings on the participant and the bereaved. Oral history is the recording of unique experience, it captures and preserves voices and individuals are involved in the process of producing their own life histories. A motivation for recording oral history can be the chance to create a lasting life story record. Oral history is accessible as a form of biography since it provides an opportunity for participation across a range of abilities.

**Methods:** This is a mixed method study. We are conducting a literature review; identifying other services involved in life story work, nationally and internationally; exploring views about oral history with patients and the bereaved using an interview and questionnaire approach; and analysing an oral history archive which contains over 200 interviews with people approaching the end of life.

**Conclusion:** Findings to date indicate that oral history is well received; patients value the opportunity to create an audio life history and family and friends are pleased to have a voice record of the deceased. However this research is equally identifying barriers to participation and addressing whether oral history is always welcome in bereavement. Results from this study are shaping the direction of present and future oral history services in palliative care.

**Abstract number:** P1-144

**Abstract type:** Poster

### How Do Children and their Parents Experience a Family Bereavement Group - A Longitudinal Qualitative Survey

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**Research aims:** More than 50 projects for bereaved children are available in Germany. We investigated motivations to participate and perceptions of effectiveness in children and parents participating in one of these groups (Trau Dich Trauern).

**Methods:** Using a mixed method design, an open questionnaire was sent to children and parents 6 weeks after the bereavement group answered. In addition, families were interviewed at least two years later. Recruitment was stopped when saturation was achieved. Content analysis was used to evaluate the questionnaires and transcribed interviews.

**Results:** From 2005 to 2010 160 children and 72 adults participated in 19 bereavement groups. The study included 70 questionnaires (47 children, 23 adults, response rate 30%) and interviews with 8 children and 4 adults. Half of the children and 70% of the adults were attending because they expected a positive effect for themselves (e.g. communication about emotions). The parents attended because they wanted an expert assessment and support for their children, and wanted to prevent psychological problems. They also wanted to communicate about handling loss and grief with experts and other parents. Some children (about 30%) attended because their parent wanted this. The vast majority rated the bereavement group as a positive experience (45 children and 20 adults). Children mentioned the creative work (34), the communication with other participants (16), the atmosphere in the group (12) and the

breaks (19). Most parents (19) mentioned a positive effect to their children. The participants attribute to the group that it creates a community spirit and a possibility for the grieving process, it gives orientation in the time after a loss and it reduces insecurity.

**Conclusion:** A bereavement group is experienced as helpful by children and parents. The perspective of participants added relevant categories in the discussion of impact of bereavement support.

## Education

**Abstract number:** P1-145

**Abstract type:** Poster

### Which Topics Should be Integrated in Undergraduate Palliative Care Education? Views and Expectations of 253 German Medical Students

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**Introduction:** In Germany, palliative care was introduced as a compulsory subject in the curriculum for undergraduate medical students recently. From autumn 2014 on, all exam candidates must have been trained in palliative care. There has been some debate concerning topics and contents of the new subject: Some universities decided to focus on pain and symptom control while others put more effort to convey the multidisciplinary approach of palliative care. This study was aimed to gain insight into wishes and expectations of medical students.

**Methods:** Before the implementation of palliative care as a compulsory subject, 3<sup>rd</sup> - 5<sup>th</sup> year medical students of a German university were asked to answer a questionnaire mainly including numeric rating scales from 0-10.

**Results:** 253 from 339 distributed questionnaires have been completed: 55 (from 82) questionnaires from 3<sup>rd</sup> year, 136 (170) from 4<sup>th</sup> year, and 62 (87) from 5<sup>th</sup> year students. The majority of 5<sup>th</sup> year students felt that palliative care has not been taught to a sufficient extent to them (mean 2.5 ± 2.4 standard deviation). Overall, "knowledge and skills in pain and symptom control" was rated as important (7.8 ± 2.1). However, "aids and support in reflecting the own role as physician in the care of terminally ill patients" was rated as almost equally important (7.5 ± 2.3). Furthermore, "To obtain information and aids how deal with difficult ethical questions and treatment decisions in terminal illness" was rated as the most important topic (8.4 ± 1.8).

**Conclusion:** Before implementation of palliative care as a compulsory subject, students at the end of their undergraduate medical training felt that palliative care has not been taught to a sufficient extent. They wish to get the opportunity for reflection of their own role in the care for the terminally ill, and for the discussion of ethical and legal topics.

**Abstract number:** P1-146

**Abstract type:** Poster

### Nursing Students' Attributed Impact to Palliative Care Learning: Better Nurses at the Bedside

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Students' perception after receiving Palliative Care teaching might be useful to better understand the position that this discipline should have in the curriculum. This study explores the teaching of PC from the side of the students, what nursing students think it meant to them to attend a course on PC at the University.

**Methods:** Participants were nursing students undertaking the optional subject of PC in two different Nursing Schools. All students were asked at the end of the course: What did it mean to you, personally or professionally, to participate in this PC course? Answers written by the students presented in the room (n=235) were analysed through content analysis by three researchers independently and periodical meetings

were held to review the analysis and achieve consensus. Ethics Committee approved the study. A comparison with a similar study, presented in this congress, undertaken with medicine students, is offered.

**Results:** Categories were,

- PC learning provided a holistic view of nursing,
- had a special contribution to nursing curriculum,
- added them to care for terminally ill patients and
- promoted a personal growth.

The students' emphasised PC learning showed them clearly that person care is the essence of the profession and highlighted the human part of the profession. Students identified that PC learning had its own entity and should be compulsory for all nursing students. Students stated that the subject had qualified them to understand better the patient and to know how to act with him. Finally they identified that PC teaching made them question about end of life, while helping to know them better and promote a personal development. In comparison with medicine students it was observed that nurses give more relevance to practice aspects of palliative care learning.

**Conclusion:** The sample of nursing students explored ascribe to PC learning a positive effect on them at professional and personal level emphasizing its clinical applicability.

**Abstract number:** P1-147

**Abstract type:** Poster

### Medicine Students' Attributed Impact to Palliative Care Learning: Better Doctors who Understand Better the Medical Profession

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Students' perception after receiving Palliative Care teaching might be useful to better understand the position that this discipline should have in the curriculum. This study explores the teaching of PC from the side of the students, what medicine students think it meant to them to attend a course on PC at the University.

**Design:** Medicine students undertaking the optional subject of PC in a Faculty of Medicine were asked at the end of the course: What did it mean to you, personally or professionally, to participate in this PC course? Answers written by the students presented in the room (n=284) were analysed through content analysis by three researchers independently and periodical meetings were held to review the analysis and achieve consensus. Ethics Committee approved the study. A comparison with a similar study, presented in this congress, undertaken with nursing students is offered.

**Results:**

- Flattering expressions about PC learning showed surprise or importance ("stimulating", "revealing", "thanks for teaching it".);
- prepares to be and act as a physician: it prepares you to be a PHYSICIAN (it should be compulsory, essential qualification for any future physician and to cope as doctor at end of life;
- medicine includes holistic care and family: it teaches to care in a global/holistic way;
- opens a new area of knowledge: you learn to treat the pain and other symptoms and many others (spirituality, team view, difficult questions, communication);
- it makes you reflect, grow and adds humanity;
- PC clinical experience is essential to learn the topic and all students need it.

In comparison with nursing students it was observed that students of medicine emphasise more that they have discovered a better and broader vision of the medical profession after the palliative care learning.

**Conclusion:** The sample of medicine students explored ascribe to PC learning a positive effect on themselves at professional and personal level let them understand medicine deeper.

**Abstract number:** P1-148

**Abstract type:** Poster

### Teaching Palliative Care on Wheels: An Intensive, Effective and Reproducible Method of Education

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The education of health professionals is essential for the

development of palliative care (PC). Although it is recommended the combination of theory and clinical training, not all educational programs combine both methods.

**Description:** The "Curso en Colectivo (CeC) ("bus round") incorporates both the theoretical and practical aspects of daily clinical activity of PC. It is an intense educational modality that is performed in a bus and in the place where the patient is (home or hospital).

**Objectives:** To describe the CeC in Argentina.

**Method:** While travelling to the place where the patient is, the clinical case is presented. Once at the destination, the patient and his/her family are interviewed by a faculty and 1-2 students; a 2 way communication system allows the students and faculty who remain in the bus to follow and participate in the interview. Back on the bus, discussion of the case takes place during transportation to visit of another patient.

During the afternoon and the next morning theory and practical issues are discussed with the whole group.

**Results:** 2008-11: 7 CeCs in different cities.

15 hours each; 2-3 faculty per CeC.

131 participants: physicians, nurses and psychologists.

Post CeC evaluations (77 % response rate):

100% recommended the course and considered it useful for their practice; they ranked  $\geq 9.5/10$  the clinical and theory activity.

**Discussion:** The CeC provide a particularly useful educational activity: the student experiences the PC model. It offers the possibility to reach primary care providers in their working places.

**Abstract number:** P1-149

**Abstract type:** Poster

### Palliative Medicine as an Elective in a Medicine School in Argentina, Austral University

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Often doctors and medical students express their difficulty in relating to patients at the end of life and facing suffering and death. Training during undergraduate school offers the possibility of improving care and professional relationship with the patient and the emotional environment, and manage the stress associated with the task more adequately.

In 2010, the Austral University incorporated Palliative Medicine as an optional curriculum in the undergraduate program for students of IV and V year.

The aim of this paper is to describe briefly the impact of this curriculum on students that were enrolled during the years 2010, 2011 and 2012. We present results regarding changes in knowledge and comfort of students in relation to the theme.

**Methods:** During the years 2010-2012 Palliative Medicine 85 students were enrolled, for a total of 24 hours, with a constructivist teaching model that included attendance at palliative care units. Students completed an on-line questionnaire the first and last day of the course, which tested knowledge and perception of comfort regarding the main areas of Palliative Medicine: symptom control, communication and psychosocial and spiritual support.

**Results:** There was a significant increase in knowledge between the pre- and post-course assessments. Students expressed an improvement in their comfort levels in the evaluation and treatment of pain and other symptoms, psychosocial and spiritual support to patients and their families and bad news.

**Discussion:** The addition of Palliative Medicine provided attendees knowledge concerning the main areas of Palliative Medicine. The experience gained by the student's direct contact with patients and their families was highly valued. Having an elective is an important opportunity to integrate the issue of care of people with life-threatening diseases in advanced stage in the Medicine curricula.

**Abstract number:** P1-150

**Abstract type:** Poster

### Certification of Nurses in Palliative Care

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Palliative care is not yet an independent specialty in Sweden. To develop and assure quality in the care of the dying patient the nurse must be able to work in a clinical setting, educate, develop evidence-based nursing care, conduct development projects and participate in nursing-care research. Our association has begun to give nurses the opportunity to receive a certification in palliative care which implies that the nurse possesses a high degree of

knowledge in the following areas:

- The different phases of palliative care and the nursing care processes related to each phase with respect to physical, psychological, social, spiritual/existential and cross-cultural aspects
- Guidelines and health-care programs
- Medical aspects of various symptoms of chronic and fatal diseases
- Pharmacology and medical technology
- The art and science of communication
- Pedagogical methodology and mentorship
- Nursing care development
- Clinical and research ethics
- Team interplay

The aim of the certification process is to ensure competence, development, research and the spread of knowledge within palliative care. Certification is in line with the nurses' ethical code and relevant area of knowledge. It has been approved by the Swedish Association of Nurses.

The certification process has been constructed by our management committee in cooperation with the membership. Applications meeting the criteria below result in certification.

- Qualified nurse (with bachelors degree)
- 5 years clinical work within specialised palliative care
- Course in palliative care corresponding to 15 ECT-points
- Member of SFPO
- Experience of developing or spreading knowledge of palliative care outside of ones own place of work
- Reference from immediate superior and a personal letter of motivation
- Since autumn 2011 when the process started 24 nurses have been certified. Certification is a way of ensuring quality of care and underlining the nurses' responsibility and competence in palliative care.

**Abstract number:** P1-151

**Abstract type:** Poster

### Clinical Scenario Based High Fidelity Simulation Training in End of Life Care for Medical and General Practice Trainees

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**Aim:** To assess the benefits of high fidelity simulation training in end of life care for medical and general practice trainees.

**Methods:** Two courses have been developed to provide simulation training in end of life care for non-specialist doctors undergoing core medical and general practice training. Scenarios based in acute hospital or community settings provided trainees with life-like experiential learning in order to develop skills in holistic assessment; symptom management; decision making and communication with patients, relatives and colleagues. A high fidelity mannequin allowed the recreation of clinical signs and symptoms and role-players were used as members of the clinical team and relatives. After each scenario, feedback was given to participants using video playback of the scenario and the observations of facilitators and other participants.

Throughout the courses small group teaching was also provided on specific topics. Questionnaires were completed by each participant before and after each course. Trainees were asked to rate their confidence using a visual analogue scale, in various aspects of end of life care.

**Results:** 8 GP trainees and 5 medical trainees completed the one-day course. Comparison of pre and post course questionnaires showed improved mean confidence scores in the management of symptoms; communicating with patients and relatives, making decisions about appropriate care and the use of end of life medications. Free text feedback was generally positive and participants found the interactive nature and small group format with open discussion and especially useful.

**Conclusion:** Evaluation of these initial courses suggests that high-fidelity simulation training provides a powerful model of training for medical and general practice trainees. Further development of these courses for is in progress and the possibility of extending the training to other doctors e.g. trainees in surgery and intensive care is under consideration.

**Abstract number:** P1-152

**Abstract type:** Poster

### Advanced Learning: PhD in Palliative Care - Three Years of Experiences of a Distance e-learning Doctorate within the International Observatory on End of Life Care

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**Background:** Education is a priority for the EAPC; past Congresses highlighted the need for palliative care in higher education. A significant challenge is meeting the needs of professionals working within palliative care both nationally and internationally.

**Aim:** The PhD in Palliative Care was developed by the IOELC to enable palliative care professionals to develop scholarship and research skills within their field. The innovative part time programme permits students to study via e-learning (2 years) and to undertake research from their home setting, with an annual academy based in Lancaster.

**Results:** The programme was launched in June 2010.

Analysis of the 3 current cohorts (n= 49) shows 29 international students (including Brazil, Bangladesh, North America and Slovenia) and 20 UK students. Some of the applicants were unable to take up their places due to lack of funding. The students' professions reflect the multidisciplinary of palliative care, including: medicine (n=11), nursing (n=5), social work (n=8) academia (n=7), service directors (n=6, mostly medicine/nursing), chaplains (n=3), coordinators (n=2); and others (n=6). The distance e-learning modules allow study at an advanced level and the asynchronous nature permits study at a convenient time from any geographic location. This learning approach facilitates collaboration between students and teaching staff through discussions on the virtual learning environment and tools such as webinars and wikis. Peer interaction is encouraged through cross cohort presentations of research ideas at the annual academy.

**Conclusions:** There is an interest in developing scholarship and research skills across the professions involved in palliative care. The e-learning nature of the PhD Palliative Care facilitates learning and collaboration irrespective of location. Despite the popularity of the programme, insufficient funding remains an issue and mechanisms for funding resource-poor students are required.

**Abstract number:** P1-153

**Abstract type:** Poster

### Training for Future Palliative Medicine Specialists: What Is the Role of the Multiprofessional Team?

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Since 2008 in France, trainee doctors have been able to enrol on a specialised advanced studies certificate programme qualifying them in the field of Pain/Palliative Medicine. This training gives residents in the last cycle of their studies the opportunity to commit to a 2-year programme leading to a qualification as a Palliative Medicine specialist. The Palliative Care team examines its practices in terms of delivering training to trainee doctors.

**Aims:** Improve cooperation between the resident trainee and the specialised nurse with a view to moving away from a curative stance and adopting an ethical approach constructed jointly with the nursing team.

**Method:**

1/ Review of the literature regarding the skills expected and the teaching tools available on clinical placement sites in the field of Palliative Medicine.

2/ Qualitative Survey supported by the Observatoire National de la Fin de Vie (French national end-of-life observatory): creation of four focus groups among Fixed Palliative Care Unit nursing teams and four focus groups made up of residents enrolled on this training programme.

**Results:** Young doctors will grasp the importance of the nursing diagnosis as a medical decision-making aid in situations of varying complexity. They will feel insecure about making a decision if they do not adopt an interdisciplinary approach, particularly when limiting treatment. They will encounter and take part in the construction of collective expertise in the field of Palliative Medicine for the first time. They are exposed to the "ethical concerns" of the senior doctor and the multiprofessional team around them. It will be difficult for them to adopt a palliative stance and take on board the personal subjectivity dimension if they do not shift their focus away from the curative management of pain.

**Conclusion:** The professional expertise of Palliative Medicine nurses gives them the capacity to play a role in the training of residents, within a framework of inter-professional cooperation.

## Poster sessions

Abstract number: P1-154  
Abstract type: Poster

### Palliative Care Knowledge and Attitudes of Newly Qualified Doctors Working in a UK Hospital

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**Aim:** Up to 58% of deaths in England occur in hospital. Many patients in hospital have care from newly qualified doctors or FY1s. UK medical training is approximately five years, with on average 16 hours of palliative care teaching. The aims of this study were to gain insight into the knowledge of FY1s in prescribing and drug choice in palliative care, symptom control and communication.

**Method:** Questionnaires were given to 25 newly qualified doctors.

**Results:** The study indicated that most junior doctors were not confident in prescribing palliative medications. Most doctors (87%) included analgesia and half named antiseizure medication and antiemetics as medications they would prescribe for end of life care. Far fewer included medication for anxiety, constipation, fluids, oxygen or steroids. Whilst most subjects listed hospital guidelines or the palliative care team as sources of advice, some doctors did not know where to seek help.

Pain was important was to 75% of the subjects however only half would assess breathlessness and less than half (43%) nausea. Fewer doctors would consider constipation (24%), agitation (18%), or secretions (18%). Most doctors did not feel confident in discussing with relatives and seniors about patients despite being in a position where this was necessary. Almost all (87%) felt unprepared for caring for palliative patients on qualifying.

**Conclusion:** The study showed that the majority of FY1s feel unprepared for symptoms control, palliative prescribing and communicating with relatives. There is a mixed response to the kind of symptoms reviewed and care may be suboptimal as not all FY1s know where to get advice. There is potential for breakdown of communication surrounding resuscitation status between the team and relatives. Clearly educating junior doctors in palliative care could be improved and following this study I designed a quick reference card to aid prescribing in palliative medication.

Abstract number: P1-155  
Abstract type: Poster

### Effective Collaboration between Pharmacists and Physicians Role of the Pharmacist in the Palliative Care Team

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**Aims:** Since 2010, in France, as a part of the reform in the medical school curriculum, future physicians and pharmacists start their curriculum with a joint year. Effective Collaboration Between Pharmacists And Physicians Role Of The Pharmacist In The Palliative Care Team.

Palliative care teams may include nurses, doctors, social workers, psychologist ... and pharmacists. What about collaboration between physicians and pharmacists? The objective of this work was to present a qualitative study of the view doctors have of the interdisciplinary work with the pharmacist in order to improve effective team work and palliative care.

**Methods:** A qualitative study of the opinions held by hospital clinicians of the collaboration with pharmacists by interviewing 10 practitioners according to the semi-directive interview technique was conducted.

**Results:** This study shows that, the legal responsibility of pharmacists is recognized. The pharmacist is perceived to have a fundamental role in complex assessment in palliative care as practitioner of different discipline. The quality of the training they receive is well recognized too. Pharmacists' competencies, in terms of educating patients on their health and any medical equipment, are highly appreciated by physicians.

This willingness to evolve towards an interdisciplinary approach is present despite a few time-related hurdles; in addition difficulties in communicating between pharmacists and physicians are cited.

**Conclusion:** If there is an expectation of collaboration, an understanding of how each discipline might approach "collaboration" with other health professionals is necessary to creating good teamwork in the delivering of palliative care.

Abstract number: P1-156  
Abstract type: Poster

### Integration of Palliative Care into the Undergraduate Medical and Nursing Curricula in the Republic of Serbia

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**Aims:** In 2009, the Serbian MoH published a national strategy for palliative care (pc), which acknowledges the need for pc services to be integrated into the health system & provided throughout Serbia. Introducing undergraduate students to pc is essential in developing a pc workforce for the future. Thus the aim was to integrate pc into the undergraduate curricula of all medical & higher nursing schools in Serbia.

**Methods:** A team of national & international experts led the process. Contact was made with the Deans for their endorsement of the process. Meetings were held with representatives from the faculties & a curriculum development process established. Existing curricula were reviewed & curricula drafted based on EAPC guidelines. Draft training materials were developed by the experts & circulated for comment, & minor amendments made prior to submission for approval by the university bodies.

**Results:** PC has been accepted as an elective course in the 5 medical schools in Serbia i.e. the Universities of Belgrade, Novi Sad, Kragujevac, Nis, & the Military Medical Academy. 2 other universities in Kosovo & the Federation of Bosnia & Herzegovina are also keen to integrate pc into their programs. The process of acceptance into the nursing schools is ongoing but it is anticipated that all 7 schools will integrate pc as a course. Comprehensive training materials have been developed, including a facilitators guide, presentations & a handbook for students, as there is no comprehensive Serbian PC book. 70 participants attended a day conference for the medical & nursing schools in May 2012 to introduce the curriculum.

**Conclusion:** Integration of pc into undergraduate curriculum is important in the development of pc. Getting buy-in from the Deans, thus reinforcing its inclusion within the national pc strategy was an important part of the integration process.  
*This work is funded by the EU project 'The Development of PC in the Republic of Serbia' (EuropeAid/129769/C/SER/RS).*

Abstract number: P1-157  
Abstract type: Poster

### Inclusion of Palliative Care Topics in Medical Undergraduate Textbooks

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**Introduction:** Palliative care is an advancing specialty. There has been a significant increase in the number of published research in the last decade.

**Aim:** To assess the attention to palliative and end of life care matters in undergraduate medical student textbooks recommended by an Irish medical school.

**Methods:** The top most commonly reviewed clinical textbooks from the hospital medical library were reviewed quantitatively and qualitatively in relation to Palliative care topics.

**Results:** Textbooks reviewed covered specialties of paediatrics, clinical medicine, surgery and general practice medicine. Sixty percent had no reference to palliative care or end of life care. The best resources on palliative care were the clinical medicine textbooks. The topics were divided among different specialty sections. Palliative care content accounted for between 1.8% and 2.4% of the total. It included topics related to ethics, symptom management, COPD, CCF, motor neuron disease and post-cerebrovascular accident.

The next best resources was paediatrics which had up to two paragraphs or between 0.2-0.6% of the total content devoted to palliative care. One of the resources was a general overview of palliative care as part of the oncology section.

**Discussion:** Worryingly the majority of textbooks did not reference palliative care or end of life care. Clinical medical textbooks had the most varied topics and the majority of information. Only 0.7% of total resources discussed palliative care topics. We feel there is a significant mismatch between the amount of educational material in the textbooks and the prevalence of palliative and end of life care issues that most doctors will encounter. Recognising dying and managing patients at the end of life are skills that are both important

and complex.

**Conclusion:** Despite growing recognition of the importance of palliative medicine as a subject for medical undergraduates there are still considerable deficits in available textbooks.

Abstract number: P1-158  
Abstract type: Poster

### A Vision to Integrate an Undergraduate Palliative Care Curriculum: Lessons Learned from Program Development

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After the implementation of the 2003 Canadian EFPPEC program, the Division of Palliative Care at our university developed a vision to build and integrate palliative and end-of-life care (PEOLC) education into the undergraduate medical education (ugme) curriculum.

An interprofessional (IP) team representing medicine, health sciences, palliative care educators and community hospices was established. Our vision included: promoting and developing opportunities for IP PEOLC across Faculties; seeking funding for collaborative educational research; participating in potentially relevant academic workgroups; taking leadership roles in curriculum renewal planning; actively seeking out teaching opportunities. A 2004 needs assessment demonstrated medical students' need for, and receptivity to, a PEOLC curriculum.

Pre-2004: No consistent ugme palliative care input. Less than 5 medical students/year chose PEOLC electives.

2006-2008: A new ugme curriculum integrated national PEOLC competencies and introduced first year students (MD1) to concepts of suffering, holistic care, and IP learning; MD1 PEOLC teaching in ethics (2 hours); MD3 PEOLC session (2hrs); Electives: 36 hour IP course 'Death Made Visible'; IP on-line module 'Total Pain'; increased opportunities for clinical electives.

2008-2010: New elements added: mandatory selective rotations in palliative care (MD3, 2 weeks); 'Back to Basics' review lecture (MD4, 1hr); Team OSCE; new elective IP PEOLC course.

2010-11: New PEOLC curriculum for MD2- 1 week Pain; 1 week PEOLC; exam

2011-12: MD2 - Ethics (2 hrs)  
Students (MD1-4) requesting electives in palliative care have increased (2008-2009: 14; 2010-2011: 41). Mandatory selectives: 29-30 MD3 students/year).

Curriculum change requires an approach which draws on pedagogy, through innovative, IP learning approaches; pragmatism with extensive organizing; and politics in recruiting steadfast champions to initiate change. Ultimately it is about seizing all potential opportunities.

Abstract number: P1-159  
Abstract type: Poster

### Are Palliative Medicine Trainees Evolving as Learners? Changing Learner Preferences from Informal to Formal Learning

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**Background:** A historical distinction exists in medical education between formal (undergraduate) and informal (postgraduate) learning. Emphasis is now increasing on formal learning in postgraduate training, with increased protected teaching time away from the workplace. Increasing reliance on formal learning may impede trainees' and supervisors' ability to recognise the learning embedded in workplace activity.

**Aim:** To explore how trainees' learner preferences are changing and thus help inform specialty-specific educational strategy.

**Methods:** Online surveys of palliative medicine trainees (n=57) and supervisors (n=76) were conducted at one UK Deanery plus semi-structured interviews of trainees (purposive sampling). Survey response rates were 77% for trainees and 66% for supervisors. Survey data was analysed using simple descriptive and comparative statistics (Fisher's exact test). Following member checking, interview transcripts were analysed thematically by manual analysis.  
**Results:** 65% of trainees and 88% of supervisors value opportunistic workplace learning more than learning in protected teaching sessions. 50% of 1st & 2nd year trainees report workplace learning as more important vs 85% of 3rd



& 4th years; a significant trend that junior trainees value formal learning opportunities more ( $p < 0.05$ ). These findings were consolidated at interview. 'I expect to learn through doing service provision and not separately' (4th year trainee). 'Trainees' expectations have changed - junior trainees like a large amount of formal teaching and more guidance in what to learn' (3<sup>rd</sup> year trainee).  
**Conclusions:** The majority of trainees and supervisors express a preference for workplace based learning with junior trainees valuing formal learning opportunities more than their senior counterparts. Educational strategies such as planning workplace based assessments in advance may help formalise the process of workplace based learning and bridge the gap between formal and informal learning.

**Abstract number:** P1-160

**Abstract type:** Poster

### Final Year Student Nurses Knowledge of Palliative Care: A Pilot Study

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**Background:** Palliative care aims to improve quality of life of patients and their families through the diagnosis and treatment of any physical, social or psychological issues they may be suffering. While statutory bodies recognize palliative care education should be provided at undergraduate level little had been done to implement same.

**Aim:** To investigate the knowledge levels of final year student nurses in the area of palliative care.

**Method:** A cross-sectional survey research design was employed. The sample comprised of 48 final year bachelor of science in nursing students. Using the Palliative Care Quiz for Nurses, the researcher investigated final year student nurses knowledge of palliative care. The PCQN consists of 20 statements regarding palliative care that are answered either true, false or I don't know. Two rank order questions ascertained the importance the participants gave to a number of virtues and activities to the role of the palliative care nurse.

**Results:** Results revealed the sample had a modest knowledge of palliative care with a mean of 9.28 out of 20. A number of areas were highlighted as having knowledge deficits including in relation to the philosophy of palliative care and symptom management specifically in relation to pharmacology. Participants with previous personal experience had significantly higher percentages of correct responses than their colleagues with no previous personal experience. Caring was ranked as the most important virtue for a nurse in palliative care while there was no clear consensus on the most important activity.

**Conclusion:** The results of this study indicate modest knowledge of palliative care in final year student nurses. Areas of greatest deficit include the philosophy of palliative care and pharmacology in symptom management. Educational initiatives and clinical placement could enhance student nurses knowledge and in turn improve practice.

**Abstract number:** P1-161

**Abstract type:** Poster

### EU-US Collaboration Project Integrating Self-management and Palliation Concepts (IMPACT): Health Policy and Nursing Education Implications

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**Aims:** This paper reports an EU-US collaboration utilising nursing experts from two European Union (EU) institutions and two United States (US) institutions and associated networks to reassess traditional approaches to the self-management of chronic ill-health, including palliative care, education and practice standards.

**Methods:**

1. Research and key policy documents were examined for their relevance to policy making, particularly to support self-management, empowerment and palliative care;
2. Survey conducted across all nursing schools in EU and US to ascertain what content palliative care courses have in relation to self-care and palliative care
3. Development of a conceptual framework for use in education and practice in palliative care and self-management
4. Development of website and regular postings- blog
5. Systematic review to produce database of evidence, best practice, case studies, about self-management and

palliative care 6. Development of a taxonomy of terms and definitions in self-management and palliative care, via concept analysis.

**Results:** The survey revealed few institutions with key content specifically related to self-care and palliative care. Themes from key policy (EU-US) will be presented. We have developed an interactive website for the purposes of the project. A conceptual framework for use in education and practice in palliative care and self-management will be presented.

**Conclusion:** The key outputs; curriculum guidelines in relation to self management and palliative care for us in both US and EU nursing schools will be presented.

**Abstract number:** P1-162

**Abstract type:** Poster

### Concept Analysis of Self-care in the Context of Palliative Nursing

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**Aims:** This presentation examines the concept of self-care as part of a larger study: (IMPACT), with the aim of facilitating cooperation in higher education and vocational training in the EU and US. The primary aim was to examine the concept of self-care, clarify its meaning in the context of palliative nursing and to identify its relationship to similar concepts in its application to palliative care practice.

**Methods:** Avant and Walker's method of concept analysis was used as an organizing framework to support a review of the literature and subsequent analysis of the concept self-care.

**Results:** This paper clarifies the concept of self-care in terms of its use in palliative nursing and reaches a working definition for practitioners, in alignment with definitions and clinical guidelines operating globally. A clarified definition for nursing use based on this concept analysis is proposed. Supported self-care is underpinned by 6 key

complementary attributes: (*maintaining normality; preparing for death; support from family/friends; self-care strategies/physical; self-care strategies/emotional; support from HCPs*) and 10 roles of palliative nursing, (*knowing the patient; being there; providing comfort; possessing excellent communication skills; providing emotional support; promoting independence; providing good pain and symptom control; teamwork; referral role; providing information*) which are underpinned by robust assessment, operating directly with knowledge of the patient in relation to his/her respective needs, capability and coping ability and the outcomes and processes of palliative nursing.

**Conclusions:** The attributes and roles are comprehensive, spanning the needs of the patient throughout his/her palliative care journey from maintaining normal life to preparing for death and can be incorporated into a practice framework, which embraces the importance of robust assessment and gives equal weight to both the process and outcome of palliative care.

**Abstract number:** P1-163

**Abstract type:** Poster

### Training of Volunteer Students of Medical University for Work in Multidisciplinary Team on Palliative Care

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The palliative help is the active, overall help to the patient having an incurable disease. Therefore there necessarily should be some volunteers along with the doctor, nurses, psychologist and the social worker as a part of multidisciplinary team.

The purpose is to train 25 volunteers being students of medical schools of Kazakhstan for providing the palliative help in the structure of multidisciplinary team.

Preparation method - carrying out Summer school of volunteer students of medical universities in which in volume of 30 instruction hours the students were given knowledge of the main aspects of the palliative help.

Within the 5 days the classes were given in the following subjects:

Volunteers movement. Concept and philosophy of the palliative help. International standards of palliative medicine. Basic principles of palliative treatment. Symptomatic therapy of incurable patients. Deontology in an oncology. Pain. Three-stage scheme of pain management. Organizational structure of system of the palliative help.

Ethical and cultural aspects of palliative treatment. Modern principles of the report of bad news. Legislative and legal questions in the palliative help. Work of multidisciplinary team in the palliative help. Scheduling on development of volunteers movement. A role of volunteers in multidisciplinary team.

**Summary:** Following the results of work of Summer school 26 volunteers from 6 medical universities of Kazakhstan were trained, who now work with incurable patients and carry out work on creation of the National volunteers network in the palliative help of Kazakhstan.

**Conclusion:** The role of the professional volunteer possessing the basic medical knowledge and trained for work in multidisciplinary team is very important.

**Abstract number:** P1-164

**Abstract type:** Poster

### Teaching End-of-Life Communication: A Novel Way to Engage Residents

*Koh M.*

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**Aims:** Palliative Care practitioners and educators play an important role in teaching End-of-Life communication skills to Medical Students, Residents and Fellows.

This paper describes a novel method we used for teaching 'Breaking Bad News' to Residents and shares the data we collected about the effectiveness of this teaching style.

**Methods:** The teaching module was a 1 hour Semi-didactic and Semi-Role-Play session. The first half hour (30 minutes) was a didactic lecture, which included the 'SPIKES Protocol' and simple communications skills. We also showed a positive demonstration video about 'Breaking Bad News' as well.

The next half hour (30 minutes) was a role-play whereby each Resident role-played a scenario for 10 minutes. They would then become the Surrogate for their colleague for the next 10 minutes. This process was observed by a skilled facilitator (Fellow or Attending) who debriefed them during the last 10 minutes. The ratio of Facilitator to Residents was about 1:4-6.

We ran this module 3 times and taught 30 Residents (average about 10 each session) in total. We needed about 3 facilitators during each session or a total of 9 facilitators (Fellows or Attendings).

**Results:** The Residents were asked to rate their experience on a Likert Scale ranging from (Not Helpful / Slightly Helpful / Average / Helpful / Very helpful):

Most of the Residents felt the session was either helpful or very helpful.

1. Lecture on 'Breaking Bad News' - (Helpful - 50.0% / Very Helpful - 50.0%)
2. Role-modelling (Positive demo) - (Helpful - 26.7% / Very Helpful - 63.3%)
3. Resident Role-Play - (Helpful - 13.3% / Very Helpful - 80.0%)
4. Faculty Critique - (Helpful - 24.1% / Very Helpful - 72.4%)

**Conclusion:** A short, concise teaching method comprising 30 minutes of didactic lecture, inclusive of a positive demonstration video and another 30 minutes of Resident Role-Play was effective in teaching Residents the End of Life communication skill of 'Breaking Bad News'.

**Abstract number:** P1-165

**Abstract type:** Poster

### Development of Social Work Training as Part of the Strategy to Develop Palliative Care in Serbia

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**Aims:** Palliative Care (PC) is well developed in Western Europe. In Eastern and Central Europe development can be hampered by factors such as poor access to health services, decentralisation of services, poverty & lack of training. Thus we aimed to develop a Serbian PC Social Work (SW) training program as part of a larger multi-disciplinary program aiming to embed PC within the state health & social systems.

**Methods:** A scoping exercise was conducted to examine the social care system, its legal foundations & the current education & practice of SW in relation to the integration of PC. Since 1995 SW training is at university level & the Institute of Social Protection (ISP) supports continuing education. Current training contains limited PC thus the need for PC training was endorsed by the Ministry of Social Welfare.

**Results:** A training program was developed & approved for accreditation in Oct 2012 by the ISP, utilising recommendations from the EAPC task force on PC SW and the UK recommendations for the role of generalist social work. Prior to attending this course, all course participants

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undertake a multi-disciplinary course on the philosophy of PC & on PC knowledge & skills development. The further two-day SW training was developed & includes content reflecting the competences and skills required by social workers in PC and endorsed by social workers, their managers & the ISP. Elements of the course will be addressed in this paper.

**Conclusion:** Course evaluations will provide opportunities to reflect on the content & impact of the training. It is currently the only European government accredited course in PC for generalist social workers & will make a contribution to the next stage of the EAPC Task Force on SW in PC, which aims to develop elements of PC curricula for undergraduate & post graduate social worker education across Europe. This work is funded by the EU project "The Development of PC in the Republic of Serbia" (EuropeAid/129769/C/SER/RS)

**Abstract number:** P1-166  
**Abstract type:** Poster

### **Transforming End of Life Care: An Integrated Educational Initiative Run by Palliative Care Specialists for Non-specialist Health Care Professionals who Provide End of Life Care in Hospital and Community Settings in England**

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**Aims:** Radical transformation in the National Health Service is leading to integration of hospital and community services. We are at the forefront of this change and the development and implementation of tools to improve patient care at the end of life. Face-to-face training remains scarce and expensive, but integration presents opportunities for those who do not normally meet to learn together. The National End of Life Programme has endorsed use of national end of life care tools e.g. AMBER care bundle & Liverpool care pathway. These are practical but need to be seen in context of the patient and clinician experience and palliative care overall. Levers of change have included CQUIN (Commissioning for Quality and Innovation) targets.  
**Design:** A 2 day novel, practical and relevant package was set up for face-to-face interdisciplinary learning for up to 30 clinicians from hospital or community settings. Using the tools and targets as levers it runs bimonthly. Topics include use of the tools, prescribing end of life drugs, discharge management and bereavement. Structured positioning of delegates aids communication between disciplines, who would normally rarely meet. Use of case based learning prompts dialogue, which has led to a more empathic understanding.  
**Results:** Uptake is good and well evaluated (see abstract A-518-0007-00903). It has generated commissioning interest and is now a local CQUIN, bringing income to our organisation. Palliative care team members have enhanced their teaching skills and relationships with frontline workers.  
**Conclusion:** The initiative aids integration between hospital and community services and improves knowledge of end of life care provision. End of life care tools and local commissioning, in conjunction with an integrated organisation, have optimised course development and delivery. It has been well received and feedback confirms its usefulness. We aim to reach a wider range of health care professionals particularly from the hospital setting.

**Abstract number:** P1-167  
**Abstract type:** Poster

### **Exploring Palliative Care Principles in the Early Medical Student Curriculum**

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**Aim:** The EAPC requirement to have Palliative Care principles discussed early in the Medical School curriculum lead to the design of a new and innovative small group teaching session for 2<sup>nd</sup> year medical students. The aim was to look at the broad principles of Palliative Care within the context of patient, carer and healthcare professional experience of significant illness. This used Palliative Care as an example of holistic care, and included psychosocial issues and multi-disciplinary teamworking.  
**Methods:** The sessions were for groups of 12 students. Each group was further divided so that 4 students rotated in turn to speak with patients, health care workers and staff from allied services. The students discussed with patients and carers their experiences during their diagnosis and

treatment. The health care workers were asked about their roles and how the differing professions worked together. Students were encouraged to ask about the impact of the work on the health care workers. Each session was facilitated by the patient or individual worker rather than by a member of the university thus enabling a personal view.

**Results:** Students, professionals and patients evaluated the sessions and this data was analysed. The students reflected this was an area of practice they had not had exposure to, and felt that these sessions provided an insight into the patients' feelings and concerns that they had not considered before. Students had not previously considered multi-professional team working and appreciated the opportunity to explore the working role of others.

This work has shown that students learn well in small groups and can start to understand the impact of disease on patients, families and professionals at a very early stage.  
**Conclusion:** This method of teaching introduced students to the basic principles of Palliative Medicine early in their training and evaluated well. The delivery of the session is labour intensive but if coordinated well is worth the investment.

**Abstract number:** P1-168  
**Abstract type:** Poster

### **Challenges in Implementation of Palliative Care Educational Programs in Former Soviet Countries - Georgian Experience**

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**Research aims:** Beginning of XXI century showed remarkable increase in global aging, together with rising incidence and prevalence of oncologic diseases, AIDS and chronic progressive illnesses. All these have led to huge numbers of incurable patients, requiring the relevant complex medical and social care due to symptoms and suffering from their illness. A new direction in public health, called Palliative Care (PC), serves to this very aim. Between former soviet countries (FSC), Georgia was one of the leaders to develop PC services since 2002 and several successful steps have made during this period. The research aim of the study was to identify the main challenges and barriers in implementation of PC education in FSC in example of Georgia.

**Study design:** The interviewing of 150 health care professionals, health care administration staff representatives and society in Georgia, Kyrgyzstan, Armenia, Tajikistan and Azerbaijan was performed. The level of their interests, experience, knowledge and motivation were evaluated by specially designed questionnaires. The respective database was created and analyzed.

**Results:** In most FSC PC still on very basic level of development. The clear understanding of the substance, role, place and educational status of PC still remains one of the most essential hindrances on the way of implementation PC Educational Programs and its incorporation in National Healthcare System as well.

**Conclusion:** According the Georgian experiences the most frequent and similar challenges were noted in implementation PC Educational Programs in FSC:

**Understanding of PC Missing the palliative care modules and courses in all level of medical education; Education for medical professionals; Missing the recognition of palliative care in medical societies and between authorities; Lack of resources (medical services, human and financial); Opioids Availability and opioidphobia in Society and between the Medical Professionals; Stigma; Lows and Regulations.**

**Abstract number:** P1-169  
**Abstract type:** Poster

### **Pain Management and Home Care Services - An Unequal Equation? Barriers to Implementing an Adequate Pain Management in Home Care Settings**

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**Research aims:** Nurses from home care services are required to implement the *German National Standard for Pain Management in Nursing* when caring for patients with cancer. As part of a research project, the standard recommendations were modified and expanded to reflect more properly the health care realities for nurses in home care settings. The aim of the study was to assess whether or not the modifications helped to ease the implementation of the standard requirements.

**Study design and methods:** A qualitative design was

implemented using focus group interviews, transcripts and qualitative content analyses. Nurses from 14 home care units were invited to participate in five interviews, each thematically structured along the recommendations of the *National Standard* (i.e., pain assessment, pharmacological treatment, drug-induced side-effects, non-pharmacological treatment, education).

**Results:** Each home care unit delegated a representative to take part in at least one of the five interviews. During the first interview, nurses clearly acknowledged the benefits of the modifications. Yet, they also reported about their individual lack of knowledge on the subject matter. The first three interviews brought forth many barriers and problems, which impeded the proper implementation of the requirements. Communicating pain assessment results or documented side effects with a patient's general practitioner was stated as problematic. Yet, this was not the case, when the communication involved physicians with a background in palliative medicine.

**Conclusion:** The findings of the study revealed problems in the implementation of the National Standard due to a lack of knowledge and a difficult interprofessional communication process. The interviews show that the participants are willing and motivated to engage in the topic, however, they are still in need of additional implementation strategies in order to meet all of the requirements put forward in the *National Standard*.

**Abstract number:** P1-170  
**Abstract type:** Poster

### **Stepping Out: Introducing an End-of-Life Care Programme to a Critical Mass of Local Care Homes**

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**Aims:** The Six Steps to Success programme was launched in the UK to support the delivery of end of life care in care homes. 29 of the 109 nursing and residential homes (3,600 beds) in our locality (NW England) have undertaken the programme and this poster demonstrates the impact of the programme upon the knowledge, skills and confidence of care home staff.

**Design:** The programme, delivered from the Hospice Hub by End of Life Care Facilitators, includes:

- A pre & post course self-assessment of knowledge, skills and confidence
- Post workshop evaluations
- An end of programme questionnaire.

This poster describes the analysis of these.

**Results:** The programme met the needs and expectations of 100% participants. 100% found the education clear and felt well supported by the EoLC facilitators. Evidence shows that the cohort improved in knowledge, skills & confidence across all topics when measured on a 5-point self-assessment scale. Qualitative analysis of feedback indicates that the care homes are working as a team to utilise end of life tools & improve patient experience approaching the end of life.

**Conclusion:** The Six Steps to Success Programme has enabled care homes to bring about organisational change & develop frameworks to improve End of Life Care in their place of work. By working together, sharing experiences & ideas, supported by their facilitators & the local hospice, care homes have developed comprehensive end of life care policies which have enhanced delivery of high quality care. By rolling out the programme to a large number of care homes over a 12 month period we are creating a ground swell of enthusiastic motivated care home staff with a desire to collaborate with those working in other health & social care settings to improve the experiences of their patients & relatives.

**Abstract number:** P1-171  
**Abstract type:** Poster

### **Palliative Care Education: Building Resilience for Communities to Care for AIDS Patients in an Urban Slum. A Case Study Kawempe Home Care, Uganda**

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Kawempe Home Care is a community based organisation that provides comprehensive holistic care to patients with HIV/AIDS and Cancer. The organisation works with community volunteers to provide care and support to patients with advanced AIDS or Cancer. They monitor and support medication adherence, give basic nursing care and psychosocial support.

The volunteers are identified among the patients who are living positively with AIDS and are recommended a

community leader. The volunteers then undertake a five day education programme on home based palliative using the World Health Organisation care givers booklet and the Government of Uganda's Home Based Care training manual. The trainees are also given training in communication skills, counseling and report writing and a five day practical training session at a patient's home. The volunteers are then assigned parishes to work in and are given mentors to guide and support them for 6 months induction training.

Analysis of the clinical and virologic outcomes of AIDS patients started on antiretroviral therapy between January 2008 and December 2009 showed: A total of 306 patients were started on ART and got adherence support. A three year survival rate was 86.4% for 235 patients. The average CD4 cell trends at baseline, 6, 12, 18, 24 and 30 months was 136, 395, 409, 428, 489 and 525 cells/ml respectively. Baseline average weight was 55.3kgs and average study weight was 61.4kgs. Baseline viral load was not done, but 12 and 18 months tests revealed 83.7% and 86.4% viral suppression.

The results showed high three year Survival rate and high levels of virologic suppression signifying good treatment outcomes. These results may in part be attributed to the support of the community network of care for the community based medication adherence support. Further research studies should include randomisation of this intervention to further substantiate the evidence base.

**Abstract number:** P1-172

**Abstract type:** Poster

### Educational Programs of Cancer Prevention Center in Palliative Care in Georgia

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**Background:** Hospice and Palliative Care (PC) is a relatively new but rapidly developing medical discipline in Georgia. Still PC is not included in a list of medical specialties and its subspecialty for different specialties. In 2007 aspects of Palliative care components were integrated into Georgian legislation

- Law of Healthcare;
- Law of medical activity;
- Law of patient's right;
- Law of the narcotics, psychotropic drugs, precursors and narcologicalaid.

**Goals:** These changes develop necessity of providers of PC in Georgia and initiative of undergraduate and postgraduate education for Georgian physicians and nurses in PC.

Inclusion of this discipline in undergraduate and postgraduate education was initiated by the Cancer Prevention Center and started by Department of Oncology of Tbilisi State Medical University (TSMU) in 2006.

- Curriculum development and undergraduate education:
- More than 200 medical students educated since 2007
- More than 100 nurses educated since 2007 • Palliative Care curriculum designed for oncology and family medicine residents
- More than 70 physicians participated since 2007
- Postgraduate education for physicians
- Short courses in Pain Management and Symptom Control
- Course for specialization in Palliative Care
- the guideline for chronic pain management and recommendations for the patients were created by the team of experts and adopted by the MOH (2012);
- Pain management was included in all residency programs which can cover this field; (2011)
- Master class Course developed and delivered on October 2007 in Tbilisi, Georgia - Organized by CPC (Cancer Prevention Center), - ESO (European School of Oncology),

**Outcomes:**

- 1) awareness of Georgian society about their rights for PC;
- 2) Education of Georgian medical society about benefits of PC;
- 3) Education of general practitioners and primary care physicians for providing of basics of PC;
- 4) rising of demand and preparation of human resources for spread out of PC all over the Georgia.

**Abstract number:** P1-173

**Abstract type:** Poster

### Palliative Care Education for Medical Students: Analysis of an Exercise on "Delivering Bad News"

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**Objective:** Systems for palliative care education have not yet been established at medical schools. Only 10% of universities with medical schools have a palliative medicine course that covers palliative care education. Education at medical schools primarily involves unidirectional lectures, and practical training related to communication is rare.

During the five-year period starting in 2007, our university provided 10 sessions of bidirectional lectures for students in the third year of the six-year medical school program. Practical training reports were analyzed in order to obtain suggestions for future palliative care education.

**Methods:** Practical training on "Delivering bad news" was conducted on a total of 43 students who enrolled in a series of lectures on "palliative medicine". Practical training was performed in two 10-minute parts, after which feedback on the exercise was given by the simulated patients to students. Following the training, students wrote a report in free response format. The report contents were then analyzed using Word Miner<sup>®</sup> text mining software. Using all the words appearing in each report as primitive variables, words having similar meanings were organized and classified into items as component variables to analyze educational effects.

**Results:** A total of 33 subjects described the training as "difficult", with the main reasons being "nervousness" and "unease". On the other hand, 25 subjects found the training "meaningful", with the main reasons being "responsibility", "professionalism", and "relationships of trust". In the item "Communication", a relationship was observed between "importance" and "consideration".

**Conclusion:** Incorporation of practical training related to communication into the early stage of medical education may not only enable learning of the importance of communication, which forms the basis of palliative care, but also contribute to formation of physician responsibility.

**Abstract number:** P1-174

**Abstract type:** Poster

### An Assessment of the Impact of an Interdisciplinary Teaching Programme on Self Efficacy and Attitudes Towards Caring for Palliative Care Patients between Candidates from Different Professional Backgrounds

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**Aim:** To evaluate the impact of an interdisciplinary teaching programme on self efficacy and attitudes towards caring for palliative care patients between candidates from different professional backgrounds.

**Design:** The study employed a before and after (B-A) longitudinal design using a validated thanatophobia and self efficacy questionnaire which enables measurement of change over time. Questionnaires were completed pre and post course and 6 months after course completion. The results were analysed using SPSS.

**Setting/participants:** Participants were recruited from the candidates participating in the European Certificate in Essential Palliative Care course between April 2010 and June 2010. Inclusion criteria were completion of the course and age greater than 18years. Exclusion criteria were unwillingness to give informed consent or complete questionnaires and not completing the course.

**Results:** 23/24 candidates consented to participating in the study and completed the initial questionnaire. 19 (83%) candidates returned the second and a total of 13 (57%) candidates completed all of the questionnaires. When comparing the Thanatophobia Scale results from each questionnaire we found a small change from before and immediately after the course, but a statistically significant change both before and 6 months after the course was completed and post course and 6 months later. When comparing the Self Efficacy Scale results from each questionnaire we found a statistically significant improvement in self efficacy scores pre and post course, pre course and 6 months after course completion and a non significant improvement pre course and after 6 months.

**Conclusion:** This study shows that the European Certificate in Essential Palliative Course is a significantly effective way of improving palliative care throughout a variety of settings across a range of professions.

**Study funding:** From the hospice. Ethical and R&D approval gained

**Abstract number:** P1-175

**Abstract type:** Poster

### Exploring Education and Training Needs amongst the Palliative Care Workforce in England

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**Aims:** Education and training are recognised internationally as essential parts of providing high quality palliative care. As part of a larger study to explore the extent of palliative care need in two acute hospital settings in England, we report the perceptions of health care professionals regarding their training and educational needs.

**Methods:** Phase 1 involved eight focus groups and four individual interviews with 58 health professionals from general practice, specialist palliative care and acute hospitals, exploring their experiences of palliative care and perceived education and training priorities. Phase 2 of the study involved a survey of palliative care need at two hospitals in England. Hospital based doctors and nurses completed questionnaires to identify patients with palliative care needs according to a standardised definition and to respond to questions about their training and education needs.

**Results:** Professionals identified that lack of training and education were among a range of barriers to the provision of palliative care. Participants felt that while care pathways were perceived as useful guides, they were not adequately trained to address prognosis and goals of care with patients and their families. In Phase 2 of the study, 171 nursing staff and 81 medical staff completed the questionnaire and two thirds of this sample felt they required additional training in palliative care; 87% of doctors and 95% of nurses reported that they would take up palliative care training if it was made available to them.

**Conclusions:** More work is needed to examine and clarify the interplay of: behaviour change, setting, the 'cure' orientation approach, type of health professional, and nature of any educational intervention in order to effect sustained behavioural change.

**Abstract number:** P1-176

**Abstract type:** Poster

### Cardiology Fellowships in Palliative Medicine: Would this Improve Training in Advanced Heart Failure Management?

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**Aims:** It is accepted that palliative care for non-cancer conditions lags behind that for cancer. To equip future cardiologists with the necessary knowledge, skills and behaviour, end of life care has been incorporated into the 2010 UK Cardiology Curriculum. This survey evaluates the confidence of trainees in managing end of life issues in cardiology patients.

**Methods:** An online questionnaire was distributed to all UK registrar-grade British Junior Cardiac Association members. **Results:** 219 respondents:

**Clinical Experience:**

- 69% of trainees experience difficulties in palliating patients with advanced heart failure.
- Less than 25% regularly start opioids, antiemetics or laxatives and only 5% consider using anti-depressants.
- 73% feel that the care that they provide patients with advanced heart failure is poor or only adequate. Over 50% do not feel equipped to discuss advanced care planning and end of life issues when seeing advanced heart failure patients in out-patient clinic.

**Training:**

- 94% of trainees feel that the palliative care team play an important role in the management of patients with advanced heart failure but only 54% seek specialist palliative care input when experiencing problems
- 45% report receiving no training in palliation of advanced heart failure symptoms. 57% are unhappy with current provision of training.
- 86% think that end-of-life training is important or very important within the curriculum.
- Trainees' suggestions include workplace-based supervision with additional training days, closer links with local hospices and specific fellowships for cardiology trainees in palliative care.

**Conclusions:** This survey shows that despite being part of the national curriculum for training in cardiology since 2010, trainees' level of confidence in delivering end of life care in advanced heart failure and discussing prognosis is poor. This could be rectified by closer links with palliative care as well as fellowship/exchange programs between the specialities.

**Abstract number:** P1-177  
**Abstract type:** Poster

## Palliative Care Education Program in a Tertiary Medical University in Bangladesh

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The article describes the palliative care post graduate education courses in a tertiary medical university in Bangladesh. Among the different courses there exist three days introductory courses for doctors, nurses, community volunteers, family members, policy makers & media personnel. The 7 day courses are for MD residents and six weeks basic certificate courses in palliative medicine (BCCPM) for doctors and palliative nursing (BCCPN) for nurses. The majority of the health care professionals working in hospitals and in the communities often look after patients with palliative care needs. The university recognized the urgent need to assist Bangladeshi doctors in developing the medical skills required caring for patients and their families who are faced with terminal illness and the physical, emotional, psychosocial, and spiritual distress associated with end-of-life issues. The three day courses are presented as six hour face-to-face teaching sessions for three consecutive days. The course is also designed to meet the needs of health care professionals who wish to develop specialist palliative care knowledge and skills with time. Since 2008, 93 doctors & nurses & 86 community volunteers for introductory course, 23 doctors for BCCPM & 14 nurses for BCCPN have registered for the course. A combination of availability of background material, interactive theory session and clinical exposure are the core of the course. The courses have been jointly organized, run and evaluated by the centre for palliative care of the university as well as by the WHO Collaborating Centre at the Institute of Palliative Medicine of Calicut, Kerala, India. The participants of certificate courses are eligible to apply for the Wolfson International Bursaries, UK. The university has come out with a curriculum for the six weeks Basic Certificate Courses in 2012 after three pilot courses and a consensus workshop supported by Bangladesh University Grants Commission.

**Abstract number:** P1-178  
**Abstract type:** Poster

## Developing the Role of the End of Life Care Key Worker in the Acute Setting

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National figures show that 58% of all deaths in England occur in the Acute setting. The delivery of high quality end of life care (EoLC) should therefore be a part of the core business of Acute services however numerous reports describe the need for improvements (DoH 2008, National Audit Office 2008, NCEPOD 2009).

In order to bridge this gap, one of our aims was to establish a Trust-wide network of EoLC Key Workers positioned in all in-patient clinical areas to champion EoLC. A supporting document 'Developing the End of Life Care Key Worker Role' (Nov 2011) was produced by the Hospital Palliative Care Team in order to clarify the rationale, requirements and responsibilities of such a role.

It was recognised that the undertaking of such a role must be underpinned by education, training and support and so a programme was developed to standardise and address the training needs of Health Care Professionals undertaking the role of EoLC Key Workers. The programme is based on the National End of Life Care Programme's (NEoLCP) 'The route to success in end of life care in acute hospitals' (June 2010) and 'Common core competencies and principles for health and social care workers working with adults at the end of life' (DOH 2009) and comprised the following study days

- 1: Discussions as the end of life approaches
- 2: Assessment, care planning and review
- 3: Co-ordination of care
- 4: Delivery of high quality care in the Acute setting
- 5: Care in the last days of life
- 6: Spiritual care and presentations

Training Needs Analysis and Skill Set Assessment was undertaken pre and post course both to ensure educational needs were met and to assess the impact of the course.

There is a trained EoLC Key worker on every in-patient area.

Course evaluation demonstrates learning and increased knowledge, skills and confidence in EoLC

A sustainability plan is in place.

**Abstract number:** P1-179  
**Abstract type:** Poster

## Partnerships in Palliative Care Education. A Five Year Experience between Albania and United Kingdom

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**Aim:** The aim of this study is to highlight the importance of international partnerships between organizations working in palliative care in different countries. PCEC is an Albanian medical NGO with 7 years experience in palliative care education. PRIME is a UK medical NGO with more than 12 years of education in palliative care. Both organizations have worked together in the last 5 years to develop palliative care education for healthcare professionals in North Albania. Palliative care education is crucial for the development of palliative care services in Albania and lack of education is one of the major obstacles to offer good palliative care services for cancer and chronic patients in Albania. PCEC and PRIME have organized together 13 palliative care courses. We have included on our training four regions of North Albania (Lezhe, Shkoder, Kukes, Peshkopi). To date more than 500 healthcare professionals (family doctors, general practitioners, specialist doctors, nurses, pharmacists) have attended our courses.

**Methods:** Regular contacts with the health professionals have been maintained in order to inform them with the dates and venues for the courses. Regular contacts between PCEC staff and PRIME staff have been organized. The main topics offered for participants were: Principles of palliative care, history of palliative care, pain control, symptom control, communication in palliative care, psychological, social, spiritual and bereavement support.

**Results:** 13 palliative care courses have been organized from November 2007 to November 2012, more than 500 participants attended, most of them general practitioners.

**Conclusion:** Palliative care education is vital for the development of palliative care services where palliative care is not a recognized specialty. Partnering with a palliative care education organization from a developed country is important to set up to date palliative care education in a developing country.

**Abstract number:** P1-180  
**Abstract type:** Poster

## Developing an End of Life Care Community Forum

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**Background:** Embedding end of life care in nursing homes is difficult to sustain using education packages alone. Ongoing clinical support needs to be provided if change is to be sustained. A dedicated end of life forum model was developed to address these issues in establishing positive working relationships between generalist and specialist providers.

**Methods:** 18 nursing homes enrolled with a planned programme of care, following a scoping exercise. Positive engagement with local advance care planning teams was crucial to success and a range of resource and educational materials were given to each home.

**Results:** There has been an increase in use of end of life tools with reduction in hospital admissions at end of life. Electronic communication links have been strengthened and links to 24hour helpline have increased.

**Conclusion:** The forum has provided an opportunity for improvements in patient's pathway. Staff have been empowered to utilise end of life tools and a NH key champion model has been developed. Ongoing delivery and development of the forum will require commitment from all service providers and continued funding from local health community.

Further work to be done on evaluating benefits of forum to include wider service users

**Abstract number:** P1-181  
**Abstract type:** Poster

## Sharing the Load. A Collaborative Approach for Meeting the Need for Palliative Care Education for General Practitioners

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**Background:** People who work in end of life care report the need for greater training in the knowledge and skills to give high quality end of life care for all; this is particularly true for community and generalist providers like General Practitioners.

In Merseyside and Cheshire Cancer Network GP education courses continue to be heavily subscribed to. Successful programmes have been running for over two years and a collaborative approach was adopted for 2012 to aid delivery across a wider area with a sharing of resources.

**Course aims:** To provide evidence based updates on a range of symptom management topics.

To provide information about use of end of life tools.

To provide opportunity for facilitated group discussions.

**Course delivery:** The course was run between January and June 2012 and consisted of 6 evening meetings. Three local specialist palliative care teams delivered 2 sessions each enabling pooling of clinician time enabling further delivery of future courses. The course included the following aspects 60 minute seminar delivered by senior clinician in Palliative Medicine

60 minute facilitated group work with feedback.

Each session was individually evaluated at the end of whole course.

**Results:** Demand and attendance throughout the course remained high.

Further evaluations to follow.

**Conclusion:** Accepted and successful model for delivering GP education.

Encouraged networking and establishing links between generalists and specialist providers.

Improved collaborative working patterns between local units.

**Abstract number:** P1-182  
**Abstract type:** Poster

## Nurse Practitioners as Mentors in Teaching Hospitals

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**Aims:** This is an exploratory study to describe the impact of palliative care nurse practitioners (NPs) as educators and mentors for medical students, residents and fellows.

Mentoring is an advisory role; an experienced professional guides another individual in their personal and professional development. In the U.S. NPs in academic settings may serve as mentors to both nursing and medical students and residents. This is particularly true in newer specialties where physician mentors are fewer and in those specialties where interdisciplinary care teams (IDTs) are the norm. Additionally, in the U.S. where the demand for board certified palliative care physicians exceeds their availability for both patient care and medical education, specialty trained and experienced NPs help fill that gap.

**Methods:** Former medical students, residents, and fellows (N=21) who rotated through this 544 bed tertiary care teaching hospital's palliative care and hospice services were surveyed with Survey Monkey. The questionnaire was designed based on the palliative care literature, functioning of the NPs on the IDT, and literature on mentoring.

**Results:** Preliminary results of 12 respondents found that on a scale of 1-10 the mean rating of NPs as important mentors was 9.4; 75% reported that an NP influenced their choice of medical specialty. All respondents indicated that NPs modeled interpersonal skills in IDT meetings and when having difficult conversations with patients/families and assisted families in making difficult health care decisions. At least 75% of respondents indicated that NPs influenced them in each of the 17 examples of mentorship listed on the survey.

**Conclusions:** NP involvement in medical education and mentoring may support future physicians' professional development, choice of specialty, and preparation for working in IDTs. Further study across academic medical settings is needed to fully elucidate the NP's role and relative contributions. The study was internally funded.

**Abstract number:** P1-183  
**Abstract type:** Poster

## International Medical Education in Palliative Care: Pilot Research on Undergraduates (IMEP)

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**Background:** The provision of education and training in palliative medicine for medical undergraduates across Europe is variable. Hence, it is likely that newly qualified physicians are entering practice with variable skill sets. Accordingly, assessing the preparedness and attitudes of newly qualified physicians in practicing palliative care is crucial. Such data will inform the ongoing development of medical curricula, which is crucial in light of demographic challenges facing Europe in the coming decades.  
**Aim:** To establish four translations (Spanish, French, German & Italian) of two validated psychometric assessment tools (Self-Efficacy in Palliative Care - SEPC; Thanatophobia Scale), and collect illustrative pilot data across seven European countries.  
**Design:** Organised as a Taskforce of the EAPC Steering Group on Medical Education, the IMEP study group will complete backward and forward translations of the SEPC and Thanatophobia Scale using EORTC criteria. Using convenience sampling, pilot data from each country (per country, n = 40) will be collected to test the applicability of the translated instruments and provide illustrative data for nominal comparison.  
**Results:** To date, EORTC structured translations in French and Spanish have been achieved, with German and Italian translations due for completion late 2012. Pilot data already collected from Ireland and England will be collated with developing data sets from Spain and France, and data to be collected in Germany, Italy and Switzerland.  
**Conclusion:** The availability of multiple translations of these validated psychometric assessment tools will enable intra- and international assessment of how existing undergraduate curricula is preparing tomorrow's doctors to meet the needs of the expanding cohort of palliative care patients. Such evidence may help influence the integration and strengthening of Palliative Medicine within existing undergraduate medical curricula.

**Abstract number:** P1-184  
**Abstract type:** Poster

### Using Reflective Diaries to Explore the Lived Experience of a Volunteer Training Program to Support Patients in the Last Hours and Days of Life

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**Background:** In the UK over 53% of patients die in hospital. Volunteers have a significant presence in many Hospitals, providing services to support staff and patients; however, few volunteer training programs focus on the last hours and days of life. A pilot training program (Care of the Dying Volunteers - CODV), using existing European models, has been developed and recently engaged within a large university teaching hospital in the North of England, to train volunteers to support patients (and their relatives/friends) in the last hours and days of life.  
**Aim:** To examine CODV's experiences of the training program through the analysis of reflective diaries.  
**Method:** Following recruitment interview, volunteers attended a 12 week training program. Data was collected via weekly reflective diary to record thoughts and feelings. Data were qualitatively analysed using a framework approach to identify emergent themes.  
**Results:** A total of 19 volunteers, aged between 18-79 years, attended training. 185 completed diary entries were fielded. Three themes emerged:  
(i) motivation for volunteering  
(ii) impact on volunteers  
(iii) group dynamic.  
A common shared motivation for volunteering was that 'no-one should die alone'. Participants had an understanding of the potential impacts of volunteering on their own life. Cohesiveness within the group provided the volunteers with a sense of safety to disclose and share experiences.  
**Conclusion:** The findings have implications for the ongoing support of volunteers. Group sessions beyond training facilitated peer support and encouraged sustainability. Further research is needed as the volunteers go on to support dying patients, to explore if their motivations and perceptions of impacts change throughout the process, to inform future CODV training programs.

Funded by: The Dimbleby Marie Curie Cancer Care Research Fund

**Abstract number:** P1-185  
**Abstract type:** Poster

### Abstract withdrawn

**Abstract number:** P1-186  
**Abstract type:** Poster

### What Are the Training Wishes and Needs of Medical Registrars in Assessing and Managing Pain in Patients with Dementia in the Acute Hospital Setting?

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**Aims:** Pain in patients with dementia (PWD) is under-assessed and under-treated. Despite the increasing incidence of dementia, little is known about the training needs of doctors that must be met to deliver high quality care. We studied trainees' perceptions of their current skill-base and training needs in pain assessment/management for PWD.  
**Methods:** An electronic survey was sent to all higher medical specialty registrar trainees in General Internal Medicine, London, UK (n=1149, response rate 16%). Analysis using SPSS v19, reported scores, proportions and odds ratios (OR).  
**Results:** Confidence scores (1-10 scale) for assessing/managing pain in PWD were 7 (IQR 5-8) and 7 (IQR 5-7), respectively. Despite these high confidence scores, only 22% were aware of guidelines for pain assessment/management in PWD. When presented with evidence that analgesia can reduce agitation in PWD, 68% reported they would consider changing their practice. Only 17% of trainees received training on assessing and 21% on managing pain in PWD. Care of the Elderly (COE) trainees were more likely than non-COE trainees to have received training in assessing (44% vs 6%, p<0.001) and managing (48% vs 12%, p<0.001) pain. They also had greater awareness of relevant guidelines (48% vs 11%, p<0.001) and use of pain assessment tools for PWD (40% vs 4%, p<0.001). There was no association between stage of training and likelihood of having received training in assessing (OR 0.96, 95%CI 0.73-1.26, p=0.76) or managing pain (OR 0.99, 95%CI 0.77-1.26, p=0.99). Senior trainees were no more likely to be aware of guidelines than junior trainees (OR 1.20, 95%CI 0.94-1.54, p=0.15).  
**Conclusion:** There was mismatch between perceived confidence in assessing and managing pain and actual awareness of relevant guidelines. COE trainees were more likely to have the relevant knowledge-base. Efforts to improve training should target non-COE trainees and the importance of specialist input in the care of PWD is reinforced.

**Abstract number:** P1-187  
**Abstract type:** Poster

### Giving Palliative Care Education and Support Across Continents and Cultures

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Over the last ten years links have been forged between a charitably funded cancer centre in Pakistan and a UK hospice. This involves nursing placements with formal and informal education at the hospice for senior nurses from Pakistan, electronic journal access, and visits by hospice staff to the cancer centre to provide direct education. In addition, due to the absence of a palliative care consultant in Pakistan, we have established monthly face to face videoconference sessions of one hour duration between the senior nursing team in Pakistan and a senior consultant and nurse educator at the hospice where complex cases are discussed and support and advice is offered.  
Of the seven sessions and seven cases discussed so far, issues raised included practical challenges in maintaining clear communication via a web link through changing time zones; knowledge and availability of drugs and equipment, and cultural differences for patients, families and staff. Similarities in hospital palliative care identified between UK and Pakistan included difficulty in recognition of the dying patient and acceptance of change in approach from curative to palliative treatment by specialty teams (66%). Challenges in communication were also identified between the palliative care and specialty teams, patients and families

(66%). A more proactive approach was identified in Pakistan with the issue of Do Not Attempt Cardiopulmonary Resuscitation decisions and innovative services in regard to electronic prescribing and follow-up assessments by telephone to patients in the community, which could be emulated in the UK.

Review of the cases afterwards demonstrated that care had been positively influenced by the advice given. In particular the palliative care nurses felt empowered to influence the specialty teams in decision making at the end of life.

In conclusion, the partnership has been beneficial to both parties and empowered nurses to provide high quality palliative care to patients.

**Abstract number:** P1-188  
**Abstract type:** Poster

### In Search of a Good Death: Challenges to Providing Optimal End of Life Care in a Hospital Setting

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**Background:** Surveys show most patients want to die at home. However 53% of UK deaths occur in hospital where end of life care is often poor and do not attempt resuscitation (DNAR) orders, evidence of advanced care planning (ACP), are often not completed. Clinicians are advised to use the 'surprise question' to identify patients that need ACP. Barriers previously identified include: lack of training, time, appropriate opportunity and experience; personal discomfort; and perceived lack of patients'/carers' understanding.  
**Aims:** We investigated experiences, beliefs and attitudes of staff in a district general hospital towards end of life care.  
**Methods:** Doctors and nurses of varying grades were invited to complete a multiple-choice questionnaire during Dying Matters Awareness Week 2012.  
**Results:** Amongst the 73 doctors (49% male) there was a high degree of confidence (eg 76% agreed/strongly agreed they were comfortable talking to patients/relatives about death). This did not correlate with familiarity with the 'surprise question' (23% said they were familiar but only 3% gave a correct response), or knowledge of the most distressing end of life symptom (only 18% identified shortness of breath correctly), or knowledge of the patient group with the highest unmet palliative care needs (23% identified patients with Respiratory diseases). 40% doctors believed "palliative care is a specialist skill that should be delivered by specialists". Amongst nurses there was a similar high degree of confidence which did not correlate with knowledge demonstrated.  
**Conclusions:** There is a pressing need for greater expertise in general palliative care amongst hospital professionals. Accurate prognostication is challenging; the surprise question is useful in prompting ACP. We identified a mismatch between knowledge and confidence levels amongst doctors and nurses in our sample. Lack of awareness of their need for education may represent a barrier to healthcare professionals accessing training.

**Abstract number:** P1-189  
**Abstract type:** Poster

### Teaching Reluctant Physicians to Prescribe Opioids in a Former Soviet Republic

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Armenia is building palliative care services. Current efforts are focused on building legal frameworks, institutional strengthening of palliative care and educating health professionals. Medical education does not include teaching physicians how to assess pain and to prescribe opioids. National health care system has about 2000 family doctors and general practitioners and nearly 60 oncologists working in primary health care settings. None of them have received training in palliative care or in chronic pain management. Physicians are discouraged from using opioids and face many regulatory and legal obstacles.

To bridge this gap Armenian Pain Control and Palliative Care Association with support of Open Society Foundation developed the first course in pain management and opioid prescribing in 2011. Since that time 21 oncologists and 10 family doctors were trained in 2 week forty hours intensive courses. Course covers basic theories of pain pathology, pharmacology pain relief medications, including opioids and practical skills in pain assessment and application of the WHO pain ladder to assess pain and to achieve control.

## Poster sessions

Pre-post test and course evaluation questionnaire shows significant improvement in knowledge of audience (average 67% correct answers in post-test vs. 47% in pre-test,  $p < 0.001$ , for some topics post test increased by up to 70%), their satisfaction (measured by post training evaluation questionnaire), but revealed problems and challenges as well. They particularly are lack of bedside training, difficulties with recruitment of trainees, their certification, completion of classes by level of knowledge and interest.

All these challenges should be addressed, discussed, and overcome to improve and finalize the course.

**Abstract number:** P1-190  
**Abstract type:** Poster

### 'Going For Gold' - Enabling Generalists to Better Work with Specialists in End-of-Life/Palliative Care across the UK with National Adoption of GSF Training Programmes

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**Objective:** The UK focuses on a broad definition of End of Life Care and in improving generalist and specialist end-of-life care provision for all people in every setting in the final year or so of life. The Gold Standards Framework (GSF) is a major part of the NHS End-of-Life Care Strategy and focuses on enabling generalist provision of end-of-life care for all patients with any life-limiting illnesses in whatever setting. It improves quality of care, workforce collaboration, confidence and coordination with specialists and reduced hospitalization. It has had remarkable success in improving generalist provision of care in primary care and the biggest care homes palliative care programme in England. The National GSF Centre in End of Life care is the leading provider of end of life care training for generalists in the UK, working with St Christopher's Hospice as its first GSF Regional Centre and other hospices.

**Method:** This presentation provides an overview of GSF underpinning principles, use in primary care, care homes, hospitals and domiciliary care plus IT support. Also evidence base, spread cascade, UK policy and political support, and becoming a national quality improvement programme, and includes use of e-learning, and IT developments. It will explore development of integrated cross-boundary care across a wide area. In addition examples of adapted international use are included and integration in other areas.

**Outcomes:** An overview of the context of end-of-life care in the UK, policy developments, hospice/specialist palliative care, care for non-cancer patients, long-term care and practical suggestions on ways forward. Also lessons learnt in developing local and national momentum, getting national policy into practice. It will include GSF training, tools and measures with suggestions for local use and development in generalist end of life care to enable the generalist frontline workforce and improve palliative care collaboration.

**Abstract number:** P1-191  
**Abstract type:** Poster

### Going for Gold - Achieving a Gold Standard of End of Life Care in GP Practices - Findings from the Pilot Next Stage GSF Primary Care Training & Quality Recognition Accreditation

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**Context and aim:** Over 95% of GP practices in the UK have adopted the principles of Foundation Level GSF i.e. they have a GSF/Palliative Care Register and a meeting to discuss these patients. However, in 2009/10, the National primary Care Audit confirmed that only 25% of people who died were included on the register, most of these were cancer patients, but importantly, all of the people included on the register received better coordinated care. Therefore, Next Stage GSF Going for Gold Training was developed, a distance learning practice based training programme with 6 modules, homework and independent assessment.

**Method:** 7 practices then progressed towards GSFPC Accreditation, using the GSF accreditation process. This looks at 5 areas; right patient, right care, right time, every time and includes 10 key metrics and examples from each of these 5 areas included in a portfolio, After Death Analysis Audit of 10 further patients and a follow up phone call.

**Results:** The results showed a significant improvement in numbers of people included on the register, numbers of people in care homes and non-cancer patients, increase in uptake of advance care planning discussions, DNAR, carer assessment and support and use of significant event analysis.

**Conclusion:** Significant improvement was seen in all and outstanding results were obtained from several practices. Particular improvements included earlier identification and

inclusion on the GPs GSF/Palliative Care Register leading to better systematic care of patients. Additional benefits were improved confidence of staff, pride in this area of work and development of a sustainable plan. One practice said: "This was one of the most worthwhile projects we have ever done as a practice."

This demonstrates that real progress can be made by primary care teams, encouraging further practices to build on Foundation Level to such Quality Recognition.

**Abstract number:** P1-192  
**Abstract type:** Poster

### Palliative Care at Home: The PaTz-project

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In the South of the Netherlands the Comprehensive Cancer Centre facilitated small groups of family doctors together with nurses from the public health service to start and entertain a register of palliative care patients. We followed the Gold Standard Framework translated and adjusted to the Dutch situation.

In meetings every six weeks they discuss the physical, psychosocial and spiritual needs and wishes of the patients and their relatives, in order to anticipate what will be important in the care for this patient. They discuss illness trajectories and also they make an inventory about patients wishes at the end of life. There is also attention for transfer to the emergency units whom are available during nights and weekends.

We would like to present the results, the registers, the transfer forms and some tools we're using to discuss all aspects of care.

**Abstract number:** P1-193  
**Abstract type:** Poster

### Current Overview of Palliative Medicine Teaching in the Spanish University

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**Introduction:** There are many recommendations of national and international organisations to incorporate palliative care teaching in the medical school. European Higher Education Area ("Bologna process") has supposed review of the curriculum in every academic degree. The aim of this study was to determine which medical schools in Spain have included palliative care in their new curricula.

**Method:** We reviewed the curricula of medicine from all spanish faculties identifying subjects with the words "Palliative Medicine" or "palliative care" included in their denomination.

**Results:** 20 of 39 medical schools have a palliative care course. In six faculties is taught as a single subject, with an average of 3 academic credits. When palliative care is taught with other subjects (as Oncology, Geriatrics, Family Medicine and so on) the number of credits is variable. In 14 of 20 centres is a mandatory subject.

**Conclusions:** A half of medical schools in Spain including a palliative care course in their new curricula. Palliative medicine is gradually incorporated into the training of future physicians Spanish.

**Abstract number:** P1-194  
**Abstract type:** Poster

### What Makes an Objective Structured Clinical Examination (OSCE) a Useful Method of Learning in Undergraduate Cancer Care Education?

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**Introduction:** Objective Structured Clinical Examinations (OSCEs) are commonly used in healthcare education to assess clinical skills. They are widely used as assessments for progression (summative assessment), but potential use of OSCEs as assessments for learning (formative) was highlighted by Harden and colleagues who developed the OSCE in the early 1980s. A teaching OSCE has been used in the 4<sup>th</sup> year Cancer and Continuing Care course at Leeds University School of Medicine (UK) for the last 2 years. It has evaluated very highly but it is unclear from the literature and from local evaluations why students find this method of

teaching so useful.

The aim of this research was to look in more depth at students' beliefs about the cancer care teaching OSCE to elicit what makes it a useful method of learning.

**Methodology:** Q-methodology is useful to analyse opinions, perceptions and attitudes in clinical and non-clinical settings (Cross 2005) and has been used within medical education, for example to research student attitudes and learning styles (Valenta et al 2001), and also within palliative medicine education to assess learning competencies (Gaebler-Uhing 2004). Statements about the teaching OSCE were generated from the literature and previous evaluations. Following informed consent students were asked to complete a "Q sort"; that is rank the statements from agree to disagree. This allows a more useful analysis of why the OSCE is beneficial than asking students to complete questionnaires about the OSCE. Ethical approval was granted by the University of Leeds Education Research Ethics Committee.

**Results:** The Q-sort analysis of the student's beliefs about the value of this method of teaching in cancer care education will be presented. The most useful components of a teaching OSCE in undergraduate education will be discussed along with suggested application in other medical schools.

**Abstract number:** P1-195  
**Abstract type:** Poster

### Does a Junior Doctor Rotation Post in Palliative Medicine Impact on Career Choice and Does it Improve Future Clinical Practice?

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**Aims:** In the UK, Modernising Medical Careers (MMC) has restructured training doctors' career progression, with medical graduates entering a 2-year Foundation Programme (FP) of mixed specialities. During the 2<sup>nd</sup> year they then choose & apply for speciality training. There are relatively few palliative care posts available during the FP. This study aims to find out if

1) undertaking a palliative care post during the FP influences junior doctors to choose palliative care as a career and

2) if the post helps with skills for future clinical practice.

**Methodology:** A cross-sectional retrospective survey using a web-based, anonymised questionnaire of all doctors participating in a foundation year 2 (FY2) programme of mixed surgical and medical specialities in a UK hospital trust, which includes a 4-month hospice based post in palliative care. Summary statistics are used to describe data.

**Results:** 15 doctors had previously undertaken this post and were contacted, 10/15 replied (67% response rate). Prior to starting the post, 6/10 (60%) had considered pursuing a career in palliative care, whereas after finishing the post this figure had risen to 8/10 (80%). 7/10 (70%) reported that completing this post had influenced their career choice. Additionally, 9/10 (90%) felt that this post had changed the way they practice medicine, specifically by improving communication skills, symptom control, advance care planning and team working.

**Conclusions:** Results suggest that completing a junior doctor training post in palliative medicine influences doctors' career choice, making them more likely to consider palliative care as a career. In addition, future practice was changed in the majority of participants, and skills specific to palliative care were learnt. Limitations of this study are its size and possibility of response bias. To further support the evidence that posts of this nature are beneficial, we propose to repeat this study within all deaneries in the UK.

**Abstract number:** P1-196  
**Abstract type:** Poster

### The Use of Drama in Palliative Medicine Education for British Medical Students

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**Introduction:** Medical humanities and arts-based teaching tools offer an opportunity to achieve competencies required in undergraduate palliative education. Humanities disciplines can help students to reflect, develop multiple perspectives, and consider ethical issues around dying and death in combination with their clinical experience.

**Aims:** To design, implement, and evaluate a pilot teaching session using medical humanities within the core palliative care curriculum for medical students.

To use drama as a stimulus for discussion and reflection of communication and issues in palliative care, with relation to their experiences.

To collaborate with the University arts faculty to create an innovative drama performance.

To assess preliminary feasibility for integration into the curriculum with student reactions.

**Design and methods:** A one hour live drama performance and facilitated discussion was delivered to 44 fourth year students at the end of a six week cancer and continuing care module. Recruitment of a drama student and interdisciplinary discussion led to a performance adapted from theatrical literature with themes of illness narrative and multiple perspectives.

Immediate free-text anonymised comment cards collected student reactions, which were examined by thematic analysis using emergent coding. One discrete criterion was devised for if the session was 'useful'.

**Results:** 79.5% said the session was 'useful', 9.1% 'not useful' and 11.4% 'unspecified'. Positives highlighted the alternative teaching style as enjoyable and engaging for discussion, whereas criticism focussed on unequal issue representation in the performance.

**Conclusion:** Drama was largely used successfully to stimulate personal and professional reflection of fourth year medical students with discussion of palliative issues. Further development and higher level evaluation is required, however this pilot shows promise for drama as a teaching tool in palliative undergraduate medical education.

**Abstract number:** P1-197

**Abstract type:** Poster

### Nation-wide Physicians' Education Project for Basic Palliative Care in Japan: Outcome Evaluation of the Palliative Care Enhanced Program on Assessment and Management for Continuous Medical Education (PEACE)

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**Aims:** Palliative care is an essential part of medicine, but most physicians have not had the opportunity to develop palliative care skills. In Japan, following the establishment of the Cancer Control Act in 2008, the Palliative Care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) was launched to educate physicians in basic palliative care.

To date, approximately 20,000 physicians have completed the program. The aim of the present study was to determine whether PEACE improves physicians' knowledge of and attitudes towards palliative care.

**Methods:** Knowledge of, attitudes to, and difficulties regarding palliative care were evaluated before, just after, and then 2 months after completion of the program using a mailed questionnaire sent to physicians participating in PEACE at one of 15 centers in Japan in October-December 2011. Knowledge was measured using the PEACE-Q33 questionnaire (nine domains, 33 items). Attitudes and difficulties were evaluated using the palliative care self-reported practice scale (PCPS; six domains, 18 items) and the palliative care difficulties scale (PCDS; five domains, 15 items), respectively.

**Results:** In all, 217 physicians participated in the study. Significant improvements were noted on the PEACE-Q33 questionnaire compared with baseline after completion of the program, which were maintained at 2 months (21.5±5.1 vs. 29.5±2.1 and 29.5±2.5, respectively;  $P < 0.01$ ). Similarly, significant improvements were noted for total scores on both the PCPS and PCDS 2 months after completion of the program (62.4±13.8 vs. 69.3±9.9 [ $P < 0.01$ ] for the PCPS; 44.2±10.1 vs. 39.1±10.5 [ $P < 0.01$ ] for the PCDS).

Improvements occurred in all domains of the PCPS ( $P < 0.01$ ), whereas no significant changes were noted in two domains of the PCDS (i.e. Special Care Support and Communication For Medical Staff).

**Conclusions:** Participation in PEACE improved physicians' knowledge of and attitudes towards palliative care.

**Abstract number:** P1-198

**Abstract type:** Poster

### The Effects of Medical Students' End-of-Life Care and Medical Humanities Training in the Community

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**Research aims:** At present, the training course about end-of-life care in the community was still not enough at the medical education in Taiwan. Our study designed the students participate in the real practice of end-of-life care in the community and surveyed the effect of reflection of

medical humanities based on previous palliative care curriculum.

**Methods:** Our study developed the course about end-of-life care at different care settings in the community according to the student's competence by the method of "action research". The tutors of the field adjusted the course contents by the serial process of "plan, action, reflection and revision" to fit the real situation. In the meanwhile, they taught the students should foster the communication skills and compassionate attitudes related to the medical humanities during the interactive courses with patients and their families at the different care sites in the community. The tutors and the students shared the care experiences in the small group after every activity of caring interaction.

**Results:** Our study had set up the five-day training course about end-of-life care at the rural community in the middle Taiwan. The students finished the lecture of the end-of-life care in the community by the electronic medium or internet before they entered the course. The students showed high satisfaction about the interactive activities after completing the whole course. The most common learning feedback statements were as the following: comprehensive awareness of end-of-life care, the importance of the role of home care physician and nurse, the function of qualified nursing home and long-term care facilities to afford palliative care at the community, the cultural needs of patients to wish to die at home accompanied by their loved family.

**Conclusion:** Our model of the training course about end-of-life care to the medical student will be shared to the formal curriculum of other medical schools in Taiwan in the future.

## End of Life Care

**Abstract number:** P1-199

**Abstract type:** Poster

### Attitudes and Practices of Nurses towards Palliative Sedation Therapy: A Systematic Literature Review

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**Background:** Palliative sedation therapy is increasingly used within given circumstances, in selected palliative care patients, by practitioners in Europe. Nurses perform a number of important roles during this therapy.

**Aim:** To systematically review the evidence on the attitudes and practices of palliative sedation therapy by nurses, and to make recommendations to inform clinical guidance.

**Data sources:** Ten electronic databases, four relevant journals, reference lists of included studies Review methods: This review was limited to empirical studies written in English language from January 1990 to July 2012, of sedation within a palliative care context only. Studies were excluded if they were not solely related to nurses, involved patients < 18y, and if the sedation was for procedural or ICU uses.

**Result:** Following paper selection and data extraction, nine studies were included: four quantitative studies, four qualitative and one mixed methods. Younger nurses, with fewer years of experience, less palliative care training were more unsettled with the practice of palliative sedation. Also, nurses who worked in the hospital (e.g. oncology, MICU) agreed on palliative sedation much less frequently than nurses who worked at home, nursing home or in hospices. Belief system, religion and life philosophy appeared to influence the nurses' attitudes. The main themes from the quantitative studies were patient's most recent clinical assessment, eligibility for sedation, patient-family-team readiness for the procedure, and medico-ethical considerations.

**Conclusion:** The process of deciding for palliative sedation appears a challenging one in itself. However, hospice and palliative care unit nurses appear to have a professional attitude whenever the indications were clear and communication with patients, family members and physicians were in place.

**Abstract number:** P1-200

**Abstract type:** Poster

### Deciding Correctly the Moment for Applying the Terminal Care Protocol

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**Background:** Terminal care protocol was the first protocol to be introduced in our service. Our service offers services in several settings. In a qualitative study with staff going through the process of implementing the protocol one issue

was the fear of not recognising the appropriate moment to start patients on the protocol.

**Aim:** To analyze the application of the terminal care protocol in the first 3 months of introduction of this protocol in our palliative care service.

**Methods:** A retrospective study of files of patients dying in our palliative care service in the first 3 months of application of the protocol. We specially analyzed the special documentation concerning the terminal care protocol from the files.

**Results:** In the first 3 months after the implementation the protocol 122 patients died in our care in the inpatient or home. The protocol was used for 56.56% of patients.

Initiation of protocol correlated directly with the number of days of care ( $p < 0.05$ ). There was no significant difference between the implementation of the protocol by inpatient unit or home care staff. The length of application of the protocol was for 84% patients between 1 to 4 days. 78% of patients met all the criteria for the applying of the although just 2 out of 4 were required by the protocol. Reasons for the non-use protocol were: the sudden deterioration, patients transferred to other medical services, patient and family refused the application protocol and that staff waited patients to fulfill all application criteria.

**Conclusions:** Although the end-of-life protocol was the first protocol implemented in our unit and the study was performed in the first three months from the beginning, the medical staff managed to use it in proper time and with proper results.

**Abstract number:** P1-201

**Abstract type:** Poster

### Topic - Organisation of Services

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Current UK government initiatives in End of Life Care (EOLC) are keen to reduce the fragmentation and disjointed working of organisations when coordinating care. The Palliative Care Funding Review has clearly recommended that a lead provider for palliative care be identified in every Clinical Commissioning Group to coordinate palliative care services.

An established hospice recognised the need for a more clearly defined model for coordination of EOLC and therefore undertook an initial fact finding project to identify how EOLC is currently accessed and coordinated across the areas served by the organisation. A recommendation from this report was to progress a possible partnership with an out of hours provider as our preferred partner in collaboration with other providers. The rationale being that the hospice can provide end of life expertise alongside the out of hours provider providing call handling and OOH expertise. This would be the first phase towards coordinating EOLC.

The hospice and out of hours provider brought together a group of palliative care nurse specialists and nurse advisors (call handlers) to develop a greater understanding of both their differing roles and the established palliative care call handling pathway. From there, they developed 'triggers' to refer patients to the appropriate professionals and a system to refer directly on to the nurse specialists. A system was also put into place that allows any professional working out of hours to refer directly to the nurse specialist. Funding was provided for 1 year by the hospice and with a contribution towards funding from NHS Commissioners if certain targets are met.

Initial results show that whilst it has been slow to take off, patients have benefited by having access to a nurse specialist out of hours that has ensured consistent symptom management, prevention of admission and relieving family distress. The call advisors have gained in knowledge and confidence in handling palliative care patients.

**Abstract number:** P1-202

**Abstract type:** Poster

### Emotional Vulnerability & Burden Care in Palliative Care Patients and their Family Caregivers

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## Poster sessions

Current research shows how end of life patients and caregivers suffer significant depressive and anxious emotional disturbances and high burden levels or "Caregiver Burden Syndrome".

We present a descriptive and correlational study with measures taken on a single-time-phase. Sample: 139 palliative care patients (50,70% Chronic Obstructive Pulmonary Disease, 8,70% cancer and 40,60% frail elderly) and main caregivers.

We aim to analyze:

- anxiety and depression levels in a sample of patients and their caregivers (HADS),
- perceived caregivers' burden levels (Zarit Burden Interview),
- correlation between emotional vulnerability and caregivers' burden levels,
- correlation between the length of hospital stay and emotional vulnerability and burden levels, as well as number of hospital admissions and emotional vulnerability and burden levels.

Data indicates that 46,9% of patients have significant anxiety symptoms and 40,6% in depression. Anxiety and depression measures show a positive and significant correlation ( $r_p = 0.405$ ,  $p < 0.01$ ).

Also, 49,9% of family caregivers have significant anxiety symptoms and 23,4% in depression; positive correlations between burden and depression levels ( $r_p = 0.430$ ,  $p < 0.01$ ); anxiety and burden levels ( $r_p = 0.459$ ,  $p < 0.01$ ); depression and anxiety levels ( $r_p = 0.596$ ,  $p < 0.01$ ). Moreover, data shows a positive correlation between burden levels and anxiety levels in patients ( $r_p = 0.347$ ,  $p < 0.01$ ).

There is a positive correlation between the length of hospital stay and depression levels in patients ( $r_p = 0.211$ ,  $p < 0.01$ ) and family caregivers ( $r_p = 0.305$ ,  $p < 0.01$ ), and between the number of hospital admissions and anxiety levels in caregivers ( $r_p = 0.195$ ,  $p < 0.01$ ).

These results are the beginning of a research and intervention program. Our data corroborates main results of current scientific literature that outline the relevance of designing and implementing emotional support programs for caregivers.

**Abstract number:** P1-203

**Abstract type:** Poster

### Planning Ahead for Patients with Motor Neurone Disease (MND)

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**Aim:** To audit advance care planning (ACP) for MND patients under the care of a Regional MND Centre multidisciplinary clinic, with reference to discussion about end of life care and documentation of the patient's wishes. Secondly, to assess the sharing of information between the hospital and the hospice / community setting.

**Method:** Retrospective Case note review of MND deaths during a 2 year period.

**Results:** Data was collected from 38 deaths. 58% of patients died within 12 months of diagnosis. Place of death was hospital (47%), home (29%), care home (8%) and hospice (13%). 42% had received Non-Invasive Ventilation (NIV). There was evidence of ACP in 28 (74%) patients. This took the form of an Advance Decision to Refuse Treatment (18%), an advance statement about preferred place of care (13%), a 'Do not attempt resuscitation' order (53%) and medical letters or notes describing the end of life care plan (63%). ACP focused on the preferred place of care (14/28), resuscitation (12/28), ventilation (11/28), artificial feeding (10/28) and antibiotics (3/28). There were significant gaps in sharing of information between the hospital and community setting; of 13 patients with DNAR forms, only 2 patients had the DNAR documented in both sets of notes. Information sharing was most successful via copies of clinic letters (shared in 12/14). Overall, although only 56% of patients died in their preferred place of care, end of life care for 76% of patients was deemed to have completely or partially complied with the patient's wishes.

**Conclusion:** A proactive approach to end of life planning by the multidisciplinary team led to evidence of planning ahead in 74% of patients. DNAR orders and compliance with refusal of ventilation and feeding were more successful than achieving preferred place of care (PPC). Where PPC was not achieved, 71% of patients died in hospital. Work is needed to strengthen ACP and coordination of care locally to reduce hospital deaths and improve patient care.

**Abstract number:** P1-204

**Abstract type:** Poster

### To Move or Not to Move? Considerations about Transfers to Other Care Settings in the End-of-Life Care of People with Intellectual Disabilities

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**Background:** Most people prefer to stay in their own environment until the end of their life. Familiarity is also an important value for people with Intellectual Disabilities (ID). However, end-of-life care at home may not always be the best option. A framework to guide relatives and care professionals in these decisions is lacking.

**Aim:** To gain insight into the considerations of people with ID, relatives and care professionals when they are confronted with dilemmas about care setting transfers at the end-of-life.

**Methods:** Mixed methods were used: a literature study was performed to synthesize what was found about care setting transfers in this target group. Focus group discussions, using moral case deliberation, were used to elicit considerations about care setting transfers of relatives and care professionals. Nominal group technique was used to elicit considerations of people with ID. Questionnaires were sent to about 500 physicians, nurses and social workers to study considerations of a broader group of care professionals.

**Results:** The wish for persons with ID to stay in their own environment can be in conflict with providing high quality end-of-life care. The wish to stay at home was based on ensuring emotional security and autonomy according to persons with ID, relatives as well as care professionals, and also reflected the wish of care professionals to care for their clients until they pass away. Elements that seemed to determine perceived quality of care were the available nursing competencies, self-confidence in providing end-of-life care, availability of 24-hour care and housing facilities. The emotional security of other residents also played a role. **Conclusions:** Choices about care setting transfers require an open attitude of relatives and care professionals to be able to identify and weigh all considerations and underlying values, such as respect for autonomy, emotional security of both the person with ID and other residents, and quality of care.

**Abstract number:** P1-205

**Abstract type:** Poster

### Effects of Advance Care Planning on End of Life Care: An Overview

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**Research aims:** Advance care planning is the process of discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future. There has been an ongoing debate about the appropriate outcome measures and desired effects of advance care planning. The aim of this research is to give an overview of studies on the effects of advance care planning.

**Study design and methods:** We searched Pubmed, Embase and Psycinfo databases for experimental and observational studies on the effects of advance care planning that were published between 2000 and 2011.

**Results:** Our search resulted in 2100 papers which included 72 relevant studies. Most studies were observational (88%), originated from the United States (81%) and were performed in nursing homes (40%) or hospitals (40%). Written advance directives (39%) and do-not-resuscitate orders (30%) were most often studied. Advance care planning was often found to decrease aggressive treatment, to increase the use of hospice care and to prevent hospitalization at the end of life. Mixed results were found for congruence between preferences and care as received, satisfaction with care, and symptom burden.

**Conclusion:** The effects of different types of advance care planning have been studied in different settings, in different populations, and with different outcome measures. There is some evidence that advance care planning positively impacts the quality of end of life care. Extensive advance care planning interventions may be more effective than written documents alone. More research is needed on the extent to which it increases congruence between patients' preferences and care as received.

**Abstract number:** P1-206

**Abstract type:** Poster

### Factors Influencing Death at Home in Patients Followed by a Homecare Team in Barcelona, Spain

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**Background:** Several studies have been performed in different European countries and abroad about determinants of place of death. In Spain families have a strong influence in the care of patients (pts) but end of life (EOL) issues are not usually widely talked about among relatives.

**Aim:** To describe factors that appear to influence death at home in Spain.

**Patients and methods:** Observational descriptive study. Advanced cancer patients visited by 2 homecare teams were included throughout 6 months. Socio-demographic and neoplasm data were collected; as well as functional status, physical and emotional symptoms, EOL issues and place of death. The study was approved by the local ethics committee and pts signed consent.

**Results:** 115 pts were assessed. Mean age 72.9±13.2 years. 67.8% were men. Main cancer diagnoses: lung 23.5%, colon 8.7%. 59% had metastasis. Barthel (IB) and PPS index at 1<sup>st</sup> visit were 55.7±25 and 50[10-70] respectively. 67.8% had no cognitive impairment and 31.3% died at home.

In the bivariate analysis, there was a relationship between dying at home and IB >50 ( $p=0.016$ ) and PPS < 40 at 1<sup>st</sup> visit ( $p=0.001$ ), as well as caregivers without emotional suffering ( $p=0.012$ ), main caregiver without illness ( $p=0.045$ ), caregivers not overwhelmed ( $p=0.004$ ), having talked about end of life (EOL) issues with the patient and the family together ( $p=0.003$ ) and pts copying well with the current situation ( $p=0.000$ )

Logistic regression analyses revealed that PPS < 40 (OR: 0.911; 95% CI 0.881-0.984), having talked about EOL issues (OR: 12.055; 95% CI 2.366-61.430) and pts copying well with the current situation (OR: 5.001; 95% CI 1.777-14.073) predicted dying at home. When the three factors were present in concomitance, the probability of the patient dying at home was 83.7%.

**Conclusions:** In a culture where we do not generally allude to end of life in conversations, approaching the subject with pts and families together elevates greatly the chance of the patient dying at home.

**Abstract number:** P1-207

**Abstract type:** Poster

### The AMBER Care Bundle: The Reliable Implementation of Best Practice End of Life Care in Acute Hospital Wards

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**Aim:** To standardise the delivery, alongside existing treatment pathways, of key elements of care to hospital patients with uncertain potential for recovery. These patients have limited clinical reversibility and are judged to be at risk of dying in the next 1-2 months.

**Methodology:** A care bundle was developed using the Institute for Healthcare Improvement's reliable design methodology. The concept of reliability emphasises the importance of measurement of adherence to process alongside patient outcomes. Healthcare processes in general perform poorly in this regard. The focus of the AMBER care bundle is to ensure the delivery of each of the key elements of care which, based on casefile review, are:

1. a clear medical plan
2. an escalation plan
3. nursing and medical staff dialogue and consensus
4. patient and/or carer engagement and discussion of prognostic uncertainty and preferences.

The reliability of implementation was assessed by case file sampling and compared with baseline case file reviews conducted prior to the implementation of the care bundle. **Results:** Baseline sampling of 19 files of patients with uncertain recovery showed: 79% patients' care contained element 1, 58% element 2, 37% element 4, 37% had all 3 respectively measurable elements of the bundle addressed (element 3 was excluded at this stage). Follow-up



sampling of 44 patients suitable for the care bundle (Jul 10 to Sep 11) showed: 100% patients' care contained element 1, 93% element 2 and 82% element 4. 77% patients received all 3 elements of care. Repeat quality sampling in 2012 showed 72% (of n=40) received all four elements of care. **Conclusions:** It is possible to implement a care bundle to reduce variability in the delivery of key elements of care for this group of patients. Feedback within our hospital and the national network currently implementing the care bundle suggests a meaningful impact on patient and staff experience. A mixed methods evaluation to formally assess these impacts is underway.

**Abstract number:** P1-208

**Abstract type:** Poster

### Transition Points in Palliative Care Trajectories

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Palliative care (PC) interventions impact on quality of life, costs and survival. Generalists are ideally suited to incorporate PC into their practice with guidance regarding how and when to access specialist services for those with complex needs, relevant for aging populations in technologically advanced settings.

**Aims:** To identify, harmonize and share out criteria -other than prognosis, incorporating limits between life prolongation and optimum symptom management - to inform professional decision making to refer to specialist services. To implement straightforward protocols for professionals to access resources, matching level of professional intervention to needs complexity in timely fashion.

**Method:** Interdisciplinary professionals groups worked over time to: Determine pathologies with available criteria to determine decline and irreversibility (advanced or terminal phase). Agree and document local criteria, collate comments and consensus from specialist groups and incorporate to electronic referral protocols. Communicate professionals.

**Results:** Change points were identified, defined and validated for all major pathology groups clinical trajectories. Data relating to 2769 referrals show:

- (1) Tendency to earlier referrals being made and
- (2) A moderate increase in patients with non-malignant conditions.

**Conclusions:** Clearly defined criteria to inform decision making can help patients and families receive comprehensive, individualized, coordinated care and support at the right time. Primary, secondary and palliative care can work together to identify objective changes in patients evolution, such as an acceleration in clinical deterioration, absence of response to treatment escalation or repeated drops in their basal situation that should trigger the recognition of meaningful points from the diagnostic, monitoring and treatment to provoke a transition from a care viewpoint. We want to these changes and points in time to be called Palliative Transition or Trigger points.

**Abstract number:** P1-209

**Abstract type:** Poster

### Designing a Track and Trigger Chart to Guide Care of the Dying in Acute Health Care Facilities

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**Aims:** Quality health care is care that aligns safely with patients and families' expectations. The aim of this presentation is to describe a proposed model of care to improve care of people dying in acute hospitals that best meets the needs of the dying person and closely mimics care delivered in acute situations.

**Methods:** A literature review to identify how patients and their families perceive quality of care at the end of life was undertaken. This was compared with the literature that describes usual care offered to dying in acute situations. This allowed a gap analysis to help develop solutions.

**Results:** When facing imminent death, people have been able to articulate a number of issues they perceive to be of paramount importance, including optimal physical symptom management; a clear understanding of current

state of disease; engagement in discussions regarding care delivery; privacy to spend time with those identified as important to the person; to remain as alert as possible for as long as possible; and to retain a sense of humour. Families report that they wish the dying person to receive care tailored to the dying person's current needs and that they value timely symptom control measures. Families also perceive an important aspect of care to psychological and emotional support for themselves.

In contrast, the clinical reality is that many people die with poorly controlled symptoms with families often feeling quite isolated despite being in hospital.

**Conclusion:** As a result, a track and trigger chart for the dying has been developed aligning care of the dying with usual care in acute hospitals.

**Abstract number:** P1-210

**Abstract type:** Poster

### Why do Hospice Palliative Care Clinical Nurse Specialists Admit Patients into Hospice at the End of Life?

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**Aim:** To investigate why Hospice Palliative Care Clinical Nurse Specialists (PCCNS) admit the greatest number of patients into Hospice at the End of Life (EoL)?

**Methods:** An interpretive phenomenological approach was used to explore the implicit information held by the Hospice PCCNS by finding the triggers that lead them to admit EoL patients into the Hospice. Semi-structured interviews were carried out, the questions being extrapolated from a literature review about places for EoL. Each participant in the study checked the transcript to ensure accuracy and to enhance the validity of the study. The analysis into themes was carried out using an adapted Colaizzi method. Two nurses interpreted the transcripts independently. The findings were also compared to the findings of the literature review.

**Results:** The four most prevalent themes identified as triggers for admitting patients were: the coping abilities of the informal carer, complex symptom management, lack of resources in statutory services both in staffing and perceived competence in EoL and the patient's social situation. The first three were priori themes and the fourth was emergent. **Conclusion:** The main themes identified in this study were echoed in the literature review indicating the methodology was effective as an investigative technique. To facilitate a patient's desire to stay in their preferred place of care at the EoL, the 4 issues identified should be the focus of Government and local investment. There is a clear role for a robust Hospice at Home (HaH) type of service that can support carers and generalist professionals throughout and help to manage symptoms. The HaH service can provide physical care for patients earlier in their disease trajectory to prevent carers becoming exhausted and deflecting potential crises at the EoL leading to admission. This service may also provide in-reach services into other healthcare settings to allow good palliative care to be given in these settings also.

**Abstract number:** P1-211

**Abstract type:** Poster

### The Association between Assisted Living Organizational Characteristics and Palliative and Hospice Care Use in Florida

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Close to one million seniors live in assisted living (AL) settings in the U.S. ALs are non-medical community-based living arrangements that are not licensed as a nursing home (NH); provide shelter food, 24-hour supervision/oversight and personal care services in activities of daily living.

Palliative care (PC) and hospice enable "aging in place" which is to remain in AL until death to avoid transfer to higher levels of care (e.g., NH). The association between organizational structures and processes and PC use in AL has not been studied in prior research. This study examines which AL structural and process characteristics are associated with hospice use/PC use/discharge to NH. Three separate logistic regression models were analyzed for the likelihood of hospice use, PC use and discharge to NH in a stratified random sample of AL facilities in one U.S. state (N=76). The models included structural (resident case mix, staffing levels, discharge criteria, license and profit status) and process (training, administrator attitudes, presence of PC services) characteristics. The findings showed that for ALs which reported end-of-life care was important to the AL mission there was a 4.2 times higher likelihood to use hospice (Odds Ratio [OR]= 4.20, CI=1.18-14.90); each

increase in administrator attitudes towards using hospice increased the likelihood of hospice use by 8% (OR= 1.08, CI=1.10-1.16). For each increase in the number of NH discharges ALs were 3.4 times more likely to use PC (OR= 3.42; 1.21-9.70). ALs were 60% less likely to discharge residents who were in need of PC and ineligible for hospice (OR= 0.40; CI= 0.17-0.94). ALs with an Extended Congregate Care license were 91% less likely to discharge to NH (OR= 0.09; CI= 0.02-0.45); each increase in direct care staffing levels increased the likelihood of discharge to NH by 7% (OR= 1.07; CI =1.01-1.13). These findings suggest that organizational characteristics are associated with increased use of hospice, PC and NH.

**Abstract number:** P1-212

**Abstract type:** Poster

### The Development and Testing of a Dignity Care Pathway (DCP) for Use by Community Nurses with People Receiving End of Life Care at Home: Patient Experience

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**Aims:** This study has developed, implemented and tested a complex intervention, the Dignity Care Pathway (DCP), providing an evidence based approach to conserving the dignity of patients and their families receiving end-of-life care at home by community nurses (CNs). The primary aim was to explore the feasibility and acceptability of the DCP from the patients' and carers' perspectives. A secondary aim was to explore the ability of the DCP to allow individual dignity related needs to be assessed and subsequently met.

**Methods:** The DCP is based on the theoretical model developed by Chochinov et al (2002). The DCP has 4 sections; a manual; Patient Dignity Inventory; reflective questions and evidence based care actions. A qualitative design underpinned by the philosophy of Merleau-Ponty was employed for the evaluation of the DCP. Data collection included focus groups with CNs (39) at the beginning and end of the study; individual interviews with patients (30); informal carers (4). Interview data were analysed using framework analysis.

**Results:** The analysis of the patient and carer interviews resulted in four theme categories and 16 subthemes. Experience of DCP; responding to my illness concerns; how illness affects me as a person; how illness concerns affect my relationships. Participants found the use of the DCP beneficial as they were given the opportunity to discuss concerns that might have not been raised otherwise.

**Conclusions:** The DCP helps CNs deliver psychosocial care, previously identified as a difficult area for CNs in practice. CNs use of the DCP helps patients receive individualised care, which directly relates to the issues they have identified as most distressing and/or important and their preferred measures to address these issues, allowing increased information and support to carers. The use of the PDI facilitated patients communication of their dignity-related needs to community nurses, which highlighted increased satisfaction with the support they received.

**Abstract number:** P1-213

**Abstract type:** Poster

### Comparing Outcome Measure Tools among Cancer Patients in Bangladesh

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**Aim:** Administering and reviewing patient response to outcome measure tools among cancer patients at a tertiary referral centre in Bangladesh.

**Methods:** At initial phase we conducted a pilot study with 15 patients to test our questionnaire as we conducted forward backward translation at another site Dhaka Medical College Hospital; After testing and making required changes; Our research methodology was descriptive cross sectional type of study; We chose the National Institute of Cancer Research And Hospital (NICRH) as our primary research site We recruited (n=330) patients according to the inclusion criteria (age > 18 years, confirmed diagnosis of cancer, cell phone access for follow up ) informed consent was obtained: Data collected over a six month period from May 2012 to October 2012. We administered five types of assessment tools ESAS, BPI-S, MDASI, EORTC QLQ C 30 and EORTC PAL 15; To reduce bias we named each questionnaire Q1 to...Q5 administered Q1,Q2-Q5 and patients labeled as

P1, P2, P5 and first patients received Q1 first day second patient Q2 and so forth. Data analysis was conducted using SPSS software.

**Results:** Among the total number of patients (n=330) we had 188 (58%) male. Almost 20% of them had lung cancer; Among women predominant was breast cancer 76 (23%); Pain Score was 5.5 out of scale of 10 and it was consistent among all tools.

Patients ranked the questionnaire to their liking

1. ESAS
2. EORTC QLQ C 30;
3. EORTC QLQ PAL 15
4. BPI-SF and
5. MD ASI

**Conclusion:** It is important to understand patients perspective before we use the common Outcome Measure Tools among culturally diverse group.

**Abstract number:** P1-214

**Abstract type:** Poster

### Main Reasons for Acute Palliative Care Unit Referral

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**Background:** Referral to the Acute Palliative Care Unit (APCU) should be made when a patient with advanced, progressive disease with limited prognosis experiences complex symptoms, comorbidities, patient/family communication or other disturbing issues (within an inpatient or outpatient setting).

**Aim:** To evaluate most common reasons for hospitalization in APCU according to previous place of care.

**Methods:** We have reviewed charts of all patients (pts) admitted to APCU since February 2007 till end of January 2012. We compared major reasons for referral to APCU between a previous hospitalized (OUTpts) or pts in home care (INpts).

**Results:** During five year period of APCU there were 706 pts admitted in 899 hospitalizations. In 456 cases pts were referred from outpatient setting, in 443 cases pts were already hospitalized before being transferred to APCU. In all pts the most common main reason for APCU admission was complex pain (41,0%), in OUTpts 47,6% and 34,3% in INpts. Next most common main reason for admission was fatigue (all 13,5%; OUTpts 10,7%; INpts 16,3%), followed by dyspnea (all 11,7%; OUTpts 10,1%; INpts 13,3%), bowel obstruction (all 6,6%; OUTpts 4,1%; INpts 9,0%), nausea/vomiting (all 6,5%; OUTpts 6,4%; INpts 6,3%). Pts were hospitalized on average 7,66 days (OUTpts 7,01 days, INpts 8,3 days). A mean time of first referral to APCU was 36,1 days before dying (OUTpts 45,4 and INpts 27,7 days).

**Conclusions:** Most common main reason for APCU referral was complex pain, more frequent in OUTpts comparing with INpts. In our institution referrals to APCU are usually late; usually too late to achieve maximum benefits of comprehensive multiprofessional palliative care.

**Abstract number:** P1-215

**Abstract type:** Poster

### Concordance and Discordance between Advance Directives and Health Care Proxy Opinions: A Randomized Vignette-based Study

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**Background:** A written advance directive can occasionally contradict the opinion of a health care proxy. How such contradictions affect doctors' decision-making is not well known.

**Methods:** We mailed to a sample of generalists and internists (N=853) three vignettes that described medical decisions in incompetent patients. The vignettes were prepared in several versions and allocated at random. All vignettes were produced in 4 versions: one with an advance directive, one with a proxy opinion, one with both, and one with neither. In the first vignette the directive and the proxy agreed on the recommendation to forego further care, in the second one the advance directive opposed further care but the proxy favored it, and in the third one the wishes were reversed. The outcome variable was the decision to forego a medical intervention.

**Results:** Concordant advance directive and proxy opinion reinforced each other (odds ratio of avoidance was 35.7, p<0.001 compared to the absence of directive or proxy). When the directive and the proxy disagreed, their net effect was attenuated, but still favored foregoing the intervention (odds ratios of avoidance were 2.1 and 2.2 for the 2 discordant vignettes, both p<0.001). The average effects - i.e., odds ratios of a decision in the intended direction - were

4.4 (3.5 - 5.5) for an advance directive and 6.4 (5.0 - 8.1) for a proxy opinion when they opposed further care, and 2.9 (2.2 - 4.0) for an advance directive and 1.7 (1.2 - 2.3) for a proxy opinion when they favored further care.

**Conclusions:** Both written advance directives and proxy opinions influence doctors' decisions. In case of disagreement, the rule "when in doubt, abstain" appears to apply. Globally, directives requesting care were less effective than directives opposing care.

**Abstract number:** P1-216

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P1-217

**Abstract type:** Poster

### Preferences for Care at the End of the Life in the British Asian Hindu Community: A Qualitative Analysis Using Focus Groups

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**Background:** In the UK most people prefer to die at home but many still die in hospital. People from black and minority ethnic groups are even more likely to die in hospital but little is known about their wishes at the end of life.

**Aim:** To explore preferences for place of death among the British Hindu community and to identify barriers that prevent this.

**Methods:** Focus groups among Indian Hindus living in London. Data was analysed using the framework approach.

**Results:** All 14 participants considered home to be the preferred place of death. Whilst filial piety was viewed as underpinning the delivery of practical and emotional care at the end of life, multiple barriers to achieve home deaths were voiced and included:

- (i) Little knowledge of palliative care or hospice;
- (ii) language and cultural barriers that hampered accessing help from statutory services;
- (iii) the conflict between traditional Hindu culture with modernity;
- (iv) difficulties in families becoming caregivers; and (v) a reluctance to ask for help at this critical time.

**Conclusion:** The study adds to an emerging and important literature highlighting the complex challenges in realising home deaths among an ageing minority community. We recommend

- (i) that public health initiatives are developed to raise the profile of palliative care and
- (ii) a greater emphasis among service providers is placed on identifying and valuing the social capital present among the Hindu community. These will enable more people who wish to die at home to achieve this.

**Abstract number:** P1-218

**Abstract type:** Poster

### Palliative Care Consultation Service and Palliative Care Unit: Why Do We Need Both?

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**Background:** Palliative care (PC) infrastructure has developed differently around the globe. Whereas some institutions consider the palliative care unit (PCU) a valuable component, others report that the sole provision of a state-of-the-art palliative care consultation service (PCCS) suffices to adequately care for the severely ill and dying.

**Objective:** To aid institutional planning, this study aimed at gathering patient data to distinguish assignments of a concomitantly run PCU and PCCS at a large hospital and academic medical center.

**Methods:** Demographics, Eastern Cooperative Oncology Group performance status, symptom/problem burden, discharge modality, and team satisfaction with care for all 601 PCU and 851 PCCS patients treated in 2009 and 2010 were retrospectively analyzed.

**Results:** Patients admitted to the PCU versus those consulted by the PCCS:

- (a) had a significantly worse performance status (odds ratio [OR], 1.48);
- (b) were significantly more likely to suffer from severe symptoms and psychosocial problems (OR, 2.05), in particular concerning physical suffering and complexity

of care; and

(c) were significantly much more likely to die during hospital stay (OR, 11.03).

For patients who were dying or in other challenging clinical situations (suffering from various severe symptoms), self-rated team satisfaction was significantly higher for the PCU than the PCCS.

**Conclusion:** This study presents a direct comparison between patients in a PCU and a PCCS. Results strongly support the hypothesis that the coexistence of both institutions in one hospital contributes to the goal of ensuring optimal high-quality PC for patients in complex and challenging clinical situations.

**Abstract number:** P1-219

**Abstract type:** Poster

### Nurses' Role in Decision Making about Palliative Sedation

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**Context:** Nurses play an important role in the care of patients undergoing palliative sedation. Despite this, only little research has been focussed on the nurses' contribution to the process leading to the application of palliative sedation.

**Research aims:** The aim of this study is to clarify the nurses' role in the decision making process concerning this end-of-life-intervention.

**Study design and methods:** 35 nurses from different palliative care settings were asked to participate in an in-depth semi-structured interview, conducted by six trained interviewers. Data collection occurred from October 2008 to April 2009. Data were analysed using the constant comparative method with NVivo software.

**Results:** Important nursing tasks in the process leading to palliative sedation were observing the patient and drawing attention to significant changes in their condition, therewith providing information on which the decision to perform palliative sedation was made. Respondents did not speak of themselves as final decision makers, but exerted influence through care planning and participation in multidisciplinary meetings, depending on their level of experience. The nurse was often the first contact person in communication with the patient and their relatives.

**Conclusions:** The nurses role in the decision making process leading to palliative sedation encompasses many aspects, one of the most important being the role of declarant, for which observation of signs and symptoms was considered important. Nurses gain influence through their specific expertise in proposing a care plan, but also by facilitating communication within the care team and between care takers and patients and their relatives.

**Funding:** Funding for this study was provided by the Netherlands Organisation for Health Care Research (ZonMw) and the hospice kuria.

**Abstract number:** P1-220

**Abstract type:** Poster

### Perceptions of Nurses Concerning Sedation Depth during Palliative Sedation

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**Context:** Nurses play an important role in the management of continuous palliative sedation for dying patients with refractory symptoms. Little is known about their views concerning the required depth of sedation and proportionality of sedation.

**Aim:** The aim of this study is to explore the views of palliative care nurses regarding sedation depth, and to assess differences between nurses working in different institutions.

**Study design and methods:** Data were collected in semi-structured interviews with 35 nurses in three different palliative care settings (home care, hospice and hospital), focusing on the last case of palliative sedation the nurse had been involved in. Interviews were coded and analyzed with qualitative data analysis software Nvivo.

**Results:** Perceptions with regard to the goal of sedation and communication emerge as major themes related to the depth of sedation. Achieving deep sedation was considered the most important goal by most nurses. Achieving adequate symptom control was mentioned more often by hospice nurses than by nurses working in the other settings. However, achieving adequate symptom control prevailed in importance over the importance of maintaining communication (i.e. consciousness) with the patient. Furthermore, the manner in which monitoring is (systematically) performed also plays a role in achieving the required sedation depth.

**Conclusions:** Based on nurses' perspectives, preconceptions with regard to the goal of sedation related to the proportionality of palliative sedation may play a role in eventual determination of sedation depth. The role of adequate monitoring in the guidance and maintenance of sedation depth needs to be explored further.

**Funding:** Funding for this study was provided by the Netherlands Organisation for Health Care Research (ZonMw) and the hospice kuria.

Abstract number: P1-221  
Abstract type: Poster

### A Cinderella Service- improving End of Life Care Provided by Domiciliary Home Care Teams in Peoples' Homes and Boosting Confidence and Competence of Staff

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**Context:** Domiciliary care workers play an important but often unrecognised role in supporting people to remain at home as they near the end of life. Despite this, few received specific training in end of life care. Focused training might enable home care workers to improve the quality of care for such people and contribute to better coordinated cross boundary care, working alongside their providers in primary care.

**Aim:** Improving end of life care provided by Domiciliary Home Care Teams.

**Method:** GSF End of Life Care training was introduced to six Domiciliary Care Agencies in Manchester City supported by the Local Authority. A trainer from each agency completed the GSF Train-the-Trainer programme, and then worked with 10 carers at a time over a 3 month period. The programme used action based learning and reflective practice in 4 modules, with DVD, Good Practice Guide and workbooks, with interactive, and qualitative and quantitative evaluation.

**Results:**

- Improved communication, working relationships and collaboration with District Nurses and GPs
- Increased Advance Care Planning discussions, now part of the initial assessment plan, with information to others to improve coordination of care
- Service users were keen to be involved in ACP discussions
- Improved staff confidence and empowered staff, which in turn leads to improved communications with professionals
- Increased awareness of the knowledge they already possessed and future training needs

**Conclusion:** This work highlights the important role that Domiciliary Care Workers play, and the importance of empowering care staff who interact with the service users on a daily basis. Use of the train the trainers GSF Domiciliary Care Training Programme helped to improve care for people nearing the end of life and collaboration and coordination with others. It was well received and felt to boost the confidence and competence of Domiciliary Care Workers. Further spread and evaluation is planned.

Abstract number: P1-222  
Abstract type: Poster

### Hospice Care: What Factors Can Explain the Increasing Percentage of Patients who Died at Home?

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**Background:** Death at home is desirable aim and a central quality index in palliative care. Within the Hospice, which has been active 17 years, we find steady significant rise in the percentage of patients in our care who die at home.

**Aims:** The aim of the study is to check suppositions regarding the influencing factors of patients dying at home, whilst having an internal discussion within the framework of hospice team with the aim of continuing to improve the treatment given to patients.

**Method:** Internal discussions within the framework of the hospice team and checking the medical records of patients who died within the last 4 years.

**Results:** The percentage of patients who died at home in the years 2009-10 was 70.9%, and increased to 78.8% in 2011-12. From the check of the medical records, according to the suppositions of team members and from professional literature, no difference was found between the 2 time periods within demographic factors (age, gender, land of birth), diagnosis, the average length of treatment and number of home visits. In addition we checked the relationship between 3 modes of treatment and rate of patients dying at home.

1. Joint home visits by a doctor and a nurse.
2. Involvement of Social Worker and other therapists.
3. Holding open "family discussion" towards the preference at the end of life.

It was found that amongst patients who died at home there was a higher rate of influence of the 3 modes of treatment compared to patients who died in hospital (X compared with Y).

**Summation and conclusions:** Inter-disciplinary teamwork of doctors, nurses and other staff is one of meaningful sources for giving quality palliative treatment. The ability to have an open discussion also contributes to the rise in percentage of those dying at home. The study enabled the staff to observe that the factors of treatment improve the standard and quality of treatment and will advance the future treatment for all our patients.

Abstract number: P1-223  
Abstract type: Poster

### Implementing the Gold Standards Framework (GSF) into a Tertiary Cancer Centre

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**Background:** The GSF was developed in 2000 to improve palliative care in primary care. National dissemination was facilitated through a cascade approach with a Central Team supporting local facilitators. **GSF has been shown to improve:**

- Quality of care
- Co-ordination and communication
- Patient outcomes and cost effectiveness.

Acute hospitals have been described as the missing link in providing seamless, co-ordinated high quality end of life care. There has been no experience of implementing GSF into a tertiary cancer centre.

**Aim:** To explore the views of health care professionals working in a tertiary cancer centre about the knowledge and skills they have in identification of patients in the last twelve months of life and the use of advance care planning tools.

**Method:** Three questionnaires were distributed to health care professionals

- Base line survey assessing knowledge and skills
- Organisational Questionnaire
- After death analysis for Trust deaths

**Results:** The baseline questionnaire was distributed to 152 staff. The response rate was 76%. The organisational questionnaire was distributed to 3 wards and the Head of Nursing. The Response rate was 100%. The After Death Analysis examined 86 deaths in the Trust. Complete results from the three questionnaires will be presented with details of the subsequent action plan.

**Conclusion:** Interim results from the surveys have demonstrated that healthcare professionals require further training in the identification of patients at the end of life and the use of advance care planning tools. A comprehensive education package delivered over 6 months will aim to address the needs of staff.

Abstract number: P1-224  
Abstract type: Poster

### Case Manager - End of Life Care: A New and Innovative Role

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There is strong emphasis in palliative care to develop methods to support the meeting of preferences for those at the end of life, particularly regarding place of care. One method to support this in the in-patient setting is the development of discharge facilitator roles for this group of patients. It is crucial that the discharge of patients with complex, rapidly changing needs is well coordinated, effectively communicated, with appropriate support arranged. One new and innovative role developed to support this is that of Case Manager - End of Life Care (CM-

EOLC) which aims to facilitate discharge of patients rapidly nearing the end of their life from the inpatient setting to their preferred place of care (PPC) in a timely and coordinated fashion. Since September 2012 three CM-EOLC have been working with specialist palliative care teams (SPCT) in the hospice and hospital setting, identifying patients with complex needs nearing the end of life and facilitating discharge to their PPC. Referrals to the CM-EOLC come via the SPCT with the level of input varying on patient specific criteria. Responsibilities include: facilitating rapid discharges home of dying patients, arranging equipment and packages of care, communicating with relevant parties, supporting decision making and giving advice. Documentation is in use to record input from CM-EOLC and outcomes for patients. Data will be presented descriptively to illustrate information gathered between September 2012 and February 2013, reflecting numbers of patients referred to CM-EOLC, the level of input delivered and the number and type of discharges facilitated. Results will be used to highlight good practice and identify areas for improvement where needed. This role focuses on facilitating discharges of patients nearing the end of life, applying specialist knowledge to ensure preferences are being addressed and met. This phase of data collection will be used to inform further development in this area.

Abstract number: P1-225  
Abstract type: Poster

### The CoMPASS:ION Study (Care Of Memory Problems in Advanced Stages: Improving Our Knowledge): Workshops with Health and Social Care Professionals

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**Aims:** This study is part of a UK-wide mixed methods programme of work to develop a complex intervention to improve the end-of-life care for patients with advanced dementia and their carers. The aim of the workshops was to identify good and poor practice in the care of dementia patients, to identify gaps in service provision and training/support needs for professionals.

**Study design and methods:** To stimulate discussion and the generation of solutions we used a realist synthesis approach, basing the workshops on four vignettes that typically occur in the care of people with advanced dementia.

1. Care home patient repeatedly admitted to A&E.
  2. Patient has cardiac arrest, ambulance paramedic attempts resuscitation for 20 minutes.
  3. Carer has problems coping with patient but does not want her admitted to a care home. The district nurse disagrees.
  4. A nurse suggests 'dementia' is the reason for a patient's aggressive and distressing behaviour. Her carer thinks she is in pain but she is not prescribed analgesics.
- Workshops were facilitated by 2 members of the research team, lasting for approximately 2 hours. Detailed notes were taken during each workshop and thematic analysis was applied to the data.

**Results:** 4 workshops were held in London, Edinburgh, Solihull and Belfast with 44 participants. Commonly occurring themes include: lack of understanding dementia and recognising it as a terminal illness; difficulty in diagnosing dying; communication issues for both professionals and families; lack of advance care planning/advance directives and care plans; unrecognised and untreated pain; the skill mix needed in care homes and the need for a palliative approach.

**Conclusion:** A complex range of skills are needed to look after this population effectively. The results from these and future workshops are an important part of gathering the evidence base for the development of a complex intervention to improve the end-of-life care for patients with advanced dementia.

Abstract number: P1-226  
Abstract type: Poster

### Improving Communication: Hospital Specialist Palliative Care to Community Health Care Professionals

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**Background:** Following discharge from a tertiary cancer centre a Specialist Palliative Care Team (SPCT) found their advice and recommendations were not conveyed to community Health Care Professionals (HCPs). To redress this, and supplement the oncology discharge letter, the SPCT utilised their own letter template, the aim being to improve

the transition of patients with complex symptom management and/or those requiring psychological support. Letters were sent to all HCPs involved in the individual's care.

**Aim:** A survey was undertaken to ascertain community HCPs' opinion on the usefulness of the newly introduced discharge letter and identify ways in which information and/or communication may be improved.

**Method:** SPCT discharge letters were sent over a six month period. A survey form comprising three closed questions and seven open-ended questions was sent to all community HCPs involved with each patient, one week following discharge. Recipients included GPs, District Nurses, Specialist Palliative Care Teams, Hospice at Home, and professional carers. A thematic analysis was applied to the open-ended questions.

**Results:** 51 survey forms were sent, pertaining to 18 discharge letters. 33 replies were received, of which, 94% said the letter was 'very useful', 97% said the length was 'about right' and that they wished to continue to receive them. The letter format was reported as being clear, concise, relevant, and succinct. 30% wanted a rationale for drug choice and titration, and/or oncological information (medications and/or treatment).

**Conclusion:** Overall findings suggest the SPCT discharge letter improves communication following discharge. The need for community HCP education needs to be explored as some drug choices and titration may require the knowledge and skills of SPC clinicians. The need for additional oncology information needs to be redressed. This survey shows that the tertiary SPCT discharge letter improves their communication with the community HCPs.

**Abstract number:** P1-227  
**Abstract type:** Poster

## How to Share a Terminal Patient's Desire amongst the Medical Team? - From the Experience of a Nurse on Terminal Sedation

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**Objectives:** This study aims at clarifying features and issues concerning inter-team awareness of sedation needs as clinical knowledge during terminal palliative care.

**Methods:** This interpretive case study was undertaken by focusing on the narrative of one member of 20 nurses with 3 or more years of clinical experience. Semi-structured interviews were conducted to discuss a memorable case of palliative care. The hermeneutic methods of Benner et al. (1994) were used to interpret nursing practice under specific conditions.

**Ethical review:** This study was approved by relevant hospital and university ethics committees.

**Results:** During daily involvement with a female patient with lung cancer, a nurse repeatedly heard her plead, "I don't want to end my life in pain, give me something to make me sleep." The patient found it increasingly difficult to breathe. The day her sedation regime was started, the nurse was on night duty. The sedative dose was ineffective, and there were no adequate instructions from a doctor consulted by telephone. Seeing the suffering patient, the nurse felt her condition differed from the patient's wish, and she resented the doctor for not increasing the sedative. However, the following day, during the death conference, the nurse was shocked to learn that the patient had only told her last desire to her.

**Conclusions:** Various gaps arise even if staff follow the Guideline about terminal sedation. In a terminal stage patients may experience mood swings and reveal different things to different team members depending on their relationship. Moreover, nurses who deal directly with patients as individuals may find it hard to share with team members their impressions of a patient that was acquired at specific times and in specific locations. Each team member has their own fragmented view of a patient. Some means are required to arrive at a shared view that more closely corresponds with the reality of the situation.

**Abstract number:** P1-228  
**Abstract type:** Poster

## A Retrospective Baseline Audit to Assess Current Practice in Identification, Communication and Advance Care Planning for Christie Patients in the Last Year of Life

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**Objectives:** The main aim of this audit is to assess current practice within The Christie in relation to identification, communication and future care planning for patients in the last 12 months of life.

The Christie hopes to improve the Palliative care involvement in patients care, in line with current initiatives, and will use this baseline data to set realistic targets for improvement.

**Method:** This is a retrospective case note audit of the last 100 deaths of Christie patients at the 31<sup>st</sup> March 2012. An online proforma was developed and used to gather information relating to the 5 standards.

**Results:** 80 sets of case notes were eligible and accessible for inclusion. From the documented evidence reviewed: 48% of patients were identified as being in the last year of life, 48% had an opportunity to discuss prognosis, 94% were involved in their treatment plans, 66% had an offer of referral to specialist Palliative care services and 55% had communication of prognosis with their General Practitioner. There is a breakdown of the results for each standard; looking at time before death outcomes occurred and other details of interest.

**Discussion:** The results have highlighted a need for improvement in identifying patients approaching the end of life; the implementation of prognostic indicator tools has been suggested. Participation in advanced communication skills training has been suggested as beneficial to improve discussions around prognosis. Promotion of Palliative care and joint working with Oncology may be a way to improve end of life care. Development of the existing web based portal system may improve information sharing between The Christie and the community.

**Abstract number:** P1-229  
**Abstract type:** Poster

## The Behavior Intention and Predictors of Truth Telling with Terminal Cancer Patients in Taiwan - From the Patient, Family, Physician and Nurse's Viewpoints

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**Research aims:** To investigate the physicians and nurses' attitude and behavior intention for truth telling and the families' barriers or patient's willingness that they encountered when executing it in Taiwan.

**Study design and methods:** The multi-center surveyed by stratified random sampling in Taiwan. The subjects were 109 attending physicians, 301 primary nurses, 81 terminal patients and 107 families recruited from 9 medical center and district hospital. The data was collected by interview with structured questionnaire. First, descriptive statistics were computed. Next, univariate analysis were calculated and then stepwise regression analysis that examined the linear combination among various independent variables and the outcome variable was conducted to identify the relative values of the important variable related to behavior intention for truth telling willingness.

**Results:**

- 1) Nearly all of the terminal patients (98.5%) who know their poorly disease condition, they does not regret knowing the facts;
- 2) The most difficult situation that the physicians and nurses encountered is of different opinions from different family members, especially during the time making the decision on whether or not signing the consent form of "executing no CPR";
- 3) The nurses have more distress at facing a patient who does not know his/her terminal situation than the physicians do;
- 4) For the physicians, "benefits of truth telling" ( $\beta = 0.31$ ) "bads of truth telling" ( $\beta = 0.25$ ) and "Truth disclosure" ( $\beta = 0.19$ ) are the predictors of doctors' behavior intention for truth telling. The 17.2% of the variances are explained.

**Conclusion:** More than eighty percents of physicians and nurses approved to develop the guidelines of truth telling for terminal conditions. This research reveals that hospice training course is an important factors to improve the physicians and nurses' intention behavior about truth-telling.

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**Abstract number:** P1-230  
**Abstract type:** Poster

## Patients' Experiences of Hospice Referral: A Phenomenological Study

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Discussion of hospice care may cause distress to the terminally ill patient. The aim of this study was to describe the patients' experience of the hospice referral process. This qualitative study was designed using phenomenological principles to understand the lived experiences of others. Suitable subjects were identified in the inpatient unit of St Andrew's hospice, a 30-bedded specialist palliative care unit in Lanarkshire, Scotland. Those who consented participated in a semi-structured interview conducted by one of the two researchers. 11 interviews were conducted between Nov 2007 - March 2008. The interviews were audio recorded and transcribed verbatim. The researchers performed content analysis to describe the essence of the emerging themes. The main theme was the benefit derived from the experience of the hospice package, the all encompassing nature of hospice care. Participants preferred to focus on their actual hospice experience, which was overwhelmingly positive. However, they described the referral process with reference to their pre-conceptions and their previous knowledge of palliative care. Few participants were distressed when hospice was mentioned. Many, in fact, were relieved as they felt alternative care in a hospital would be unsuitable. Many focussed on previous negative hospital experiences. Several participants were distressed by time spent on the waiting list, anxious that a bed would not be offered. Few participants had a clear understanding of the term 'palliative care'. The authors conclude that a well communicated discussion about hospice and palliative care is likely to be well received and those awaiting a bed should be regularly updated.

**Abstract number:** P1-231  
**Abstract type:** Poster

## Symptom Clusters in Advanced Cancer Patients during Terminal Phase of their Illness in a Northern City of Turkey

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**Introduction:** Cancer patients experience many symptoms that frequently present together as clusters. The identification of these clusters with regard to the cancer-site, cancer-stage, etc. carries potential importance to guide the management of patients. Here, we aimed to identify specific symptom clusters in advanced cancer patients followed by a multidisciplinary palliative care team.

**Patients and methods:** The study included all adult cancer patients with end-stage disease referred to two physicians primarily dealing with terminal cancer patients were included. The patients were evaluated by a multidisciplinary team on a weekly base. The demographic data and the patient informations (symptoms and signs, the primary disease, and etc) were prospectively entered into a database. The data from examining charts were reviewed retrospectively and analyzed with descriptive and hierarchical cluster analysis with SPSS 18.0 (Chicago, IL).

**Results:** Ninety three patients (62 male, 31 female) were included. The mean age of patients was 64.4±10.79 years. The mean BMI of patients was 23.87±4.92 kg/m<sup>2</sup> on admission. The primary tumors were of gastrointestinal origin (41%, n: 38). The main presenting symptom of the patients was pain (84%, n: 78). The other symptoms were in decreasing order; tiredness (97.8%), pain (91.4%) insomnia (91.4%), dyspnea (60.2%), cough (%), nausea (60.2%), vomiting (60.2%), constipation (74.2%), loss of appetite (74.2%) and. The confirmatory analysis showed the following symptom clusters:  
1) tiredness, pain, anorexia and insomnia,  
2) nausea, appetite and constipation),  
3) dyspnea and cough

**Conclusion:** Multiple cancer-related symptom clusters might occur in terminally-ill patients. A thorough understanding of clustered symptoms rather than focusing on single symptoms could help to manage patients appropriately.

**Abstract number:** P1-232  
**Abstract type:** Poster

## Patients' Views of Partnership Working between Specialist and Generalist Palliative Care Providers

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**Background:** A key focus of UK policy is improving partnership working, and multidisciplinary involvement across the spectrum of palliative care provision. Most palliative care occurs in a generalist setting rather than a specialist palliative care setting. Ensuring effective partnership working between generalist and specialist providers of palliative care is therefore necessary for improving patient care.  
**Aims:** To explore patient experiences of, and priorities for, partnership working between specialist and generalist providers of palliative care.  
**Methods:** Qualitative semi-structured interviews were conducted with patients with palliative care needs (n=28) recruited in two hospices in northern England.  
**Results:** Data has been analysed using a modified thematic approach. Results highlight that not all patients can identify the main health care professional (HCP) supporting them. A few patients acknowledged the Community Matron as the main facilitator of their care. Issues cited as important with regard to HCPs include good relationships; continuity; being able to contact someone for help and advice when needed; helpfulness and willingness in dealings with patients. The majority of patients said they had not experienced difficulties getting care when they needed it, but this view was accompanied by concerns about poor communication and receiving conflicting advice from HCPs.  
**Conclusion:** Patients' views in this study reveal that many are satisfied with their care, especially care provided by their local hospice. Asked about how care from health care providers could be improved, a significant number expressed dissatisfaction about lack of continuity, poor communication and poor 'bedside manner'. Views of patients who participated in this study informed the development of a questionnaire tool to explore partnership working from the perspective of health professionals.

Abstract number: P1-233  
 Abstract type: Poster

#### India vs UK: A Comparison of Doctors' and Nurses' Attitudes towards Palliative Care

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**Aims:** This study aimed to explore the differences between attitudes of clinicians in India and the UK, and use this knowledge to drive further improvements in palliative care services in India, by guiding future policy making.  
**Background:** Palliative care in India is a young discipline. There is no palliative care teaching in the national MBBS course, nor is there a nationwide palliative care policy. This contrasts with the UK where the hospice movement began in 1967. Palliative care is a well-established speciality and is taught as part of medical and nursing students' standard training.  
**Methodology:** Partially validated questionnaire. 51 clinicians were opportunistically sampled in India, 48 in the UK. Data analysis was performed using Microsoft Excel.  
**Findings:** Indian clinicians considered religion to be more important in helping them care for patients (Mann Whitney U test  $z = 2.62$ ,  $p < 0.01$ ) and chose 'nursing at home' as their most important resource, compared to 'palliative drugs' in the UK. Indian clinicians ranked their 'own views' second when making treatment decisions, whereas UK clinicians ranked this fourth.  
**Recommendations:** If resources such as opioids could be made more readily available in India, then clinicians may view it as more important. India has strict laws governing opioid prescribing, which should be relaxed in order to allow this. The increased emphasis on 'own views' of Indian clinicians indicates a paternalistic medical culture. Specific palliative care education, which is currently absent from the medical student syllabus, may help change this.

Abstract number: P1-234  
 Abstract type: Poster

#### Healthcare Professionals' (HP) Understandings of Advance Care Planning (ACP) in End of Life Care for People with Primary Brain Tumours (PBT): A Qualitative Study

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**Background:** Patients with PBT have poor prognoses and early and prolonged palliative care needs. Significant, fluctuating and progressive cognitive decline is common. Early ACP may enable discussion of decisions about the future. Yet there is little evidence of ACP in practice.  
**Aim:** To explore how HP working in PBT understand the palliative needs of patients and approach ACP in their work.  
**Method:** Qualitative study using semi-structured interviews. Participants are recruited purposively according to discipline (neurosurgeons, neuro-oncologists, clinical nurse specialists, allied HP), experience, age, sex, ethnicity (N=15). Data is analysed with framework analysis.  
**Results:** Initial findings (N=5) suggest ACP is complex in PBT patients. ACP discussions usually take place in the context of patients' anticipated cognitive decline. Accordingly, participants felt ACP discussions should happen early in a patients' illness. Participants reported how ACP discussions involved difficult existential themes around illness, dying and death and they tried to approach discussions sensitively. They agreed ACP discussions should not be formulaic, or imposed on patients. Discussions often happen ad hoc. Participants felt ACP is shared amongst the multidisciplinary team, but worried that therefore no one engages in or takes responsibility for ACP. Participants did not use a standardised way of documenting ACP. In general, they chose to communicate content of discussions to their teams through informal conversations and at meetings.  
**Conclusion:** The lack of standardised documentation and assumption of shared responsibility amongst professionals may lead to some patients missing the opportunity for ACP discussions or their choices not being fulfilled. Given the nature of discussions, formalising their place and content may be problematic. Findings will inform the development of an ACP based intervention which can later be tested for feasibility and acceptability.  
**Funder:** National Brain Appeal.

Abstract number: P1-235  
 Abstract type: Poster

#### Survey on Beliefs and Opinion of Oncology Health Professionals about Palliative Sedation

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**Background:** Palliative Sedation (PS) has been defined by palliative care professional boards. Often opinions from other health professionals don't necessarily match, which can be a cause of tension in the daily clinical work. We have found it interesting to begin by determining what oncology health professionals (OHP) really know about this procedure and their agreement with the PS definition.  
**Aim:** To describe beliefs, opinions and expectations about PS of OHP and to determine the degree of agreement with the SECPAL's Palliative Sedation definition.  
**Material and methods:** Using the current PS definition endorsed by the Spanish Society of Palliative Care (SECPAL), we split it up into conceptual parts, and developed a self-administered questionnaire for personnel working in Oncology, Haematology and Palliative Care Services in a cancer institute.  
**Results:** Of 125 questionnaires, 105 (84%) were evaluable (physicians 51.4%, nurses 28.6%, aux 13.3%). Females 71.4%. All OHP had heard about PS, the main source of information was from colleagues. Two-thirds of OHP think patients don't suffer but 32.7% think that they may be uncomfortable. PS is seen as euthanasia by 2% and 11% think it shortens life. PS decision-making was considered difficult, but family support makes it easier when deciding for a relative (66.3%) or oneself (41.8%) (P=0.018). End of Life Information is perceived as a topic to be discussed in advance with the patient and family by 87.6%. It is felt that this subject should be discussed publicly and more information is needed (88%). The study found a 70.3% agreement with SECPAL definition. Poor agreement was found in obtaining patients consent.  
**Conclusions:** SP is known as a procedure for end of life care to alleviate suffering, OHP showed an acceptable agreement with the SECPAL's definition. Most people see family as supportive in the decision-making process, but it's felt that more information is needed.  
 This study has no financial support.

Abstract number: P1-236  
 Abstract type: Poster

#### A Randomized Controlled Study Including Health Care Staff Caring for Patients in Cancer at the End of Life: Results from an Educational Intervention on Existential Support

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**Objectives:** To determine the effects of an educational intervention focusing on existential issues on nurses' perceived confidence in communication and their attitudes towards caring for dying patients.  
**Methods:** A randomized controlled trial was conducted with an educational intervention focusing on existential topics as life and death, freedom, relations and loneliness, and meaning. The intervention included five 90 minute sessions over an eight week period consisting of theoretical education combined with individual and group reflections. 102 nurses in oncology wards, hospice wards and palliative home care teams were randomised to either education group or non-education group. Primary outcomes, confidence in communication and attitudes toward care of dying patients were measured at baseline before the educational intervention started, immediately after, and five months later. Distribution was given as mean, SD, median, min and max, number and percentages. Data were analyzed with Mann-Whitney U-test, Fishers' exact test, Chi-square test, Wilcoxon Signed rank test, sign test and Spearman's correlation coefficient.  
**Results:** In the education group confidence in communication increased significantly from baseline, to both first and second follow-ups, i.e. immediately after and five months after the education. The attitudes toward care of the dying did not increase in the education group.  
**Conclusion:** An education including existential topics with reflection over time improves healthcare staffs' confidence in communication when caring for patients in cancer at the end of life. This is important information for healthcare managers with limited resources. Further studies are needed to explore how patients experience healthcare staffs' communication skills after such education.

Abstract number: P1-237  
 Abstract type: Poster

#### Anticipatory Medication 'as Stock' for Residents who Are in the Dying Phase: A Project in 3 Nursing Care Homes

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The Gold Standards Framework for Care Homes [GSFCH] and the Liverpool Care Pathway [LCP] guidance suggests the importance of obtaining anticipatory medication for the control of symptoms in the last days of life for nursing home (NH) residents. There is considerable wastage however as NH residents are dispensed anticipatory drugs on a named-patient basis. There is also evidence that when these drugs are not available residents are hospitalised inappropriately.  
**Aim:** The aims of the project were to explore the frequency of symptoms experienced in the dying phase and to explore whether there was a need for residents to have their own supply of drugs by examining wastage. The idea was to establish a process in order for homes to obtain anticipatory medication as 'stock' and to capture the benefits of doing this.  
**Process:** The managers of three 'GSFCH accredited' NHs, who had shown interest in obtaining medication for the last days of life, met with a local GSFCH facilitator, specialist palliative care pharmacist and a pharmacist from the regulatory body. A formal proposal that included a list of necessary medication and how to acquire them was written. The NH staff developed the required Standard Operating Procedures which were discussed with relevant general practitioners. A prospective audit on medication used was commenced.  
**Results:** Significant improvements in the availability of anticipatory medication were found. 53% of residents were symptomatic highlighting the need to have anticipatory medication available. No medication other than 'stock' was required by NHs. By using stock drugs, there was a potential saving of £2,649 if each resident had been prescribed individual medication. All staff involved perceived that this work had been beneficial.  
**Conclusion:** Anticipatory medication 'as stock' for people dying in NHs is an important step forward. There is less wastage of medication, less delay in controlling symptoms, reduced call out of GPs and less anxiety.

Abstract number: P1-238  
Abstract type: Poster

## An exploration of the Role of the Key Champion in the Process of Implementation of the Liverpool Care Pathway for the Dying Patient in Intensive Care Model Pathway (LCP ICU - MP)

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The LCP programme is a model of best practice to support evidence based high quality care for dying patients and their relatives/carers. The LCP ICU-MP was developed specifically for use in ICU settings and was successfully piloted across 10 ICU Services within the Cheshire and Mersey Critical Care Network (CMCCN). A 'cascade' model of training was adopted to support its implementation within these ICU settings. This approach involved the recruitment of Senior Nurses to become project Key Champions, to act as change agents in each site by becoming the conduit for education, training and support for staff in the use of the LCP ICU-MP in the clinical environment.

**Aims:** To elicit the views of key champions to understand their experience of undertaking this role, including the identification of associated benefits, barriers and learning outcomes.

To use these findings to review and refine the implementation model for use in future dissemination projects.

**Method:** A focus group comprising 12 key champions was undertaken at the end of the implementation phase. The discussion was guided by a semi-structured topic guide, and was audio-taped and transcribed verbatim. A Thematic Analysis was then undertaken.

**Results:** Three initial themes emerged that impacted on the success of the implementation process in each of the sites: Commitment to the project (by staff at various levels); Time constraints and competing work priorities; Role benefits and challenges.

**Conclusion:** The findings will be discussed in terms of their potential to facilitate the review and refinement of the Role of the Key Champion and the implementation process for use in wider dissemination of the LCP ICU-MP. This study was funded by Merseyside and Cheshire Cancer Network (MCCN) on behalf of the CMCCN.

Abstract number: P1-239  
Abstract type: Poster

## Continuous Sedation (CS) until Death: A Bibliometric Analysis (1945-2011)

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**Aims:** Sedation at the end of life is a complex medical and ethical topic, increasingly debated in the palliative care literature. However, little is known about the characteristics and trends within scientific publications in this field of research. The aim of this study was to map the existing literature through the bibliometric analysis of scientific publications on continuous sedation until death.

**Design:** Four electronic databases (MEDLINE, PubMed, EMBase and PsycINFO) were searched for indexed material published between 1945 and 2011. This search resulted in 273 published outputs that were analysed using bibliometric techniques.

**Results:** Evidence revealed a growing rate in scientific publications from the beginning of the 90s falling into a wide range of publication types such as comments/letters (26.7%), empirical research articles (23.8%), theoretical/conceptual articles (18.7%), reviews (12.8%), case reports (8.0%), and editorials (5.0%). Outputs were published in 94 journals of varying scientific disciplines (medicine, palliative care, ethics, law), the majority of which (72.3%) was classified under Health and Medical Sciences. Journal of Pain and Symptom Management was identified as the major journal in the field covering 12.1% of the total publications. Countries of origin of research activity and publication confirmed the international spread of research on the field. Japan and the Netherlands were found to be the leaders in research article productivity while the UK and the USA ranked top in terms of the quantity of scientific publications.

**Conclusion:** This is the first bibliometric analysis on continuous sedation until death to provide a representation of the general characteristics and trends regarding the evidence as well as a baseline with which to compare future studies.

**Keywords:** End-of-life care, continuous sedation until death,

bibliometric analysis  
Abstract number: P1-240  
Abstract type: Poster

## Sedation in End of Life Care: The Conceptual Debate over Terminology and Definitions

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**Aims:** The lack of consensus regarding nomenclature to describe sedation at the end of life has made interpretation and comparison of the results of studies and case analyses problematic and has created confusion in both clinical and research fields. This paper aims to explore and account for the conceptual debate over terminology and definitions assigned to sedation at the end of life over time.

**Design:** Six electronic databases (MEDLINE, PubMed, EMBase, AMED, CINAHL and PsycINFO) and two high impact journals (NEJM & BMJ) were searched for indexed materials published between 1945 and 2011. This search resulted in bibliographic data of 328 published outputs. Terms and definitions were manually scanned, coded, and linguistically analysed by means of term description criteria and discourse analysis.

**Results:** Terminology of sedation at the end of life was observed to have evolved from simple to complex terms. Definitions of sedation varied in length, comprising different aspects of the practice such as indications for use (to palliate; to relieve), pharmacology (psychotropic agents; sedative drugs), patient symptomatology (profound anguish; physical distress), target population (terminally ill; imminently dying), time of initiation (close to death; in the last phase of life), and ethical considerations (deliberately; without intending to cause death) in combinations of a minimum of two or more of these aspects.

**Conclusion:** Given the diversity in the terms used to describe sedation and the range of understandings associated with the meaning of the practice, reaching consensus is bound to be difficult. Still, the conceptual confusion that currently exists in the literature needs to be resolved and a base of commonality to be built on which to design research and enhance practice of sedation in end of life care.

**Keywords:** Sedation, end-of-life care, conceptual debate, terminology, definitions

Abstract number: P1-241  
Abstract type: Poster

## Is 'Liverpool Care Pathway (LCP) for the Dying Patient' in Evidence to Be a Useful Instrument also for the Inpatients in a Palliative Care Unit?

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Liverpool Care Pathway was initially developed for better End-of-Life-Care for institutions which in their daily routine do not have much experience in care of dying patients (J. Ellershaw). The aim we saw in the present investigation was to work out if the LCP also makes sense during End-of-Life-Care of the inpatients in a Palliative Care unit, i.e. in a setting where death-and-dying is managed by an experienced staff.

**Procedure:** Hereto we examined 40 completed LCP cases. The following criteria were evaluated:

- 1) duration of LCP care in days;
  - 2) goals of the care;
  - 3) Interviewing of the Palliative Care unit team in following points:
    - 3.1. practicability in the everyday life,
    - 3.2. processing optimising, especially concerning the decision-making or recognising the transition point to turn to terminal care,
    - 3.3. influence on the process of communication within the interdisciplinary team.
- Results:** We found out that Liverpool Care Pathway (LCP) is helpful in managing critical situations also in a PC unit setting, especially due to
- 1) ensured transparency of what was done,
  - 2) optimising of standards which provides more safeness feeling to colleagues who are less experienced,
  - 3) becoming a good training instrument for the PC staff regarding their role in further implementation of LCP in other departments of the hospital.

Abstract number: P1-242  
Abstract type: Poster

## Appropriateness of Hospital Admissions at the

**End of Life: Perspectives of GPs and Nurses**  
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**Aim:** With many patients being transferred to hospital in the last days of life, we wanted to explore the perspectives of general practitioners (GPs) and nurses on hospitalizations at the end of life and how they consider the appropriateness of such hospitalizations.

**Methods:** Five focus groups with GPs (N=37) and three with nurses working in hospital, home care or care homes (N=23). Participants were asked about their experiences and opinions about hospitalizations at the end of life. They were prompted to assess the appropriateness and avoidability of such a hospitalization in patients with cancer, organ failure or dementia.

Transcripts of the focus groups discussions were analyzed by two researchers using open, axial and selective coding with QSR-NVIVO 10. Results were regularly discussed in the research team.

**Results:** The participants of this study generally agree that a hospitalization at the end of life is clinically appropriate in a limited number of events and conditions (eg. gastro-intestinal obstruction), and only when it is likely that there will be a comfort benefit, that can only be achieved by a diagnosis or treatment in a hospital. On the other hand there was also agreement that a hospitalization at the end of life is appropriate when it has a psychosocial benefit, in keeping with the patient's and/or relatives' preferences (eg. to take away anxiety) or when the current care setting is not able to provide adequate care continuously and adequate alternative care settings are not readily available.

**Conclusion:** GPs and nurses agree that a large proportion of hospitalizations at the end of life can be avoided although they may be appropriate, taking into account the psychosocial benefits and the lack of adequate sub-acute alternatives. These findings will be used to develop an assessment procedure to evaluate whether a hospitalization at the end of life is appropriate or necessary.

**Funding:** This study is part of the FLIECE-study, funded by IWT.

Abstract number: P1-243  
Abstract type: Poster

## Results from the UNBIASED Study (UK - Netherlands - Belgium International Sedation Study): Reported Practices of Physicians and Nurses in Three European Countries

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**Background:** Continuous sedation in end of life care is an important and frequently necessary but highly contested intervention in the care of dying patients with otherwise refractory distress. There have been few studies which allow international comparisons to be made and which investigate the perspectives of physicians and nurses from different care settings.

**Aim:** to understand what intentions and practices are reported by physicians and nurses involved in continuous sedation in end of life care for cancer patients in the UK, Belgium and the Netherlands.

**Methods:** Qualitative case studies in hospitals, hospices and home care settings, comprising interviews with nurses and physicians involved with the care of patients who had died of cancer and received continuous sedation for refractory symptoms.

**Findings:** We studied 84 cases (22 UK; 35 NL; 27 BE) 57 physicians (17 UK; 18 NL; 22 BE) 73 nurses (25 UK; 28 NL; 20 BE). UK respondents often described sedation as a 'side effect' of their intent to control symptoms. They perceived a continuum to exist from the 'normal practice' involving low doses of sedatives given commonly for terminal restlessness, to rare situations where it was exceptionally challenging to bring suffering under control. In contrast, respondents in Belgium and the Netherlands typically/often described how they sought to respond to a patient's request for sleep or to enable patient's 'choice' of sedation. Reported practice in the Netherlands was framed by recommendations in a national guideline. In contrast in Belgium practice was typically reported as targeted at achieving and sustaining deep sedation.

**Conclusions:** continuous sedation at the end of life is

practised and perceived differently by physicians and nurses in the three countries, with the most notable feature being the caution reported by UK respondents, compared to those in Belgium and the Netherlands.

**Abstract number:** P1-244

**Abstract type:** Poster

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**Abstract number:** P1-245

**Abstract type:** Poster

### The Impact of "Self-perceived Burden to Others" and "Posttraumatic Growth" on Quality of Life for Terminally Ill Cancer Patients

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**Research aims:** Feelings of imposing physical, emotional, social, and economic hardships on families are common among terminally ill patients, however facing mortality and realizing the fragility of life may foster a positive transformation in one's perspective on life. Researchers identified "self-perceived burden to others" (SPB) and posttraumatic growth (PTG) as two important themes that is related to psycho-social and existential suffering at the end of life (EOL). Therefore, the aim of this study was to investigate the roles of "SPB" and "PTG" on quality of life (QOL) of terminally ill cancer patients.

**Methods:** A prospectively, longitudinal study was conducted on 188 Taiwanese terminally ill cancer patients recruited by convenience sampling and died during the study period to evaluate the impact of SPB and PTG on their QOL. McGill Quality of Life Questionnaire, Self-Perceived Burden scale, and Posttraumatic Growth Inventory were used to measure QOL, SPB and PTG, respectively. The generalized estimating equation (GEE) model was used to assess the independent impact of SPB and PTG on QOL while simultaneously controlling for common predictors of QOL.

**Results:** The GEE results indicated that if terminally ill cancer patients reported less symptom distress, lower anxiety and depressive symptoms, more emotional and affective social support but lower tangible and social interactive social support, and greater sense of coherence, their QOL was significantly higher. After controlling for the aforementioned factors, lower SPB ( $\beta = -0.12$ ,  $p = .0004$ ) and higher PTG ( $\beta = 0.15$ ,  $p < 0.0001$ ) significantly improved terminally ill cancer patients' QOL.

**Conclusion:** In addition to relieving physical symptom distress, decreasing anxiety and depressive symptoms, providing emotional and affective social support, and enhancing coping capabilities, facilitating post-traumatic growth and reducing self-perceived burden to others may improve cancer patients' QOL at EOL.

**Abstract number:** P1-246

**Abstract type:** Poster

### Factors Influencing End-of-Life Treatment Preferences of Older Latino Advanced Cancer Patients

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**Context:** Understanding end-of-life (EOL) treatment preferences is central to quality EOL care.

**Aims:** To compare EOL treatment preferences of older Latinos with advanced cancer to those of their contemporaries without cancer and to identify the clinical, demographic, psychosocial, cultural and system factors influencing the preferences of older Latino advanced cancer patients.

**Methods:** Older Latinos with advanced cancer and a comparison group of older Latinos without cancer were interviewed to determine if they preferred a treatment approach focused on life extension or palliative comfort care. Chi-square tests were conducted to compare the preferences of those with and without cancer. Bivariate analyses were conducted between treatment preferences and clinical, demographic, psychosocial, cultural and system-related measures to identify factors influencing patient preferences.

**Results:** Thirty-four baseline interviews with cancer patients and 43 with the comparison group were completed. Forty-seven percent of patients compared to 66% of non-cancer participants preferred a palliative/comfort care approach ( $P = 0.10$ ). Cancer patients with high medical mistrust levels (75%) were more likely to prefer life extension compared to those with low mistrust levels (38%) ( $P = 0.049$ ). Other factors associated with a palliative care approach preference were having high levels of pain and low levels of well-being ( $P = 0.055$ ), having more than two comorbidities ( $P = 0.029$ ), and biculturalism ( $P = 0.025$ ).

**Conclusion:** Our findings suggest that medical mistrust, pain and well-being, comorbidity burden and acculturation are associated with EOL treatment preferences in this population. Additional longitudinal assessments will further elucidate how the combination of clinical, demographic, psychosocial, cultural and system factors influence EOL treatment preferences and inform the development of culturally appropriate communication and decision making strategies.

**Abstract number:** P1-247

**Abstract type:** Poster

### Palliative Care in Hospitals and at Home

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Treatment in hospitals usually focuses on curative aspects. When patients need palliative care, this need is not always recognized. More attention is needed for symptom control and other aspects of end-of-life care. In 2011, a project named 'Palliative Care in the hospitals' started in the South of the Netherlands. In this project, among ten hospitals, the goal is to strengthen the Palliative Hospital Care and to contribute better cooperation with other out-hospital care givers.

The hospitals are all willing to improve palliative care. In the period of 2011-2012 the hospitals are supported in the development of in-hospital Palliative Care Teams (PCT's). Palliative care experts are member of this multidisciplinary team. A PCT can contribute to improve the palliative care for individual patients. The PCT supports the principal professional caregivers in giving the best palliative care, therefore the expertise in hospitals in general is increased.

At present, the focus is to expand the cooperation with other organizations. Already a few hospitals constitute their PCT together with other organizations (homecare nurses, general practitioner, other palliative care consult teams). Aim is to support both in-hospital and out-hospital healthcare professionals in giving good palliative care. When teams cooperate, it also contributes to a better transfer from hospital to primary health care. The PCT's registrate all care and advice they give, using a standardized registration form. Therefore, research about palliative care is possible and will improve the knowledge about what factors are relevant for an effective PCT.

To contribute to the further development of palliative care in the South of the Netherlands, we want to explore best practices of in-hospitals and transmural PCT's. In May 2013 we will be able to present the first results from the registrations of the PCT's. Awareness, cooperation, connection and communication are leading topics in this project.

**Abstract number:** P1-248

**Abstract type:** Poster

### Factors Related to Place of Death among Cancer Patients Assisted by a In-home Palliative/Supportive Care

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**Research aims:** Studies focused on end of life have found that home is considered the preferred place of death for both patients and caregivers. Presently, however, more than half of patients with cancer die in hospital. Aim of this study is to identify factors related to the place of death in an Italian sample of oncological patients in home care setting.

**Study design and methods:** 1374 oncological patients, assisted at home in Bologna by a palliative home care team and deceased from 1 January to 31 December 2011. Univariate analysis with non-parametric tests (Kruskal-Wallis) and logistic multinomial regression analysis were employed in order to assess factors associated to the place of death.

**Results:** Of the 1374 patients examined, 810 (56%) died at home, 352 (24%) in hospital and 212 (15%) in hospice. We included 7 variables that were significant in univariate analysis in our study. 5 variables predictive of at-home death

were retained in the multivariate analysis. Among individual and social variables, higher age of the patient is significantly related with home as place of death ( $p < 0.001$ ), while living alone increases decreasing in hospice ( $p = 0.009$ ). Between variables related to model of care, major number of medical appointments significantly increases dying at home ( $p < 0.001$ ). Otherwise, higher number of re-admissions is significantly related with hospital or hospice as place of death ( $p < 0.001$ ).

**Conclusion:** Results of this study confirm that structured and dedicated home care facilitates the possibility of dying at home. A medical home care characterized by several and regular physician's visits influences positively the quality of assistance by helping patients to remain at home until end of life and by avoiding them improper re-admissions. These data confirm the need to introduce health policies oriented to encourage palliative home care in order to improve satisfaction of patients and families, reducing healthcare costs.

**Abstract number:** P1-249

**Abstract type:** Poster

### Validation of Schedule of Attitudes toward Hastened Death into Spanish

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**Background:** The desire to hasten death (DHD) has been frequently described in the literature in patients (pts) with advanced cancer. However, so far there is no available in Spanish validated scale that allows evaluation.

**Aim:** To assess the psychometric properties of the Spanish form of the Schedule of Attitudes Toward Hastened Death (SAHD) and evaluate the DHD in advanced cancer in-patients admitted to a acute palliative care unit (APCU).

**Patients and methods:** Adult patients admitted APCU, aware of their cancer diagnosis, no cognitive impairment and fluently Spanish speakers. The Spanish version of the SAHD was obtained by translation / back-translation following international recommendations. To assess patients' DHD it was administered the SAHD by Rosenfeld (scoring from 0 to 20) to after obtaining their consent. Interviews were conducted by a physician specialist in palliative care, previously trained to administer the SAHD. Alongside, it was administered the Hospital Anxiety and Depression Scale (HADS), and assessed the Karnofsky Performance Scale (KPS) and Barthel Index (BI). The study was approved by the Ethic's Committee.

**Statistics:** A standard descriptive analysis was carried out. To assess the correlation between scales' scores, Spearman's correlation coefficient and for internal consistency of SAHD a-Cronbach were calculated.

**Results:** We enrolled 86 pts (55 men), 71% were married, 60.5% had high school education. The main diagnoses were lung and colon cancer (24.4% and 14%). 27% were diagnosed < 1 years followed. Median KPS 50, mean HAD score 13.7, mean BI 60. The a-Cronbach coefficient was 0.92 and SAHD average score:  $5.12 \pm 5.22$ .

**Conclusions:** The results indicate optimum psychometric properties of the Spanish version of the scale SAHD. Our population showed a lower middle DHD. This study was granted by the Spanish Ministry of Health FIS P111/01353.

**Abstract number:** P1-250

**Abstract type:** Poster

### Understanding the Role of Nurses in Decisions to Use Anticipatory Prescriptions to Manage Symptoms and Distress in the Last Days of Life

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**Background:** In the UK, a key approach to improving end of life care has been the use of 'anticipatory' or 'just in case' prescriptions to manage symptoms. These are especially important in the community where nurses have the responsibility for deciding when to implement them. There is almost no research on nurses' roles.

**Aim:** To examine how community nurses work with doctors

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and pharmacists in making decisions to use medications prescribed 'just in case' of difficult symptoms patients may experience at the end of life.

**Methodology:** An ethnographic study in two UK regions: the Midlands and the North West, with community nursing teams and nursing homes. Observations and interviews were conducted with health professionals involved in prescribing, issuing and using 'just in case' medications.

**Results:** Observations (n=83) and interviews (n=72) were conducted with a range of community health professionals, including: district nurses (n=27), specialist palliative care nurses (n=18), nursing home nurses (n=16), doctors (n=8) and pharmacists (n=3). Nurses had close contact with patients and assumed high levels of responsibility. They often started the process of getting 'just in case' medications in place, by prompting doctors to prescribe. Working with doctors, nurses would recognise symptoms requiring the use of the medications and many suggested changes in dosage. Staff recognised that their knowledge and experience with end of life care directly influenced their confidence and willingness to prescribe and use the medications. Staff perceived that 'just in case' medication allowed symptoms to be managed promptly, especially 'out of hours', reducing hospital admissions.

**Conclusion:** The close contact nurses have with patients in the community means that they take a leading role in the process of making 'just in case' medication available, and using it to manage symptoms at the end of life. These data are now informing a national survey of community nurses.

Abstract number: P1-251

Abstract type: Poster

### Recognition of Impending Death in a Dutch University Hospital and Communication and Care at the End of Life

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**Introduction:** Research indicates that end-of-life care in hospitals is not always optimal. Recognition of impending death by hospital physicians is a prerequisite for communication with patients and relatives about dying in hospital and providing care adequately addressing patients' needs at the end of life. We examined if hospital physicians recognized the impending death of their dying patients and if that recognition was related with more appropriate communication and care at the end of life, and with quality of dying.

**Methods:** Post-mortem survey of hospital physicians about care in the final three days of patients who died at one of the 18 participating wards in a Dutch university hospital, between June 2009 and March 2011. Non parametric tests (e.g.  $\chi^2$ , Mann-Whitney, ANOVA) were performed to analyse data.

**Results:** In 79% of cases (N=228), the nearness of death was completely or partially recognized by physicians, at least six hours in advance. In 69% of recognized cases, it was recognized three days or less before death. If recognized, discussing death with patients and relatives was more likely. Change of treatment goal into comfort care or abstinence and prescription of opioids were more likely if impending death was recognized. The presence of the physician at the time of death was less likely if it was recognized. According to the physician, the quality of death was better if it had been recognized in advance.

**Discussion:** In four fifths of deaths, the impending death of their dying patients was recognized by hospital physicians of a Dutch teaching hospital. Recognition was related with more appropriate communication and care at the end of life.

Abstract number: P1-252

Abstract type: Poster

### Effectiveness Aroma Massage on Cancer Patients

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**Aim:** Patients with cancer may use complementary therapies including aromatherapy massage in Europe. They are increasingly used to improve the quality of life of cancer patients, but its effectiveness has not been wide spread in Japan, nor not used as part of alternative medicines for these patients in the hospitals.

The aim of this study is to assess the effectiveness of

aromatherapy massage to explore how an individual sense an effect of aroma and associate it to personal well beings on cancer patients in a palliative care setting.

**Method:** Five cancer patients in palliative care setting were selected from a hospital. These patients have received a 30 min aromatherapy massage once a week up to four weeks. Narrative data was collected. Also informal interviews were conducted after aromatherapy massages. The data was analyzed using a content analysis method.

**Results:** Based on the feedbacks, aromatherapy massage effects have been classified into seven categories: improve physical symptom (pain, fatigue edema and hyposomnia), less depression, help communication through touch, feel of being cared, time of especial, acknowledgement of disease and empowerment.

Aromatherapy massage has provided the time of relaxation besides an improvement of physical conditions. Through human touch of massage and essential oils, patients become less depressed or anxious and eventually led patients to speak out current mental or physical conditions more. Furthermore, patients started to feel the time given for aromatherapy treatments as special rewarding time, encouragements to share inner feeling with others, and empowering themselves to recognize the disease and positively live with cancer.

**Conclusion:** Aromatherapy massage has effects not only improve physical symptom but also to improve the quality of life of cancer patients who are under palliative care.

Abstract number: P1-253

Abstract type: Poster

### Going Home (from Acute Hospital to Home during the Very Last Phase of Life) - Terminal Discharges from the National University Hospital under the Palliative Care Service

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**Background:** Preference for location of death is mostly at home. Some patients are admitted to the acute hospital for treatment, but their conditions continue to deteriorate due to disease progression. When patient reaches the very last few days or hours of their lives, some of them or their families may request for patient to be discharged from the hospital to fulfill patient's wish to die at home.

**Objective:** To examine the patient group who were terminally discharged from the hospital.

**Methods:** This is a retrospective review of data for all terminal discharge cases referred to palliative care service in NUH over a period of 3 years (2009 - 2011). We have collected and reviewed the demographic data of the patients, as well as comparing the cancer versus the non-cancer patient. We've also connected with the community hospice services to follow up with patient's progress and family's coping.

**Results:** In year 2009, we have a total number of 47 cases under palliative care service who underwent terminal discharge. In year 2010, the number increase to 71 cases. In year 2011, the total number cases for terminal discharges were 95. Exact prognostication remained a challenge, as the condition of a few patients stabilized for a longer than expected period after they were discharged.

**Conclusions:** We noticed an increase trend in terminal discharges, which may be related to palliative care education among the doctors, patients and families. Therefore, we may need to advocate for more resources in the community for our home hospice partners to support the patients and the families, during these very last hours of their lives.

## Epidemiology

Abstract number: P1-254

Abstract type: Poster

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Abstract type: Poster

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### Patients with Head and Neck Cancer in Palliative Care

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**Introduction and aims:** Head and neck cancer patients are associated with particular problems related to its location causing a deep impact in quality of life. The aim of this study was review those problems in our patients.

**Methods:** This is a retrospective study. Data were collected from the clinical records of the patients admitted to our palliative care unit. Besides demographic data, symptoms, medication and what happened to the patients were also collected. The statistical methods are descriptive as required by this type of study.

**Results:** Between 17/06/2007, unit opening date, and 30/06/2012, 1109 patients were admitted and 112 (10%) of them had head and neck cancer. 91 (81%) were men. The median age was 58 years (39 to 94). The most frequent locations were larynx - 19 (17%) cases; pharynx - 17 (15%); face - 9 (8%); tongue - 9; pyriform sinus 8 (7%). There were differences in the particular tumor locations between genders, besides the difference in the overall prevalence. 101 (90%) of the tumors were locally advanced, and the most frequent metastatization site was lymph nodes - 53 (47%). The most frequent symptoms were: pain - 98 (88%); dysphagia - 67 (60%); fatigue - 67; sadness - 54 (48%). There were neoplastic wounds in 68 (61%) patients. 64 (57%) patients had a gastrostomy, 58 (52%) a tracheostomy, and 26 (23%) a nasogastric tube. The drugs most used were: laxatives - 82 (73%); lorazepam - 70 (63%); antibiotics - 69 (62%); morphine - 66 (59%); dexamethasone - 59 (53%). Other opioids were transdermal fentanyl - 37 (33%) and buprenorphine - 21 (19%). The median length of stay in the unit was 20.5 days (1 to 169). 96 (86%) died in the unit, 13 (12%) were discharged home and 3 (3%) were transferred to other institutions.

**Conclusion:** Head and neck cancers are associated with many problems. Their location causes feeding and respiratory difficulties often requiring devices to overcome them. Neoplastic wounds also are an important cause of suffering.

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### The Development of Do-not-Resuscitate Decisions over the Past 20 Years in the Netherlands

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**Research aims:** Although cardiopulmonary resuscitation (CPR) can save lives, it has become clear that CPR is often unsuccessful. Moreover, it could come with severe consequences. As a result, decisions have to be made about who should or should not receive CPR in case of cardiac arrest. We examined trends in do-not-resuscitate (DNR) decision-making over the past 20 years in the Netherlands. **Study design and methods:** In 1990, 2001 and 2010 a nationwide study of a stratified sample from the death registry in the Netherlands was undertaken. All attending physicians of sampled cases received a questionnaire. One of the questions was: "Did you or another physician clearly agree in advance that in the event of a cardiac and/or respiratory arrest no attempt would be made to resuscitate this patient?" We assessed trends in the frequency of DNR decisions, both at the individual and institutional level, and patient involvement.

**Results:** The response percentages were 76% (1990), 75% (2001) and 74% (2010). The frequency of individual DNR decisions in non-sudden deaths that were preceded by an end-of-life decision increased from 56% in 1990 to 70% in 2001 and 87% in 2010. The frequency of institutional decisions decreased from 11% (1990) to 9% (2001) and 3% (2010). Furthermore involvement of patient or relatives rose from 67% (1990) to 97% (2001) and 99% (2010).

**Conclusion:** Non-sudden deaths are increasingly preceded by DNR decisions that are discussed with patient or relatives.

Abstract number: P1-258

Abstract type: Poster

### Breakdown of Contacts to a Network-wide, Round the Clock Specialist Palliative Care Service Offering Advice, Support Home Visits and Resource Coordination: A Model for the Future to Support Continuity of Care

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Specialist Palliative Care (SPC) round the clock is essential; telephone advice and support during the last year of life is widely offered but coordination across networks to offer timely and cost-effective expertise is an ongoing challenge. **Aims:** To improve public PC services increasing quality, safety, resolution capacity and social dimension awareness by developing a round the clock PC domiciliary model accessed by telephone for advice (patients, family and professionals), counselling and home visits. To ascertain reasons for service use and standardize responses to allow policymakers to map out needs and offer relevant services. **Method:** Qualitative and quantitative results analysis of service first two years. Records of all contacts include information on the caller, patient, problem, action, outcome and recorded incidents. **Results:** The service, positioned within regional emergency coordinating center, had over 25000 contact in first 2 years: (15%) for pain, (6.73%) queries relating to treatment and (66%) looking for reassurance on looking after someone in last few days of life. A small percentage required one of the two experts to visit the patient, mostly the doctor. Contact distribution over 24h period including weekends and holidays shows significant identified trends. Number of calls increased over the period, particularly from professionals about patients with complex needs or approaching last hours of life. **Conclusions:** This framework seems ideal to support 24-hour SPC service within a central, structure. It helps address current PC variability in our region. Being a large city makes it cost effective (less unnecessary A&E and others transfers; round the clock bed and professional resource deployment). General and emergency practitioners' commitment to PC is high and value availability of expert advice and support, including joint visits. This approach is likely to be relevant for other setting and easily adapted to local realities.

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**Abstract type:** Poster

### Five-year Trends: Cancer Patients Are Dying at Home

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Significant country differences in the proportion of patients with cancer dying at home exist, and they are influenced by country-specific cultural, social, and health care factors. There has been considerable international research of the place of death of cancer patients although no studies have attempted to analyze this issue in Russia. **Aims:** Our aim was to examine the proportion of cancer deaths occurring at home in a large Russian region in relation to demographic factors and to identify 5 year trends in home deaths from cancer. **Methods:** The data on the place of death were derived from death registrations for all cancer deaths in the region between the years of 2006-2011. We examined the trends in home and hospital deaths for the whole region, for the city and for the rural area. **Results:** Within this period the percentage of home deaths from all causes significantly increased: in the region from 55.67% to 73.68%, in rural areas from 60.10 to 82.12% and in the city from 30.32% to 66.37% (respectively 1.24, 1.37 and 2.19 times increase). The number of deaths from cancer was consistently high and the rate of cancer patients died at home was 87.52% on average for this period. Older people with cancer were more likely to die at home (85.16% of all cancer deaths). Among all women and men died from cancer respectively 90.62% and 79.60% died at home. **Conclusion:** High proportion of home deaths from both cancer and all causes to a certain extent is the result of reducing the hospital care supply and still demonstrates low availability of specialist inpatient palliative care. These findings today highlight the need for a palliative care service establishment for cancer patients in the region paying special attention to home care what should be considered when implementing structural reforms in primary care.

### Ethics

**Abstract number:** P1-260

**Abstract type:** Poster

### Decent Care Values in Palliative Care Services: An International Demonstration Project

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**Aims:** The World Health Organization (WHO) led development of a values framework to align health care services with the needs of affected persons. This framework of Decent Care Values (DCV) is built on 6 values at three levels; Agency & Dignity at the individual level, solidarity & interdependence at the social level and sustainability & subsidiarity at the systems level. The aim of this project was to see if these values could be demonstrated by palliative care providers in actual practice. Palliative care was chosen because it is closely aligned with these values. Two demonstration sites were competitively chosen, Hospis Malaysia in Kuala Lumpur and Kibera Community Self-help Program (KICOSHEP) in Nairobi, Kenya. **Methods:** This project used qualitative & quantitative data for formative and summative evaluation. For qualitative analysis telephone meetings, focus groups, individual interviews, and site visits were used. For quantitative analysis organizational self-assessment and a modified version of the African Palliative Care Association Palliative Outcome Scale were used. Each site developed its own intervention to introduce and implement DCV with assistance from Altaram. **Results:** The project demonstrated that DCV could be introduced in different cultures and implemented in palliative care programs resulting in improvement in the quality of services. **Conclusions:** Health care providers often state that services are provided based on shared values. However we do not know if this is true and lack a coherent system for describing and measuring values driven health care. The input of affected users of health care is rarely included in the planning and delivery of health care. Providers (including palliative care) may think they know better than patients how to die. Social and community involvement in health care is rarely developed and systems lack transparency. **Funding:** This project was funded by Altaram Institute, The Diana Princess of Wales Memorial Fund, and the WHO.

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### Ethical Challenges in Nursing Homes from the Patients Perspective - First Results from Different Norwegian Regions

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**Research aims:** The aims of the present study were to investigate ethical challenges in nursing homes from the residents' perspective and to find out what patients perceive as ethical problems in nursing homes. **Methods:** Qualitative study in nursing homes with semi-structured interviews of nursing home residents. Structured questioning and open interviewing was used in this study. A total number of 25 patients from different regions and nursing homes in Norway have been included in the study. Inclusion criteria: Participants who were living in a nursing home and had the ability to give full informed consent. Nursing home residents without the ability to give informed consent were excluded. **Results:** 25 nursing home residents aged 66 - 100 years (mean 87) were included by nursing home staff. The inclusion of participants aimed for a maximal variation in the sample and included patients from nursing homes in different regions, big cities and small villages in Norway. The duration of the interviews varied from 10 - 71 minutes due to the participant's wishes, attention and health condition. Different ethical challenges described by the nursing home residents were e.g. the lack of resources (not enough time to talk to the patients; long waiting to get help) and self-determination and respect. Many participants described the importance of the relation to their caregivers as both giving and problematic. **Conclusions:** A first analysis of our qualitative data from the interviews with nursing home residents shows that lack of resources, autonomy and especially the relation to the caregivers are the most important ethical challenges from the viewpoint of the nursing home residents. Focus-group interviews of relatives will help to question our first results from the relative's perspective.

This project has been financed with the aid of EXTRA funds from the Norwegian Foundation for Health and Rehabilitation.

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### Time to Change: Proactive Palliative Care. Are We Ready?

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Palliative Care is more than symptom control. It must try to prevent suffering. **Aim:** To establish reasons why palliative care institutions and teams work in a reactive manner to patients needs rather than proactive as would be beneficial for patients. **Methodology:** This study looks at over twenty Specialist Palliative Care Units in Great Britain and Spain looking at institutional and professionals attitude towards planification of care. **Results:** A vast majority of units, despite decades of experience looking after patients continue waiting for the sick to come calling rather than find mechanism of offering early, integrated specialist palliative care. This often mean being too late. **Conclusion:** There needs to be an important shift in institutions, organizations and professionals to offer a more ethical, more humane and timely palliative care to those needing it.

**Abstract number:** P1-263

**Abstract type:** Poster

### Ethical Dilemmas around the Dying Stroke Patient - A Qualitative Interview Study with Team Members in Stroke Units

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In Sweden, individuals affected by severe stroke are treated in specialised stroke units. In these units, patients are attended by a multi-professional team with a focus on care in the acute phase of stroke, rehabilitation phase, and in the palliative phase. Caring for patients with such a large variety in condition and symptoms might be an extra challenge for the team. Today, there is a lack of knowledge in team experiences of the dilemmas that appear and the consequences that emerge. The aim of this paper was to study ethical dilemmas among health care professionals working with the dying stroke patients in acute stroke units. Forty-one health care professionals working in a stroke team were interviewed either in focus groups or individually. The data were transcribed verbatim and analyzed using content analysis. The results and ethical dilemmas that appeared were depending on "Non decisions" about palliative care or discontinuation of treatments. The lack of decision made the team members act based on their own individual skills, due to the absence of common communication tools. When a decision was made staff had "Problems holding to the decision". The devised and implemented plans could be re-valued which was described as a setback to non-decisions again. The underlying problem was "communication difficulties" and was based on culture dissimilarity and lack of knowledge of palliative care with a common value system. The conclusion of this study highlights the importance of palliative care knowledge and skills, even for patients suffering from severe stroke. To make a decision and to hold on to that is a presupposition in creating a credible care plan. However, implementing a common set of values based on palliative care with symptom control and quality of life might minimize the risk of the communication difficulties that may arise and increases the ability to create a health care that is meaningful and dignified.

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**Abstract type:** Poster

### Ethical and Cultural Aspects of Decisions for Withholding or Withdrawing Nutritional Support in Palliative Care

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Nutritional support has increased markedly while prolonging survival of patients with cancer and neurologic diseases, especially among elderly. Meanwhile a large range of nutritional support can be provided: autonomous or assisted oral feeding, using natural or supplemented food, naso-gastric tube, gastrostomy or IV nutrition. The decision of withholding or withdrawing nutritional support raises a daily ethical problem in the various care units and at home, whether one considers nutritional feeding as a medical treatment or a care. The French law in 2005 has stated that any treatment can be withheld or withdrawn, when medically futile, especially if requested

and/or accepted by the patient directly or through an advance directive.

Since then, nutrition has been considered as a medical treatment and not a care, and therefore can be withheld or withdrawn. This has raised a societal debate: Is nutritional support a way of prolonging a meaningless survival and suffering? If it is withdrawn, could one accept a slow death from hunger? Is an active euthanasia a more ethical and compassionate way to provide a death with less suffering?

In Israel only legal conditions for withdrawing have been defined. When analysed in both countries it appeared that the ethical questions raised by various practices, including the implementation of law, depend on socio-cultural and religious context, with regards to the values given to feeding, autonomy, life, quality of the survival, role of next of kin...

Further observation leads to the hypothesis that the main factor in decisions lays in the respective representations of the caregivers, patients, and their families. Only an analysis of these representations - cultural, religious, symbolic, biographic - would allow a shared decision making with regards to nutrition and therefore a good accompanying of patients in terminal care.

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**Abstract type:** Poster

## Discharging Hospice Patients to a Nursing Home - What Happens and what Next?

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**Background:** NICE guidance promotes enabling patients to choose their preferred place of care; however specialist palliative care inpatient beds remain a scarce resource in the UK. Transfer of a hospice patient to a nursing home (NH) risks distress to the patient and family, but is often justified on the grounds of equity of access to hospice beds.

**Aim:** To explore process of transfer from hospice to NH and evaluate survival times within the NH setting.

**Methods:** A casenote review of patients discharged to NH, from a 22-bedded hospice in England, with telephone follow up to establish patient progress or date of death. Over a 3 year period, 28 hospice inpatients were transferred to a NH, with notes available for 22.

**Results:** In 27% of cases NH had been mentioned prior to hospice admission. In the majority of cases NH was brought up by hospice staff (55%), though discussion was also initiated by patients (n=5), family (n=4) or community team (n=1). NH was first broached an average of 18days (1-61) after hospice admission. Response to the suggestion of NH was positive in 46% (n=10), with a clear aversion to the idea in 23%. This group had a mean hospice stay of 43days (14-93), compared to a unit average of 16days.

Of the 28 patients discharged to NH, 23 died in their NH and 5 are still living in the NH. The latter 5 patients living in a NH at the time of the study had stays of 1, 16, 30, 40 and 380 days respectively. Length of survival within the NH ranged from 1-3wks (3/23) to over 6mths (3/23), with 9% surviving 3-6wks, 39% 6-12wks and 26% 12wks-6mths.

**Conclusion:** Most hospice patients discharged to a NH survive longer than 3 weeks (87%) and many considerably longer than this. A negative response to the suggestion of NH may be less common than feared by staff. Further information is required to explore quality of life after discharge to NH and the proportion of patients in this unit to whom the idea of NH is introduced, but who deteriorate before transfer.

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**Abstract type:** Poster

## Continuous Sedation until Death and Physician-assisted Death: Different or Equivalent? A Focus Group Study in Nursing Homes in Flanders, Belgium

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**Introduction:** Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, has become a controversial topic of ethical debate. Some argue that CSD is morally equivalent to Physician-Assisted Death (PAD) or that CSD is frequently misused to perform 'slow euthanasia', despite the fact that guidelines on CSD stress the distinction between these two practices. Given the increasing incidence rate of CSD in nursing homes in Flanders (Belgium), together with the low incidence of PAD in this setting, it is interesting to examine whether and to what extent nursing home clinicians

consider these two practices to be different or equivalent.

**Methods:** Six focus groups were conducted including 10 physicians, 24 nurses, and 14 care assistants working in either public or catholic nursing homes of varying size. All discussions were transcribed and subsequently analyzed using a thematic content approach.

**Results:** For some clinicians, the distinction between CSD and PAD is clear, whereas others consider CSD a form of euthanasia. Another group takes an in-between stance: they situate CSD in a grey area between pain relief and ending life. The underlying arguments for these perspectives refer to the following themes: intention, dosage of sedative drugs, unconsciousness, and the pace of the dying process. Generally, CSD is considered easier to deal with emotionally, compared with PAD, since it results in a more gradual process of dying.

**Discussion:** This study highlights the lack of agreement among nursing home clinicians regarding the distinction between CSD and PAD. The opposing and frequently inconsistent arguments of clinicians used to claim a difference or equivalence between the two practices demonstrate that the framework of CSD - as proposed in the guidelines - is prone to abuse.

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## Vulnerability to End of Life in Advanced Cancer Patients

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**Background:** Vulnerability is a universal human condition. Feeling vulnerable comes as a result of being at risk of physical, psychological, or emotional harm. At the end of life, everyone is vulnerable. We all face mortality and thus are susceptible to the experience of vulnerability. Advanced cancer and all that surrounds it has great potential to become threatening agent and highlighting the vulnerability of the patient and family.

**Objective:** To reflect on the vulnerability in cancer patients at the end of life from different aspects such as spirituality, suffering, emotional burden of caregivers, place of death and thus be able to offer impeccable attention from palliative care.

**Method:** Review of the literature on the subject, with particular attention to those qualitative studies that analyze the narratives of patients and professionals.

**Conclusions:** Spirituality is a need of the patient should be assessed. The dying process can not be understood solely as a clinical problem, and one of the goals of palliative care is to address biological problems, but also address the crisis biographical closure. The inadequate physical symptom control, lack of distraction and feeling useless are the factors that generate more suffering in patients, making them more vulnerable. Informal caregivers of advanced cancer patients have high levels of anxiety and depression. Due to the high vulnerability of these caregivers, health professionals should direct their efforts to detect any risk in this group and give tips and resources to alleviate it. The social context is crucial to plan the return to home. We must take into account the emotional suffering and the vulnerability of the family because these factors may lead to a refusal to take care of the patient at home. We could consider the vulnerability as a mirror in which we see our reflection and discovered that like our patients, we are also fragile, ethereal and live in a continuing uncertainty.

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## Advance Care Planning (ACP) - What Do Portuguese Palliative Care Patients Think?

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**Background:** Over the last years, there has been an increasing development of Portuguese palliative care teams in the hospital setting, but we cannot expect that they can be involved with every patient who needs them. Since last august there is an advance care law in Portugal, but there are many people who doesn't know the meaning of it. As palliative care professionals, we believe people must be aware of all the implications of having an advance care plan.

**Objective:** This study pretends to identify the lacks of information about ACP and to know what are the advance care wishes people claims.

**Sample:** All the new patients in palliative care day clinic of a Portuguese cancer hospital.

**Methods:** Patients were asked if they have an ACP and what were their wishes when they formalized it. We used a questionnaire.

**Conclusion:** Most of the patients haven't thought about their ACP. Portuguese health care professionals must inform and be available to answer patients concerns about end of life care. It should also be a political and media role.

**Abstract number:** P1-269

**Abstract type:** Poster

## MORECare Capacity: Mental Capacity and Processes of Consent for Research on End-of-Life Care

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**Aims:** To undertake a meta-synthesis of the research involving individuals with impaired capacity examining the challenges experienced and solutions used to manage processes of consent.

**Methods:** Systematic literature appraisal using the databases MEDLINE, EMBASE, CINAHL, PsycINFO, and the Cochrane Library (from 2000 until September 2012). Search terms included the combination of consent and capacity (and synonyms) within three distinct patient groups: palliative care, mental health and accident and emergency. Selection criteria: primary research concerning adults with compromised capacity and processes of consent in research. Database searches were supplemented with a short-semi structured email survey to leading national and international researchers (n=317) to capture 'out of view' best practice.

**Results:** 9,916 references were identified from the literature search, 107 were included for full paper review for the palliative care group. Four main themes were identified in the analysis:

- 1) timing,
- 2) proxies and supportive decision making,
- 3) research resource and expertise, and
- 4) ethical consideration.

The themes formed a model on the processes, challenges and innovation in processes of consent for adults with compromised capacity. 317 active researchers were invited to participate in the grey literature survey, of the respondents 63% had undertaken research involving adults with compromised capacity with assent being the most common approach used, predominantly in mental health research.

**Conclusion:** The meta-synthesis provides guidance on key challenges and solutions to involving those at the end of life in research including timing, proxies and supportive decision making, resources for research and ethical considerations.

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## The Ethical Climate in European ICUs. Results from the Appropicus Study

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**Aims:** The ICU generates stress for clinicians both because of the high patient mortality and because moral dilemmas arise daily. The ethical climate is defined as the organizational conditions and practices that affect the way difficult patient care problems are discussed and decided. The aim is to determine the quality and the variability of perceived ethical climates in European ICUs as well as its relation to perceptions of inappropriateness of care and intentional jobleave.

**Methods:** A single-day cross-sectional evaluation of perceptions of inappropriate care among 1953 ICU nurses and physicians providing bedside care to adult ICU patients in 10 European countries.

A 7-item questionnaire was used to assess the (perceived) ethical climate. Factoranalysis was used to reduce 7 dimensions.

**Results:** Factoranalysis with varimax rotation resulted in a two-factor solution: the first factor (30% of variance) concerns 4 items dealing with discussion of ethical problems (do clinicians talk about feelings and opinions); the second item (30% of variance) concerns 3 items dealing with decision-making (is there bedside interdisciplinary decision-

making).

A scatterplot shows great variability between  
(1) clinicians within ICUs,  
(2) between ICUs within a country, and  
(3) between countries.

There is a clear correlation between the quality of the ethical climate and the percentage of clinicians in a given country indicating at least one of their patients as receiving inappropriate care (percentages ranging from 8% in The Netherlands to 43% in Poland). The quality of ethical climate is also correlated with intentional jobleave (percentages ranging from 17% in The Netherlands to 42% in Germany). **Conclusions:** There is high variability in the quality of ethical climate within and between European countries. Less discussing and interdisciplinary deciding about ethical problems is correlated with higher perceptions of inappropriate care and higher intentional jobleave.

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**Why Do Physicians Struggle with Do-not-Attempt-resuscitation Orders for People with Intellectual Disabilities?**

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**Aim:** To clarify the considerations and problems for Do-Not-Attempt-Resuscitate (DNAR) orders for people with intellectual disabilities from the viewpoint of ID physicians (physicians for people with intellectual disabilities).  
**Design:** A qualitative study with interviews, focused interviews and an expert meeting. In total 40 experienced and junior physicians were involved. The interviews were recorded digitally, transcribed verbatim and analysed according to Grounded Theory Procedures.  
**Results:** The ID physicians in this study struggled with the reasons and considerations to write a DNAR order. Quality of life was an important reason for decisions, but also difficult to define. The physicians were unsure about their legal position opposite the representatives. Conflicts with the representatives were a major concern. The most vulnerable part of the trajectory is the moment a bystander (often paid care staff) has to decide what to do.  
**Conclusion:** Physicians struggle with uncertainties in the process of DNAR orders. Evidence is lacking for a firm guideline. Physicians should strive to phrase medical considerations within their profession, fulfil their legal role, learn to weigh quality of life and design and implement a policy for the service provider. Most important is the dialogue with representatives and the discussion within an organization, on certainties and uncertainties.

**Abstract number:** P1-272  
**Abstract type:** Poster

**Which Patients Tend to Be Excluded from Medical Decision Making?**

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**Aims:** There is increasing emphasis on patients being involved in advance care planning. However, in the Singapore context, many patients are not even aware of their diagnosis and prognosis. The aim of this study was to describe the characteristics of these patients, and to consider how their involvement in medical decision-making can be supported.  
**Methods:** Records of adult patients referred to and accepted to the home hospice service in a one-year period from 1 Jul 2011 to 30 Jun 2012 were analysed on 19 Sep 2012.  
**Results:** Out of 3033 new cases in the one-year period, 763(25.2%) were not aware of diagnosis or prognosis, 749(24.7%) were aware of diagnosis but not prognosis and 1521(50.1%) were aware of diagnosis and prognosis. Of those who were not aware of diagnosis or prognosis (mean age 80.7, median age 82), 85.2% were not English-speaking, 540 had died - 70.2% at home, 1.5% in hospice, 27.6% in hospital and 0.7% unknown. Of those who were aware of diagnosis but not prognosis (mean age 70.3, median age 72), 72.0% were not English-speaking, 492 had died - 50.8% at home, 1.2% in hospice, 47.4% in hospital and 0.6% unknown. Of those who were aware of prognosis and diagnosis (mean age 68.0, median age 69), 65.3% were not English-speaking, 1008 had died - 55.5% at home, 1.1% in hospice, 43.4% in hospital and 0.1% unknown.

**Conclusion:** Patients who are older and not English-speaking tend to be unaware of diagnosis or prognosis and hence will be excluded from making decisions regarding their own care. Families often fear that the knowledge of their medical condition would reduce wellbeing and may even hasten death. Nonetheless, a higher percentage of patients who were unaware of diagnosis and prognosis were able to die at home, which is often viewed as a goal of home hospice services. Hence, it may be culturally appropriate for some patients not to be involved in medical decision-making. Providing palliative care in such circumstances is challenging but possible.

**Family & Care Givers**

**Abstract number:** P1-273  
**Abstract type:** Poster

**Distress in Cancer Patients: View of Family Members**

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**Aims:** The objective was to verify the opinion of family members about distress on cancer patients and the factors associated with it.  
**Methods:** A cross-sectional study was conducted from June to August of 2012 through interviews with 140 individuals with at least 6 years of schooling who were the family members of cancer patients. The Distress Thermometer was used. The ANOVA F tests for linear regression and chi-square tests were used.  
**Results:** Most family members were female (82.9%), married (50%), aged between 30 and 49 y (55%), with a mean schooling of 10.5 y (SD = 3.3) and a family income of \$ 500 to 700 (50.7%). Then types of cancer prevalent were breast cancer (18.6%), colon (9.3%), uterine/ovarian (8.57%), prostate (8.57%) and leukemia/lymphoma (8.57%). Sixty-five percent of patients were considered in distress, related worry (83.5%), nervousness (82.4%), sadness (74.7%), fatigue (67%), pain (65.9%), difficulty sleeping (63.7%), fear (58.2%), or without health insurance (57.1%), problems with eating (53.8%) and appearance (52.7%). The regression model showed a positive association (p < 0.05) of distress with the existence of private health insurance, work or school attendance, depression, fear, nervousness, sadness, worry, loss of interest in usual activities, appearance, fatigue, swelling, and difficulty sleeping.  
**Conclusion:** The opinion of relatives about the distress of patients is poorly considered in the routine assessment but can be of great help in minimizing the suffering of patients. A family which is well-informed about how to assess distress and prevent events triggering stimuli can use actions to control distress and can contribute to improving the quality of life of patients with cancer.

**Abstract number:** P1-274  
**Abstract type:** Poster

**Togethermess Close to Death**

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Living close to death makes people undergo changes and major transitions affecting relational patterns and identity, both at an individual and at a family level. The aim of the study was to deepen the understanding of togetherness in families in a stressful and demanding life situation at home. We drew on secondary analysis of qualitative data collected through 38 interviews with persons with life-threatening illness and their family members. Analysis resulted in interpretive descriptions which provided three interconnected patterns. Three patterns built togetherness close to death; named "Being an existential person"; "Being the extension of the other," and "Being together in existential loneliness". Collected, these three patterns of togetherness created dynamic levels of everyday life in the construction of family identity, We-ness, close to death. The concept of togetherness contributed to our understanding on what made people endure, and even benefitted from, this special time in life. Togetherness was seen as a driving force especially important when everyday life was turned upside down and everything was changed by life-threatening illness.  
**Conclusion:** A better understanding of patterns within togetherness could be helpful for palliative care professionals supporting patients and their family members living everyday life close to death. Furthermore,

togetherness and community seemed to alleviate some of the strains related to everyday life close to death. Togetherness thus incorporated the tension between searching for community and facing existential loneliness, reviving some of the challenges of being a family, when one family member is dying.

**Abstract number:** P1-275  
**Abstract type:** Poster

**Life Quality Training - Mindfulness for Surviving Family Members and Relatives-focus Groups**

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**Aims/objectives:** Grief and sorrow are reactions to experiences of loss. Studies reveal that grief may appear in many shapes. When we lose a close person the conceptions and models we have of ourselves and the world are threatened. One's habitual way of thinking and acting may seem meaningless.  
Mindfulness has proved to have an effect on light depressions, anxiety, improved life quality and living with pain. So far there are few experiences as to the use of the method for relatives and surviving family members.  
Mindfulness may help the bereaved in constructing a meaningful life in spite of their loss and grief. To adjust your life style, to find coping strategies and be conscious of thoughts, emotions, reactions of the body and your life. Change of focus from diagnosis and problems to personal resources and possibilities. Make a survey to find out whether the method may be an offer for families.  
**Method:** Six group sessions duration: 2,5 hours, eight persons and two instructors. Will be offered in the last quarter of the year 2012 and in the first half of the year 2013. The participants' experiences will be surveyed during spring 2013.  
**Procedures - how we work:**  
- Exercises of awareness  
- Creativity methodes e.g. incomplete sentences, drawing, movement  
- Group instructions  
- Chearing experiences in pair/and the whole group  
**Themes illustrated:**  
- "Who am I" - special focus on resources  
- If the body could talk...  
- Values - what is important to me?  
- How to find pleasure?  
- Resources, possibilities, choices  
- Grief  
**Results:** Families' and relatives' experiences will be presented in the course of Spring 2013. Results will concentrate mainly on coping strategies in daily life, less brooding, awareness, specific priorities, listening to your inner voice, sleep and experiencing joy.  
**Conclusion:** During the Fall of 2012 and Spring 2013 Life quality training - Mindfulness will be held at Hospice. The result will be summed up in April -13.

**Abstract number:** P1-276  
**Abstract type:** Poster

**The Sleep Quality of the Caregivers in a Home Palliative Care Programme**

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**Aims:** Studying the quality of sleep with a sample of carers. Researching if there would be some relationship between the features of the patients, and a poor sleep quality of the carers.  
**Methods:** Descriptive study for 4 months. We included all those main caregivers who had no exclusion criteria: age below 18 years and diagnosis of psychiatric illness. We used the Pittsburgh Sleep Quality Index (PSQI) to study sleep quality and the Zarit scale to assess the caregiver burden. All of the patients had to be able to do the Edmonton Symptom Assessment System (ESAS).  
Descriptive statistics were computed for the sociodemographic variables, the different components of PSQI, Zarit and ESAS. We calculated the Pearson's correlation between the global score of the PSQI and the rest of variables.  
**Results:** The sample consisted of 50 carers, 82% were female and the mean age was 54(±15.2) years. The mean PPS of the patients was 49.4(±14.9).  
In our sample, the total average score on PSQI was 8.7(±4.3), so the PSQI classified the 70% of the carers as "poor sleepers". 48% of carers had problems to fall asleep, 66% slept ≤7 hours, and 30% had sleep efficiency < 65%. 58% of carers had to attend the patients during the night more than 3 times a week.

## Poster sessions

We have found significant correlations between the PSQI score and "hours spent caregiving/day" (0.39), the PSQI score and dyspnea of the patient (0.34), the PSQI score and "attending the patients at night" (0.39), and anxiety of the patient and "attending the patients at night" (0.32). In our study, there was no relationship between the Zarit and PSQI results.

**Conclusion:** Most of carers have bad sleep quality, which is similar to other studies.

It appears there is a certain correlation between the situation of patients and the sleep quality of caregivers; although this fact should be proved by some prospective research.

We can't confirm in our sample there is relationship between the sleep disturbances and the caregiver burden.

**Abstract number:** P1-277  
**Abstract type:** Poster

### Introduction of a Schwartz Round at a UK Hospice: Taking Time to Be Human

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**Aim:** To present the experience of implementing Schwartz Centre Rounds in a UK hospice.

**Method:** Schwartz Centre Rounds began in the USA in the 1990s and were introduced in hospitals in the UK in 2009. The Rounds offer a chance to talk openly and honestly about situations experienced in the course of our work that challenge us at a human and emotional level. Monthly Schwartz Centre Rounds start with 3 or 4 people giving a short presentation about an experience followed by an open discussion, allowing others to offer their reflections or to talk about similar experiences.

Princess Alice Hospice is one of the first hospices to adopt the Schwartz Centre Rounds, a project sponsored by Kings Fund, who provide mentor support for the first year. A Schwartz steering group was set up with representatives from across the organisation. The main facilitator is the Head of Psychosocial and Spiritual Care, supported by an administrator, with 2 consultants sharing the clinical lead role. The rounds were opened to the wider hospice community: all paid staff, volunteers, primary care colleagues and hospital palliative care teams.

**Results:** The first Schwartz Centre Round was held at the hospice in May 2012, and to date we have had 4 rounds. The mean attendance has been 43, min 35 and max 56. 128 evaluations have been collected and collated using Survey Monkey. 103 (80.5%) felt the round was relevant to their work, 113 (88.3%) gained insight into how colleagues think/feel in caring for patients, 121 (94.5%) rated the round as good, excellent or exceptional, and 100 (78.1%) were keen to attend another round. The themes raised reflect challenging aspects of hospice work: working with problems with no solution, and witnessing great distress and despair with patients and relatives, without being overwhelmed. **Conclusion:** The introduction of the Schwartz Centre Rounds has been very positively evaluated. Over time we hope they will improve morale and practice across the service.

**Abstract number:** P1-278  
**Abstract type:** Poster

### Family Carer Perspectives of Quality End of Life Care for Dementia

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**Aims:** There is little work investigating family experiences of end of life care (EOLC) for people with dementia. Much of the quality of care (QOC) literature is focussed on or developed from the perspective of professionals. Family carers of persons with dementia; in particular often play a crucial role in their care, sometimes becoming experts through experience. This study aimed to develop an understanding of QOC at the end of life for people with dementia from the perspective of family members.

**Methods:** Semi structured interviews using a topic guide were conducted with 20 family members of people with dementia. Family members were either recently bereaved or currently caring for someone who was dying from dementia. They were recruited through purposive sampling from carer networks of UK voluntary sector groups.

Interviews were subject to thematic framework analysis.

**Results:** The interviews highlight current weaknesses of EOLC for dementia including difficult health and social care systems to navigate, with many families left to guide themselves. Key components of quality from their

perspective included maintaining the dignity of the person with dementia and the inclusion of family members in decision making and subsequent care. Finally, the interviews show the complexity of when palliative or end of life care should begin for people with dementia, with family members talking about end of life care as a prolonged period at various points in the course of the disease.

**Conclusion:** Family perspectives of QOC focus on the interactions and relationships of the patient, family and professionals. Focussing on developing the triad of relationships is important for providing high quality care influencing both the structures and processes of care. This study emphasises the importance of including family members within EOLC for dementia and the value of using family experiences about QOC.

**Funding:** 7th framework program European Commission

**Abstract number:** P1-279  
**Abstract type:** Poster

### What Concerns the Family Caregivers of Egyptian Palliative Care Patients with Advanced Cancer

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**Introduction:** Palliative care aims at improving the quality of life of patients with life-threatening illnesses and their families. The Egyptian culture is characterized by strong family bonds and, usually, health care professionals deal with the "family unit" rather than the "individual patient". Hence, it is of utmost importance to assess the needs of family caregivers caring for Egyptian palliative care cancer patients.

**Methods:** The study included 47 family caregivers of advanced cancer patients referred to an Egyptian cancer center-based palliative medicine unit. Caregivers were asked to enumerate what concerns them most about their related patient.

**Results:** The median age of related patients was 55 years, 62% were females and the majority (94%) was married. Forty-six (98%) of interviewed family caregivers expressed at least one concern and the median number of concerning issues per caregiver was 2. A total of 23 issues were identified. The most common concerns were uncontrolled pain (60%), weakness/fatigue (23%), lack of appetite/inability to eat (13%), vomiting (13%), skin lesions (11%) and lower limb edema (9%). The first concern was uncontrolled pain in 49% of caregivers, lack of appetite/inability to eat in 11%, weakness/fatigue in 9%, lower limb edema in 6%, hallucinations in 4% and vomiting in 4%.

**Conclusion:** Regarding their related patient, uncontrolled pain is the major concern for Egyptian family caregivers. There is a need to overcome barriers to cancer pain control in Egypt to relieve the suffering of advanced cancer patients and their families. Other uncontrolled symptoms and advanced cancer-related changes that limit the functional and social well-being concern a significant proportion of caregivers. Research is mandatory to assess further the needs of Egyptian family caregivers and to develop culturally sensitive palliative care models that effectively incorporate them into the care of their related patients.

**Abstract number:** P1-280  
**Abstract type:** Poster

### The Challenges of Providing Carers' Support for Palliative Care Patients in a Tertiary Cancer Centre

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**Background:** Carers play a central role in providing support to patients. However, many carers do not experience a cohesive integrated system of social support. Caring for someone who is terminally ill at home, can cause a significant level of stress and impact on both physical and psychological health. Providing carers with adequate information and additional support at appropriate times may help to prevent hospital admissions. Optimal input for carers will depend on a comprehensive assessment of the situation and their needs. Carer assessment can be challenging, particularly in a tertiary cancer centre which covers a population of 2.3 million, caring for over 7000 new patients per year and includes a large number of different healthcare organisations.

**Aims:**

1. To develop a practical method of assessing the needs of carers.
2. To develop a directory of information for carers which could be used across a wide geographical area.

**Method:** A professional group was set up to establish the

baseline needs of carers. The assessment and documentation of carers' concerns and needs was evaluated using the documentation recorded on the Trust's electronic system. Research was conducted into the information already available for carers in the region.

**Results:** A directory of information, support and advice for carers has been produced with support from the local Cancer Network. The directory includes advice on carer's assessment, advocacy support, carer's allowance, national support organisations and charities for carers. There is a core section applicable to all and separate sections dependent on location.

**Abstract number:** P1-281  
**Abstract type:** Poster

### How Well Do People with Dementia and their Family Carers Agree on Preferences for Life Sustaining Treatments at End of Life? A Pilot Study

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**Aims:** Advance Care Planning may support the consideration of the wishes and preferences of people with dementia (PWD) when making end of life care decisions. However after the PWD loses capacity, it is often left to a family carer to indicate what these might have been. We will examine how well carers can predict the choices that the PWD would make and the accuracy of proxy decisions is unclear. **Study Design:** Cross sectional study using interviews with PWD and their carers in two NHS Trusts in the UK. PWD had an MMSE range of 20-30, mental capacity and an identified family carer. Carers were next of kin or "key decision makers". The Life Support Preferences Questionnaire (LSPQ) with 3 health scenarios and 3 treatment options was used and levels of agreement calculated; PWD identified their preferences against 3 health care scenarios and carers predicted what the preferences of the PWD would be.

**Analysis:** Descriptive statistics and Kappa Coefficient (k) for agreement.

**Results:** Twenty five dyads (25 PWD & 25 carers) were interviewed using the LSPQ. The mean age of PWD=80.6, range 69-93; Carer=66.2, range 47-90. MMSE of PWD (Mean 25.2; range 20-29), Gender PWD (M=12; F=13), Carer (M=5; F=20). A wide range of ethnic backgrounds were represented and levels of education. Most agreement was found on rating current health state on LSPQ. Of all health scenarios, lowest agreement was found for resuscitation and tube feeding had the lowest levels of agreement in treatment choices. Scenario 2 (stroke and coma) showed low agreement (k: .332; P=0.052). Scenario 3 (advanced cancer) showed moderate agreement (k: .478; p=0.005) treatment issues.

**Conclusions:** Whilst this pilot is underpowered it suggests that carers may not be able to consistently predict the treatment preferences for PWD. No participants have been distressed by discussing these issues. We will now extend to a full study with 100 dyads and also examine contextual factors that influence agreement.

**Abstract number:** P1-282  
**Abstract type:** Poster

### Carers of People with Advanced Dementia: Their Experiences at the End of Life

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**Aim:** To test the feasibility of recruiting carers of people with advanced dementia, the acceptability of study tools and to explore their health and social care needs at the end of life and into bereavement. Previous research shows that carers of people with advanced dementia have high levels of carer burden, mental and physical poor health and anticipatory grief.

**Design:** Pilot longitudinal cohort study.

**Method:** Carers of people with advanced dementia (Functional Assessment Stage score 7c) were recruited from 11 care homes in London. The Zarit Carer Burden (ZCB), Brief COPE, Hospital Anxiety and Depression Scale (HADS), Inventory of Complicated Grief - pre loss (ICG), the SF-12 and the Satisfaction of Care at the End of Life in Dementia Scale (SWCEOLD) were used at baseline assessment and repeated monthly.

**Findings:** 22 carers were approached and 16 recruited (73%). The mean age was 63 (range 46-80), 75% female, 36% married and 82% a child of the person with dementia. Mean ZCB score was 16.75 (range 0-48). On the COPE (range 2-8) the most common adaptive strategies were acceptance

(mean 5.6) and religion (mean 4.5), most common maladaptive were self-blame (mean 3.1) and substance abuse (mean 3.1). On the HADS (cut off  $\geq 8$ ) 41% had possible anxiety and 12% possible depression. The mean pre-loss grief score (ICG) was 21.1 (range 10-44), SF-12 physical score 50 (range 33-52), mental health 50 (range 19-64) and mean SWCEOLD 29.5 (range 13-38). **Conclusion:** Our pilot study found it was feasible to recruit carers of people with advanced dementia and that they were willing and able to complete questionnaires on their mental health, general wellbeing and grief. Most were not burdened or in psychological distress. They had low levels of anticipatory loss and grief. Wellbeing was not impaired and they were generally satisfied with their loved ones care. These results differ from previous studies, although the sample size is small, and we will now extend to a larger cohort study.

**Abstract number:** P1-283  
**Abstract type:** Poster

### Exploring Factors and Caregiver Outcomes Associated with Feelings of Preparedness for Caregiving in Family Caregivers in Palliative Care

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**Background:** Family caregivers are central in palliative care, but they often report feeling insufficiently prepared to handle the caregiver role. Preparedness has proved to be a powerful variable that may protect family caregiver wellbeing. Preparedness refers to how ready family caregivers perceive they are for the tasks and demands of the caregiving role.

**Aim:** The aim of this study was to explore factors associated with preparedness, and further to investigate whether preparedness is associated with caregiver outcomes.

**Design:** This was a correlational study using a cross-sectional design.

**Setting/participants:** The study took place in three specialist palliative care units and one hematology unit. 125 family caregivers of patients with life-threatening illness participated.

**Result:** Being female and cohabiting with the patient were significantly associated with a higher level of preparedness. The relationship to the patient was significantly associated with preparedness, while social support, place for care, time since diagnosis, and age of the patients showed no association.

Preparedness was significantly associated with higher levels of hope and reward and with a lower level of anxiety. In contrast, preparedness was not associated with depression or health.

**Conclusion:** Preparedness for caregiving seems to be an important protective variable for family caregivers in the unique and often stressful situation, when the patient is severely ill, close to death. Family caregivers with higher preparedness had higher levels of hope and caregiver rewards and lower levels of anxiety. These effects of preparedness support the inclusion of preparedness in support models for family caregivers in palliative care. We argue that early assessments of caregiver preparedness to provide care as well as early psycho-educational interventions are vital to foster positive caregiver responses to the challenges of their role.

**Abstract number:** P1-284  
**Abstract type:** Poster

### Reducing the Psychological Distress of Family Caregivers of Home Based Palliative Care Patients: Short Term Effects from a Randomised Controlled Trial

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**Background:** Palliative care is expected to incorporate comprehensive support for family caregivers given that many caregivers suffer psychological morbidity. However, systematically implemented evidence based psychological support initiatives are lacking.

**Aim:** To prepare caregivers for the role of supporting a

patient with advanced cancer receiving home based palliative care by offering a one to one psycho-educational intervention. We hypothesised that primary family caregivers who participated in the intervention would report decreased psychological distress (primary outcome), fewer unmet needs and increased levels of perceived preparedness, competence, and positive emotions.

**Methods:** A three arm randomised controlled trial comparing two versions of the intervention (one face to face visit versus two visits) plus standard care to a control group (standard care) across four sites in Australia.

**Results:** 298 participants were recruited; 148 were in the Control condition, 57 in Intervention 1 (1 visit), and 93 in Intervention 2 (2 visits). Relative to participants in the control group, the psychological wellbeing of participants in the intervention condition improved by a small amount but non-significantly. No significant reduction in unmet needs or improvements in positive aspects of caregiving amongst the intervention group were identified. However, the intervention demonstrated significant improvements in participants' levels of preparedness and competence for Intervention 2.

**Conclusion/implications:** This research adds to accumulating body of evidence demonstrating that relatively short psycho-educational interventions can enable family caregivers to feel more prepared and competent in the role of supporting a dying relative. Further investigation is required to determine the longer term outcomes of such interventions.

**Abstract number:** P1-285  
**Abstract type:** Poster

### A Multiple Nation Originality "A Challenge in Managing a Child with HIV/AIDS"

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There are a lot of Challenges in managing an HIV child with multi-nation originality. A child with multiple nationalities refers to an offspring of parents of different races.

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. So far in Tanzania, no documentation has been made showing challenges of managing HIV positive children with multi-national originality.

This paper discusses a case study of a 14years old child living with HIV AIDS with 'three Nationalities' (Chinese, Tanzanian and Kenyan). Both parents died with HIV/AIDS 11 years ago. He currently lives with a Kenyan grand mother. Late father and mother are Chinese and Tanzanian respectively.

Before enrolment in family centered care, he had history of recurrent infection, poor drug adherence (> 1month) and poor attachment. This was due to poor social relation of the grandmother to the Tanzanian relatives. The child has faced difficulties in tracing relative for support. Language barrier of the guardian has led into poor adherence to Medication and general health hygiene.

Through family centred palliative care mode of service delivery, the issue of disclosure, proper attachment, adherence to drugs, nutrition and hygiene were addressed.

Within six months of intervention, the child has shown; improved adherence to medication, clinical presentation, good link with the family, academic improvement, reduced racial segregations, improved link with the community where the child has secured more assistance from the Tanzanian/Germany community organization.

Family centered care is a teamwork program. You need to take heart in working with children with multiple problems. Involvement of the family and patient help them to be more responsible in taking care of the patient.

**Abstract number:** P1-286  
**Abstract type:** Poster

### Explanation of Opioids for Terminal Cancer Patients: The Bereaved Family Members' Experiences and Recommendations

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**Purpose:** The aim of this study was to clarify the present conditions of the explanation of opioids by the medical staff to the terminal cancer patients and their family members and the perceived necessity for improvement in it by questionnaires to bereaved families.

**Methods:** This study was part of a cross-sectional nationwide survey of bereaved families of cancer patients, namely the Japan Hospice and Palliative Care Evaluation 2 (J-HOPE 2) study. This survey was performed in 2010 for bereaved families of cancer patients at 103 palliative care units.

**Results:** Questionnaires were sent to 1000 bereaved families, and 63% responded. Seventy three percent of the respondents answered that the patient took opioids. Families felt reassured by their experiences "It was the friendly atmosphere that a family was easy to ask medical staff a question" 81% of cases. Regarding explanation, the perceived necessity for improvement in the explanation by medical staff was "no" 41%, "a little" 43%, "fair" 14%, and "great" 2%. More than 90% of them replied that medical staff should have informed the patient as well as their families before an opioid was given to the patient for the first time.

**Conclusion:** "Friendly atmosphere" was considered to be influenced by comfort level of patient. Besides we think it important to confirm their needs before the information giving to the patient as well as their families and explain step by step in detail in order to allay the patient's concern.

**Abstract number:** P1-287  
**Abstract type:** Poster

### Patient with Schizophrenia: Coping with Cancer - Case Presentation

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**Introduction:** Schizophrenia is a severe, lifelong mental disorder with different symptoms. Physical health problems in patients with schizophrenia are common, including cancer too. Incidence of cancer in patients with schizophrenia is same as in other population (data from different studies). But, coping with cancer illness in patients with schizophrenia is a lot of questions: medical, existential, ethic, human, social.

**Case:** Ms.I.M. 47 is years old single woman, living in her parents home. The first episode of schizophrenia occurred at age of 23:she was student of medicine. Since then, she has had a many relapses and was hospitalized many times on psychiatric clinic. During that time, she worked just a few months. Permanently she thoughts about her self as a student of medicine and never moving forward. In her last staying in psychiatric clinic, medical staff discovered breast cancer and immediately referred her to oncological clinic. It was advanced breast cancer with bone and brain metastases. Ms.I. M. experiences pain, becomes restless, verbal communication is poor, immobile. While team oncologists discussed about treatment, they've let her go home for a month, because "she is non cooperable patient". She suffered a lot.

**Family background:** In same home lives 3 generation of women. Grandmother, 91 year old lady, blind , immobile. Mother, 72,seven years caring for husband in bed after hard brain strock (dying aone years before). She is exhausted physically and emotionally. Young sister, works and takes care of the family finances.

**Conclusion:** Ms. I.M. did not understand their primary illness or cancer. Schizophrenia complicated coping with cancer. Ms.I.M. has got no capacity for coping with cancer. With low cognitive ability, increase problem focused coping and decrease quality of life. In this case the big burden was on the family.

Support from institutions was poor. Both patient and family suffered much.

**Abstract number:** P1-288  
**Abstract type:** Poster

### Sleep among Caregivers to Patients Recently Admitted to Hospice: A Pilot Study

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## Poster sessions

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**Research aims:** Caring for a dying family member is a stressful experience that is likely to interfere with sleep, yet little is known about the sleep of caregivers. This pilot study aimed to examine the feasibility of a sleep study of family caregivers to patients in hospice and to report the initial findings.

**Study design and methods:** This study reports the baseline findings of a longitudinal pilot study of family caregivers providing end-of-life care. The primary family caregiver of patients recently admitted to a hospice in Norway participated if both the patient and caregiver consented. Caregiver sleep during the prior month was measured subjectively with the Pittsburgh Sleep Quality Index (PSQI). During the patient's hospice stay, caregiver sleep was measured objectively using wrist actigraphy.

**Results:** The sample included 20 caregivers (75% were female, 60% were the patient's partner/spouse and 85% slept at home) who completed the study protocol without difficulty. On the PSQI, most caregivers (65%) reported clinically significant sleep problems during the prior month. Once the patient was admitted to hospice, actigraphy indicated that 30% of caregivers averaged < 7 hours of sleep per night, and 50% had clinically significant sleep disruption ( $\geq 15\%$  wake after sleep onset). Sleep location had little effect in this small sample. Partners reported more trouble falling asleep in the prior month than other family caregivers. However, after adjusting for their older age, actigraphy data indicated that partner caregivers experienced less sleep disruption than other family caregivers once the patient was admitted to hospice.

**Conclusion:** Our findings indicate that this type of study is feasible and that sleep problems are common for caregivers of dying patients. The caregiver's relationship to the patient may be an important factor to consider in future studies. The relationship between caregiver sleep problems and subsequent caregiver outcomes requires further study.

Abstract number: P1-289

Abstract type: Poster

### Elaboration of a Manual for Palliative Patients Caregivers

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#### Aims:

- Improve the continuity of care across the different levels (primary care and secondary care) by means of coordination and homogenization among them.
- Give support to caregivers by designing a manual specifically developed for them with advice on skin care for patients nearing the end of their lives.

**Material and method:** A bibliographic review on alteration and specific skin care (especially malignant wounds) was done.

Two joint working sessions between primary care nurses and palliative care nurses were developed.

**Results:** Joint and co-ordinated work between primary and palliative care nurses grew among those who attend the sessions.

#### Conclusion:

- Joint working sessions are a good tool to improve coordination among professionals.
- Our manual attends an unmet need of support to caregivers of patients at the end of their lives.
- It stresses the self care of both patients and caregivers. It would be interesting to elaborate on the specific advice of other needs of these kind of patients. A good education for caring and advice on the tools for self caring improves the quality of life and health of both caregivers and patients. Skin care, particularly of malignant wounds, are of primary interest because of the big impact on life of palliative patients.
- Research on managing the care of malignant wounds is needed due to the lack of studies on this subject.

Abstract number: P1-290

Abstract type: Poster

### Kist: Design in the Service of Care

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**Aims:** This paper reports on the initial stages of KIST: a research project undertaken with staff and families from the Children's Hospice Association Scotland by a design team from a Scottish university. The aim of the project was to work

with children with life-shortening conditions and their families and carers to develop systems using bespoke, handmade playful objects to enable independent access to online communication.

**Methods:** The team used a co-design method - grounded in the understanding of the real life experiences, ideas and skills of the people, who use, need and run services. Design and craft methods were used to create an environment in which observation, participation, conversation, prototyping and manufacturing could happen in the same space.

**Results:** The collaborative workshops uncovered an additional need which the team are currently working on - designing a service system to enable the parents and carers of children with complex communication needs to share information about their child's personality, likes and environmental needs.

**Conclusion:** The impact of using a co-design process opportunities and needs: working together with children, their families and carers in 'craft co-creation' workshops enabled conversations about family relationships, home, music, films, sounds and other leisure and school activities to be shared and documented. The project enabled children, families and carers of children with complex communication needs to become designers of their own interactions. The paper discusses the staff and parents responses to the process and recommendations for the next stage of the process.

This initial research was funded by the Scottish Funding Council through its Spirit Innovation Voucher Scheme.

**Keywords:** Design, collaboration, craft, co-design, healthcare, public services, service design

## Medical Sociology

Abstract number: P1-291

Abstract type: Poster

### Does Health Status Affect Perceptions of Factors Influencing Dignity at the End of Life?

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**Context:** More people survive to old ages, and chronic diseases tend to become more common with age. Disease and disabilities often elicit concerns about loss of personal dignity.

**Objectives:** To investigate whether health status affect the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic characteristics.

**Methods:** Data were collected within the framework of an "Advance Directives" cohort study. The present study focused on the subsample (N=2282) of persons who completed the Patient Dignity Inventory. Health status groups were defined by use of the EQ5D-items combined with a question that asked the respondents whether they had an illness. Descriptive statistics and logistic regression analyses were used.

**Results:** Limited differences were found when comparing how people in good health and people with a poor health status perceive factors important in maintaining dignity for patients reaching the end of life. Three physical items on symptoms, roles and routines, were significantly more often considered as influential to dignity by people with a poor health status. Gender, old age, having a partner and having a belief or religion that is important to one's life were found to be determinants regarding the understanding of factors influential to dignity.

**Conclusion:** Health status seems only to affect the perceptions on physical factors maintaining dignity at the end of life. This suggests that the understanding of dignity will not substantially change as health status changes.

Abstract number: P1-292

Abstract type: Poster

### The Changing Face of Palliative Care in Ireland: A Qualitative Study Exploring Health Care Professionals' Perceptions of the Changes that Have Taken Place in the Practice of Palliative Care in Ireland

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**Background:** Palliative care services have grown and developed significantly in Ireland in the past 10-15 years. Clinical experience suggests that the practice of palliative care has changed considerably in this time. Despite one quantitative study examining the changes in relation to radiological and laboratory investigations that have occurred from 1997-2007, no study has yet looked at the impact of such changes on patients and staff, or investigated the underlying driving forces behind these changes.

#### Objectives:

1. To explore health care professionals' perceptions of the changes that have taken place in the practice of palliative care in Ireland
2. To examine how changes in palliative care, health care, and society as a whole have impacted on patients and staff in palliative care.
3. To explore how these changes might shape the future of palliative care in Ireland

**Methods:** Purposive sampling was employed. Inclusion criteria were: doctors, nurses and care attendants working in palliative care; and those who have been working in palliative care for 8 years or more. Depth interviews were conducted and recorded until data saturation was reached. The interviews were transcribed verbatim and coded using a computer-assisted qualitative data analysis software package, NVivo 9. The data were then analysed using Burnard's thematic content analysis.

**Results:** Analysis is on-going but emerging themes include the perceived increase in interventions performed, increase in workload for staff, changes in training and education, and changes in the public's perception of hospice and palliative care.

**Conclusion:** This study will contribute to our understanding of how palliative care is developing in Ireland. This will lead to recognition of progress, but will also highlight concerns about aspects of palliative care that may be lost as the speciality moves forward.

Abstract number: P1-293

Abstract type: Poster

### "Staying Independent": A Qualitative Study to Explore the Experiences of Cancer Patients Living Alone during their Treatment

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**Background:** The social and personal environment of cancer patients is an important determinant in the adjustment to their illness. However, limited research has been conducted about the influence of living alone on patients in the context of cancer treatment. The few results available are inconclusive whether people who are living alone are a vulnerable population or not. Those studies fail to reveal the complex circumstances and experiences of these patients

**Research question:** The purpose of this study is to understand how cancer patients experience living alone and how this influences their adjustment to their cancer treatment.

**Methodology:** Using qualitative methods, a purposeful sample of 32 patients living alone and undergoing cancer treatment were interviewed, using a semi-structured guide. Interviews were audiotaped and transcribed verbatim. Analysis was conducted using grounded theory techniques, and open, axial and selective coding was performed.

**Results:** Analysis found that living alone was experienced by cancer patients in two ways: as a lack of specific social support characteristics, but also as a condition from which they gain. Consequently, living alone was experienced respectively as a threat or as a resource for their adjustment to cancer treatment. Both experiences made that 'staying independent' was the key goal during their cancer treatment, this out of necessity or out of virtue. The length of living alone and the way they became to live alone had an influence on those experiences.

**Conclusion:** The study has provided qualitative insight into the experiences of patients living alone who undergo cancer treatment. This research has implications for health care providers in primary care, who have to be attentive to the different experiences of living alone and the influence of those on their experience and adjustment to cancer treatment.

Abstract number: P1-294

Abstract type: Poster

### Foreign Patients Admitted to a Palliative Care Unit (PCU). A Case Control Study

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**Introduction:** Clinical and social management of foreign patients appears to be different and more complex than native ones. Foreign patients refers to patients not born in Spain.

**Aims:**  
1. Describe foreign patients features admitted to a PCU.  
2. Compare the characteristics of native patients with foreigners.

**Methods:**

1. Descriptive and retrospective study. All foreign patients admitted consecutively to a PCU from January 2008 to October 2012 were included.
2. We conducted a case-control study to make a reliable analysis of the differences, matched for age, sex and type of disease/tumor site. The variables are presented in the results section.

**Results:**

1. Of the 1,571 patients admitted during the study period, 72(4.5%) were foreign. 45(62.5%) men and 27(37.5%) women; mean age 60.6±16.2 years, 65(90.3%) had a cancer disease and the most common cancer sites were: lung 16(22.2%), genitourinary 9(12.5%) gastroesophageal 7(9.7%). 27 different nationalities were observed, the most common being Moroccan (13;18.1%) and French (8;11.1%). Geographic clustering: Europe 22(30.5%), Latin America 21(29.2%), Africa 16(22.2%), Asia 9(12.5%), U.S. 4(5.5%). Discharge destination: deceased 59(81.9%), home 6(8.3%), other centers 5(6.9%). The average stay was 20.7±20.4 days.
2. 62 of the 72 foreign patients were matched and differences were statistically significant: presence of primary caregiver (64.5% vs 90.3% native vs. foreign patients,  $P = 0.002$ ), social intervention (61.3% vs. 40.3%,  $P = 0.029$ ), use of psychotropic drugs (79.0% of foreign vs. 96.8% natives,  $P = 0.003$ ). No difference was found in: discharge destination, opioid use, psychiatric evaluation.

**Conclusions:** Foreign patients admitted to a PCU were predominantly male, with a mean age of 60 years, of several nationalities, mainly European and South American. In the case control study foreign patients required further social intervention, fewer foreign patients had a primary caregiver, and they used less psychotropic drugs.

**Abstract number:** P1-295

**Abstract type:** Poster

**Madrid Regional End of Life Register and Specialist Palliative Care Program**

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Palliative care (PC) is included in health services and provision offered to local population. We should be able to quantify number of patients included in PC Program. Integrated patient electronic records aid comprehensive and multidisciplinary approach to care while helping extract data referent to all aspects of target PC population offering timely access to desirable clinical protocols to support patients.

**Aims:** To set up a dependable Regional Palliative Care Register; easy to update and access.

**Methodology:** A Electronic Palliative Care Record System (EPCRS) was designed as a "supranet" superimposed on local Primary Care electronic records and incorporating single electronic referral protocol; its use extended and accessed via code A99 Enfermedad Terminal by significant health professional. To facilitate early inclusion and non oncological disease, transition points were identified for most pathologies. P C professionals could subsequently incorporate patients on to the Region Palliative Care Program following a thorough assessment.

**Results:** Referrals to PC have increased and include people diagnosed with advanced/ terminal illness under internationally accepted standards (incurable, advanced and progressive illness; little possibility of responding to specific treatments; oscillating evolution and frequent crisis; intense emotional and familiar impact; poor prognosis and high resource use). Almost 3000 patients have been registered by a generalist. After SPC assessment, over 1100 were included in the PC program by a PC expert in the first 16 months. **Conclusions:** PC registers and programs can be a reality provided all health professionals have access to common documentation and are familiar with referral criteria and

protocols as part of an integral, comprehensive and multidisciplinary approach.

**Abstract number:** P1-296

**Abstract type:** Poster

**Acceptance and Making Decisions about Care in Amyotrophic Lateral Sclerosis: The Influence of Parenthood and Age**

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The care approach in amyotrophic lateral sclerosis (ALS) is palliative from the point of diagnosis. The aim of this qualitative study was to unearth key psycho-social processes which underpin how people with ALS (pwALS) engage with healthcare services. The objective was to identify key parameters of ALS service users' experiences of services.

Using grounded theory method, a diverse group of ALS service users ( $n=34$ ) in the Republic of Ireland were theoretically sampled from the Irish ALS population-based register. Theoretical sampling is a sampling procedure whereby participants were sampled based on emerging concepts in the data and not by pre-determined stratification of participants. An in-depth and semi-structured interview was conducted with each participant at their home. Interview data was coded using open, axial, and selective coding procedures. Codes formed concepts which in turn formed categories. Ageing and parenting formed two of the main categories.

We found that participants' life-stage including their experience of parenthood shaped their approach to decision-making about care. Whilst the majority of participants were resigned to the progression of the disease, participants in later life were somewhat more accepting of death (than young and middle aged participants) because they had already reared children who were now self sufficient. The majority of young and middle aged participants wished to live on in order to support both adolescent and adult children. However, desire to live on prompted participants to consider the pros and cons of life-sustaining and supportive interventions including the impact such interventions would have on their adolescent and adult children.

We hypothesise that ageing and parenting are key variables which influence how pwALS make decisions about care. Decisions about care may be determined, in part, by how pwALS position themselves at different stages of their lives.

Funding: Health Research Board of Ireland

**Abstract number:** P1-297

**Abstract type:** Poster

**Persisting Hope for a Cure among Indian Palliative-care Patients: Influence of Contextual Factors**

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**Aim:** In palliative care, many patients continue to hope for a cure even in very advanced stages of their disease when the treating physicians do not expect such cure. These hopes may be influenced and nurtured by factors which are culture specific. We wanted to understand which factors shape hope for a cure in Indian palliative-care patients.

**Study design:** We opted for an ethnographic approach (participant observation). Fieldwork was undertaken from February until October 2012 at a palliative-care unit of a tertiary cancer hospital in North India. 32 patients formally consented to participate in the study. Research notes were made on the basis of the presenting author's repeated interactions with the patients, their relatives and the treating physicians and nurses, and observations on the ward. The researchers had access to the patients' medical files. The notes were analysed using conventional content analysis.

**Results:** Hope for a cure was prevalent among these patients who had been diagnosed with incurable cancer. This hope was nurtured by the availability of alternative treatment options, most often in the form of Ayurvedic therapies, but also curative treatment which is offered in private hospitals even at a stage when the patient is highly unlikely to benefit from it. Many patients felt the information they had received regarding their medical condition was not clear. Yet, they were often reluctant to ask more information directly to the doctors. Moreover, information was hidden by

relatives who believed it would cause distress and depression, and in that way hasten death. Lack of comprehensible information allowed the patients to hope for a cure. Many held the belief that God will finally listen to their prayers and eventually grant cure.

**Conclusion:** Hope for a cure was strengthened by contextual factors. Our observations should be taken into consideration while treating and counseling patients of Indian origin in palliative care.

**Abstract number:** P1-298

**Abstract type:** Poster

**"Where Do I Go from Here?" A Cultural Perspective on Challenges to the Use of Hospice Services**

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**Research aims:** To explore cultural barriers to hospice access in New Zealand.

**Study design and methods:** Semi-structured interviews were conducted with 16 Māori, Pacific and Asian patients with advanced cancer who were either actual, or potential users, of one hospice in Auckland, New Zealand. Twenty one bereaved family/whanau caregivers and 15 health professionals involving in making referrals to the hospice were also interviewed.

**Results:** Culturally specific challenges to hospice service utilisation identified included a lack of awareness in the communities of available services as well as continuing misconceptions concerning the nature of hospice.

Language barriers were particularly reported for Asian patients and their families. Issues concerning the cultural safety and ethnic representativeness of the hospice staff were raised. Health professionals identified that their assumptions regarding preferences for site of care for different cultural groups did impact upon their decisions to refer patients to hospice.

**Conclusion:** The absence of shared cultural scripts between hospice staff and the diverse cultural groups served can create a challenge to hospice service access. Specific strategies to reduce cultural barriers to hospice use will be discussed.

**Abstract number:** P1-299

**Abstract type:** Poster

**Dignity - The Chameleon of Palliative Care? A Systematic Review**

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**Objective:** The discussion on outcome indicators in palliative care (PC) includes the evaluation of the construct "dignity". A systematic review on the use of dignity (D\*) in English language PC literature was performed to learn whether the term is used or defined uniformly.

**Methods:** A systematic search of the use of D\* in PC literature resulted in 668 references. The corresponding abstracts were analysed regarding the context in which D\* was mentioned and, whether D\* was a major topic contributing significantly to the article's content.

When dealing with D\* as a major topic references were being categorized as whether D\* was being measured, used as an argument or discussed in a theoretical or practical way. **Results:** The topical context of the abstracts was very heterogeneous, covering many areas of PC practice, among others differing patient groups, diseases, places of care. The majority of the references was made in context with hastened death (euthanasia, physician assisted suicide, Oregon Death with Dignity Act).

D\* was used ancillary only in 540 abstracts, whereas 128 were dealing with D\* as a major topic. In 43.4% of the 128 main-topic abstracts D\* was explicitly discussed in a theoretical context (the concept D\*, description of D\*), in 25.6% D\* was the object of research (Measurement of D\*/evaluation of meaning of D\*), in 20.2% D\* was explicitly discussed in a practical context (dignity therapy/dignity conserving care/dignified dying and care), in 10.1% D\* was used as an argument (e.g. for or against Euthanasia).

**Conclusions:** The heterogeneity of the topical context shows that D\* is mostly not defined clearly and suggests that D\* is not used uniformly. A subsequent discourse analysis is needed to examine the different approaches to dignity. Funded by the German Cancer Aid (grant no: 108726)

**Abstract number:** P1-300

**Abstract type:** Poster

**Oncologists' Views about Hospice Care in the Czech Republic and Slovakia**

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**Aim:** Oncologists play a major role as gatekeepers for access to hospice care. The aim of this project was to assess the association between knowledge, attitudes and demographics of oncologists in the Czech Republic (CZ) and Slovakia (SK) and their discussion about and referral for hospice care.

**Methods:** An anonymous online questionnaire was designed to explore the background information on the participants and their knowledge and attitudes to hospice care. Oncologists were invited to participate through their National Oncological society's e-mail databases after agreement with management of each society. Chi-square test and correlations were used for data analysis.

**Results:** 91 respondents (response rate 10%) completed the survey (70 from CZ and 21 from SK). 90% of them had discussed hospice care with terminal patients in last six months, 84% referred some of those patients for hospice care. There was a significant association between higher reported ratio of referrals to hospice care and self-rated knowledge about hospice care ( $p=0.035$ ) and attendance at any training in palliative care ( $p=0.012$ ). More positive attitude to hospice care was significantly associated with higher ratio of discussions about such care ( $p=0.38$ ). Age was also significantly associated with both discussing ( $p=0.048$ ) and referring for hospice care ( $p=0.011$ ) with respondents aged 33-50 years being the least likely to do so.

**Conclusion:** Both knowledge and attitudes to hospice care appear to be associated with oncologist-patient discussions about hospice care and referring patients to such care. The low response rate signifies that the results must be interpreted with caution. They might indicate low levels of knowledge and salience about hospice care in CZ and SK. Further research of oncologists' attitudes and also their reluctance to participate in surveys is necessary as more data from resource-poor countries in Central and Eastern Europe are needed. Study was funded by FP7 EURO IMPACT project.

Abstract number: P1-302  
 Abstract type: Poster

**Breaking Down Barriers: Evaluating a Marie Curie Hospice Project Aimed at Improving Access to Palliative Care by Minority Ethnic Groups**

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**Research aims:** Government policy within the United Kingdom (UK) asserts that all individuals should have access to high quality palliative care. However, there is a growing body of evidence that both internationally and within the UK, individuals from minority ethnic groups are underrepresented in both accessing and using palliative care services. A local hospice within a major city in the UK is attempting to increase minority groups' utilisation of palliative care services by employing a key worker to engage with local communities. This study aims to inform and evaluate the development and impacts of this project.

**Study design and methods:** Semi-structured interviews are being undertaken with community members of minority ethnic community groups, community healthcare professionals and hospice staff at baseline, 12 and 30 months, and at 6 month intervals with the key worker. Ethnicity data collected by the hospice is also being analysed to identify whether there are changes to the uptake of palliative care over time.

**Results:** This paper will report on data from baseline interviews with community members and health care professionals, in relation to the following areas:

- Community members' understandings of and views on end-of-life and palliative care;
- Perceived unmet needs in relation to minority ethnic health, illness, and death practices;
- Perceived barriers to the use of palliative care within minority communities;
- Educational needs of health professionals in relation to minority health, illness and death practices;
- Views on how these barriers could be addressed and palliative care could be made more accessible.

**Conclusions:** Implications will be identified for palliative care providers interested in finding ways to improve access to palliative care for minority ethnic groups.

development of the disease specific ACP model in the cancer centre and its feasibility will be examined in a Phase II study of patients with advanced cancer.

Abstract number: P1-304  
 Abstract type: Poster

**Development of a Model of Service Delivery for Palliative Care in the Republic of Serbia**

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**Aims:** A national palliative care (PC) strategy was passed by the government of the Republic of Serbia in 2009 & set out a comprehensive government policy to develop PC in Serbia. In order to operationalize the strategy & action plan support is being provided to the Ministry of Health (MoH) to develop a model of PC delivery appropriate to the circumstances & resource constraints of Serbia.

**Methods:** A model of care was developed based on the requirements set out in the national strategy. Through consultation with existing healthcare providers & policy makers a number of areas external to the model of care were identified including assessment of workload, operational procedures, quality standards, referral protocols, assessment of human & other resource inputs & performance indicators. Key proposals were designed using available Serbian practice & experience complemented with good practice from neighbouring countries & international PC. These were tested & amended through a process of participative study with existing healthcare institutions.

**Results:** A detailed specification of the model of pc delivery including the resources & organisational requirements at the different levels of health & social care delivery.

**Conclusion:** The development of a model of service delivery which translates policy into practical guidance at each level of the healthcare system is a vital component in operationalizing a PC strategy. Cooperation between separate government structures (health & social care) & the role of the non-public sector in provision remain challenging.

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**Organisation of Services**

Abstract number: P1-301  
 Abstract type: Poster

**First Five Year Experiences of a Tertiary Medical University in Provision of Palliative Care in Bangladesh**

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Despite World Health Organisation reiteration of importance of palliative care in developing countries, services are scarce patchy and inconsistent. Bangladesh is world's eighth populous country with a population of 146 million, two thirds lives in rural and one third in urban areas. Adult literacy rate is 54%. Per capita annual health expenditure is US \$ 12. The experiences of first five year of a tertiary medical university are described in this paper. A retrospective review of electronic database case notes for all registered patients was undertaken. The data were collected at the outpatient clinic during first consultation. One thousand and fifty patients with mean age 50 years, diagnosed with incurable cancer were seen during a period of 51 months from October 2007 to December 2011. Most of the patients were from middle class socioeconomic group (30%), already know about their disease status and prognosis (62%). Referred from other disciplines formed the major group (57%) of this population. All of them had been under treatment for variable period ranging from one month to four years. The most common five symptoms noted by the service providers were pain (80%), weakness (60%) loss of appetite (54%), sleeplessness (49%), Nausea (34%) and vomiting (30%). The mean daily dose of morphine was 30 mg/day (range 9-180 mg). The palliative care population in this setting is relatively older. Lung cancer is the most commonly seen cancer among the group (5%). Pain is the most commonly reported symptom, with oral morphine frequently required. An institution based medical oriented approach can play significant role in reducing the physical symptom burden but fails to ensure continuity of care. Community oriented approach could be recommended as a better approach.

Abstract number: P1-303  
 Abstract type: Poster

**Developing and Implementing a Cancer Specific Model of Advance Care Planning in an Australian Cancer Centre - Lessons from Practice**

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**Background:** Despite increasing evidence that Advance Care Planning (ACP) can improve end-of-life care, the majority of cancer patients do not engage in this initiative. The development of more disease specific ACP programmes, that tailor processes and interventions to trajectories and complexities specific to cancer patients, may lead to improved outcomes. A multifaceted programme of service development, education, and research was identified as a requirement to meet specific organisational needs as well as national and accreditation requirements on ACP in Australia.

**Results:** We will present the successes and challenges of various interventions undertaken including:

- 1) Electronic enhancement of current Health Information Services to ensure visibility of information and to allow for a more dynamic system to document ongoing conversations,
- 2) Design of ACP documents to reflect the complex nature of decision making in the cancer population,
- 3) Design of appropriate information materials and interventions to allow for healthcare decisions to be documented throughout the cancer trajectory,
- 4) Methods to identify and target learning needs for staff in a cancer centre,
- 5) Policy development and identification of key performance indicators for the cancer populations,
- 6) Utilisation of a comprehensive research programme to inform and evaluate the above strategies.

A diagrammatical framework will outline the importance of a collaborative approach to facilitate the integration of this novel program into routine practice.

**Conclusion:** The implementation of a cancer specific model of ACP is a complex intervention requiring the development of an organised clinical microsystem. Challenges which emerge throughout the implementation process will be delineated. Lessons learned will guide ongoing

Abstract number: P1-305  
 Abstract type: Poster

**Pilot Palliative Care Projects in Armenia: Results of First Year Operations**

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**Aim:** Palliative care is new in Armenia. Four pilot projects were initiated in 2011 with support from the Global Fund; the first time GF has supported palliative care development not restricted to HIV, TB, or Malaria. The aim of this project was to demonstrate that palliative care could be introduced into the national health care system and to measure its impact on the care and cost of care for patients with life threatening illness.

**Methods:** This project used a program evaluation framework to measure results. All 4 sites used the following instruments: EQ-4D, 0-10 pain scale, Hospital Anxiety & Depression Scale (HADS), Karnofsky Performance Status (KPS), & neuropathic pain screening tool (NPST). The HADS & NPST were used on admission for screening & care planning. Results for pain, quality of life, and KPS were compared to admission scores. Several trainings were held.

**Results:** 132 patients were admitted, 70 died, 8 were discharged and 54 remained on service. Average age 59.63 including 9 children. 78.5% had a cancer diagnosis. Mean length of service was 64 days median 37. All sites provided home care (3962 visits), inpatient care (25 admits), outpatient clinic (1388 visits), and 4697 regular & emergency calls. Over half of patients had anxiety & depression. Avg pain score on admission was 5.69 and 30.3% had neuropathic pain. Mean post admission pain scores decreased at all sites but ranged from -.055 to -2.5. Quality of life improved for pain, depression & anxiety not for activity, mobility & self-care. Few hospitalizations occurred.

**Conclusions:** Palliative care was successfully introduced into the Armenian healthcare system along with standardized measurement. Plans for expansion are underway. Pain control results were limited by lack of oral morphine. Methadone was introduced along with special training late in the pilot and showed improved outcomes. Hospital costs were reduced. The pilots will continue for another year with much more training & development needed.



Abstract number: P1-306  
Abstract type: Poster

**The Quality of Professional Life and Means of Support for the Palliative Care Staff**

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**Introduction:** Working in palliative care can lead to emotional satisfaction or compassion fatigue and burnout. The prevention of burnout by recognizing and modifying the factors that intervene is important.

**Aim:** To evaluate the association of certain distress factors with the risk of compassion fatigue and burnout among the professionals working in palliative care in Romania.

**Materials and method:** Survey of professionals working in palliative care, oncology and oncopediatric wards from 4 cities in Romania. The professionals were handed a questionnaire with open and multiple choice questions from 01.07 until 30.07.2012. A sample of 148 subjects was selected, 104 returned the completed questionnaires, 94 were valid. Data were included in an Excel database and analyzed using Epi Info.

**Results:** Respondents were: nurses 49%, doctors 23%, carers 17%, social workers 5%, psychologists 4% and spiritual counselor 2%. 26% consider themselves frequently and often exhausted physically and emotionally as a result of their professional activity and 74% rarely. We found an association between distress factors and professional exhaustion as follows: lethargy risk ratio (RR) of 4,08;  $\chi^2=18,22$  sleep disorder- RR of 3,42;  $\chi^2=12,99$ , anxiety-RR of 4,88;  $\chi^2=18,69$ , cynism-RR of 4,18;  $\chi^2=5,96$ , lack of motivation-RR of 4,68;  $\chi^2=4,68$  and postponement of work related duties-RR of 4,18;  $\chi^2=5,96$ . I can say "No when the task overcomes my working power" was a protective factor against professional exhaustion,  $\chi^2=6,52$  and RR=0,478% of the responders declared that they have received effective support from their families, 76% from colleagues, 31% through spiritual counseling, 20% from their managers.

**Conclusions:** Our study shows there is a statistically significant association between the physical, emotional, personal, professional distress factors and the risk of compassion fatigue and the need in educating the staff in recognizing this factors.

**Keywords:** Compassion fatigue, burnout, distress indicators, support.

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Abstract type: Poster

**The Integration of Palliative Care (PC) into Two Intensive Care Units (ICU) in a Community Hospital**

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A majority of Americans die in healthcare facilities. More than 50% of decedents spend time or die in an ICU. Audits show that a large number of decedents have had poorly managed symptoms, ignored treatment preferences and poor communication with clinicians.

South Nassau Communities Hospital (SNCH) has 406 beds including a 12 bed Medical-Surgical ICU and a 10 bed Cardiac ICU. During 2011 there were 1598 ICU admissions with an 18.9 day average length of stay. Eighty patients received CPR. One patient survived. Mortality approaches 30%.

SNCH has a Mobile Palliative Care Consultation Team (PCT) consisting of Hospice and PC physician, an Advanced Practice Nurse in PC and a PC Social Worker. Chaplains and Ancillary Services provide expertise on a voluntary basis.

High quality ICU PC is an anticipated standard. Stakeholders believe key attributes of this standard include: 1) clear, compassionate communications, 2) decision making on patient/ family centered preferences, 3) care maintaining comfort, dignity and personhood, 4) family care with open access to patients, 5) interdisciplinary team (IDT) support, and 6) bereavement care for the families of decedents.

The Improving PC in the ICU Project (IPAL-ICU) is an initiative co-sponsored by the National Institutes of Health (NIH) and the Center to Advance PC (CAPC). The project provides resources, tools, evidence and expertise to all ICU clinicians.

IPAL-ICU will be used as a guide for the SNCH PCT. We will use a nurse driven model providing Specialist PC consultations to any ICU patient/family with PC needs. Initial steps include;

- 1) taking a leadership role in an IPAL-ICU working group,
- 2) participating in ICU IDT meetings,
- 3) enhancing opportunities for team work promoting integration of PC into the ICU matrix,
- 4) define work processes especially family meetings,
- 5) education to ICU clinicians,
- 6) develop Performance Improvement projects, and
- 7) maximally utilize IPAL-ICU resources.

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Abstract type: Poster

**Developing and Implementing a New Evidence Based Hospice at Home Service**

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**Background:** A hospice in SE England running inpatient and community advisory services planned to establish a new hospice at home service (H@H) to enable more patients to die at home.

**Method:** A literature review of hospice at home services was commissioned to guide service staffing, configuration and functioning. A new, associate director-level post was funded to develop the service.

**Results:** The literature review identified a heterogeneous mix of research methodology, outcomes and service configurations. Studies also lacked detailed specifications of the services themselves. Despite this variability, the review did indicate that successful home interventions have the following characteristics: are offered for an appropriate length of time, can respond 24/7 as needed, provide equipment and medication, support informal carers as a part of the care team, and work in coordination with existing community services. Thus the service was developed to fill gaps within the existing community care landscape in the area and had the following characteristics:

- The service was delivered by senior Healthcare Assistants (HCAs) trained in Palliative Care at the hospice.
- The team of HCAs was supported by the full multidisciplinary hospice team which was already in place.
- The service was available to start at 4 hours notice, day and night, to support patients to die at home and to provide short-term crisis intervention.
- In the planning phase, 72 hours of care was allocated to each case.

**Conclusions:** There was minimal relevant, good quality evidence to guide the development of a new hospice at home service within a UK context. The service was adapted during the implementation process to respond to patient and carer needs which were not indicated in the literature but arose as the service developed. The new service has subsequently been the subject of research to evaluate its impact.

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Abstract type: Poster

**Developing Palliative Care Service in Rural Area: Is it Easy to Do?**

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**Introduction:** Palliative care in Moldova was initiated in 2006 by some non-governmental organizations, mostly in urban regions, and as a concept was introduced into the National Healthcare System in June 2008. The majority of incurable patients who live in rural regions do not have adequate access to qualitative palliative care services. In order to improve this situation some projects to initiate development of palliative care in rural regions were undertaken.

In accordance with the study conducted in 2006 on the national palliative care needs assessment in Taraclia, one of the country regions situated in the south of Moldova, less than 500 patients per year need palliative care. Under the initiative of the local non-governmental organization Association "Angelus Taraclia", Hospice "Angelus Taraclia" in October 2009 providing of the home based palliative care services to incurable adult cancer patients in Taraclia region was initiated.

**Aim:** To assess the activity of the Association "Angelus Taraclia" in palliative care development in Taraclia region.

**Method:** Review of the annual reports about activity of the Association "Angelus Taraclia".

**Results:** In October 2009 qualitative palliative care was provided to 23 incurable adult patients. The number of the patients in care gradually increased to 98 in 2010, 104 in 2011 and 99 for 10 months in 2012. In order to raise public awareness about palliative care in the region and ensure financial sustainability of the project the Association developed and ran several fundraising and charitable events. In 2011 medical palliative care services were financially supported by the National Medical Insurance Company.

**Conclusion:** In spite of the existed barriers, the Association "Angelus Taraclia", Hospice "Angelus Taraclia" has been providing qualitative home based palliative care services for incurable cancer adult patients starting from October 2009 and is the only organization of such type in the region.

Abstract number: P1-310  
Abstract type: Poster

**Trends of Development of Palliative Care in Poland - The Report of the Ministry of Health Expert Counsel on Hospice and Palliative Care**

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The Expert Counsel on Hospice and Palliative Care was raised by the Ministry of Health ordinance. The aim of the team was to work out proposals for changes in the area of palliative and hospice care (PHC) in Poland.

**Materials and methods:** The Counsel worked from Aug. 2011 to Jun. 2012 in a form of 11 meetings. There were also purposeful taskforces set in the following areas: calculation of real costs of publicly reimbursed palliative care services, changes of physician's specialization curriculum, setting patient's entry and exit criteria for publicly reimbursed PHC.

- Final documents:**
1. the assessment of the current situation of palliative care in Poland,
  2. the project of changes to the regulations on publicly reimbursed services in palliative and hospice care,
  3. the recommendations of necessary changes in organization and financing of palliative and hospice care, as well as setting the platform for collaboration with affined specializations (e.g. oncology, geriatrics, long-term care).

- Recommendations:**
1. Recommendations for changes in Ministry of Health ordinance of Aug. 29, 2009 on publicly reimbursed PHC services:
    - a. implementation of questionnaire of symptoms' intensity,
    - b. modifications of staff qualifications and headcount standards,
    - c. reimbursement of daily palliative care centre and hospital support team in PHC
  2. Increasing expenses and changes in financing of PHC
  3. Elaboration of the National Program for Development of Palliative Care
  4. Incorporating palliative medicine onto deficit specializations list
  5. Starting collaboration with the National Program against Cancerous Diseases
  6. Implementation of the rule of increasing expenditures on palliative care in proportion to the increase of expenses on oncology.
  7. Elaboration of the solution of the problem of ensuring PHC for the patients with advanced cancer and well controlled symptoms, who do not require hospitalization but who require social assistance.

Abstract number: P1-311  
Abstract type: Poster

**Nurse Prescribing in Specialist Palliative Care Improves Knowledge and Management of Medicines and Empowers General Practitioners**

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**Background:** Nurse prescribing remains high on the UK government agenda. Research has shown that nurse prescribers within community Specialist Palliative Care (SPC) do not go on to prescribe regularly (Ryan-Woolley 2007, Kinley 2007, Latter 2010); this paper provides original evidence to understand this.

**Aim:** To explore the Specialist Palliative Care Nurse Independent Prescriber (SPCNIP) role identifying the volume, nature and influences to nurse prescribing within the SPC community setting.

- Design:**
- i. Retrospective audit of home care patient prescription issuance by nurse prescribers between September-December 2011.
  - ii. Prospective audit of community 'End of life drug administration charts' (EoLDACs) between March-April 2012.
  - iii. Focus group discussion with SPCNIPs (March 2012) - data analysed using the 'Framework' approach.

**Results:**

- i. Prescriptions by 10 SPCNIPs were 52 over 4 months.
- ii. 20 EoLDACs written over 4 week period (65% by SPCNIPs and 35% by medical staff). Reasons for the SPCNIP not prescribing the charts were: Department of Health restriction (n=4), complex pharmacology (n=2) insufficient medical information (n=1).
- iii. Focus group discussion (n=7) revealed multiple influences to nurse prescribing including; organisational/national

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policy, level of organisational support, SPCNIP confidence/level of experience, and nurse concerns regarding disempowerment of the patient's GP.

**Conclusions:** SPCNIP training improves knowledge and management of medicines and empowers the patient's General Practitioner through SPCNIP education. Volume of prescriptions is not an indicator of successful prescribing within SPC; SPCNIPs develop a holistic approach, making complex decisions about prescribing while managing the competing expectations of the patient, the hospice organisation and the primary care team.

**Acknowledgements:** This work was undertaken at St Christopher's Hospice, towards an MSc in Advanced Nursing at King's College London. No external funding was received.

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**Abstract type:** Poster

### Strategy to Improve Palliative Care Delivery at Regional Level Underpinning Continuity of Care and Regional Resource Coordination: Madrid Regional Palliative Care Observatory

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International, national, regional, local standards guide Palliative care (PC) development. Implementation and outcomes evaluation is an important albeit complex process. Systems to access clinical, administrative and managerial data for analysis and presentation are needed.

**Aims:** To follow up regional PC activity with a functional framework evaluating progress and available services supported by an electronic system. To reliably inform strategic planning.

**Method:** Three phases outlined this project: Definition (working groups and plans); Design (Outcome indicators and Functional description) and Progress (validation and deployment). Electronic system construction including documentation, implementation and training resulted in new tools: to access clinical records, info PAL, and to merge information flow and PC related communication: clinical, research, training and technical support/quality, gesPAL. The venture offers automatic data collection.

**Results:** A new structure resulted: PC integral management board combining input pathways, clinical and non clinical exchange platform and output pathways. Its human-technology interphase designed to facilitate data use and operationability for: consultation, presentation and update; Information flow and bundling by clinical, functional, use and procedure categories to reach user; minimum manual interactions, data and information presentation relevant to user levels. The Regional Observatory holds PC clinical records, up to date information, makes it available to professionals, managers and policy makers: with necessary records for continuity of care such as available regional PC bed; multidisciplinary agreed plans, preferred place of care and death...24h a day.

**Conclusions:** The Observatory uses modern technology to change the face of PC provision simplifying processes. Its social and professional impact potential contributes to patient's care. Professional resource use and managerial adjustment to clinical activity and needs.

**Abstract number:** P1-313

**Abstract type:** Poster

### The Changing Face of Hospice Care

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**Background:** Palliative Care is a growing and evolving specialty. In Ireland, over 6,000 people utilised hospice services in 2009. This is predicted to increase to 16,000 people by 2016 (HSE, 2009). Improved access has been shown to increase the proportion of cancer deaths that occur in hospices. Ease of access therefore has the potential to change patients' preferences with regard to place of death. The balance between malignant and non-malignant diagnoses is also shifting. Service developments, in conjunction with advancing oncological treatments and a shifting disease burden, suggest that the characteristics of hospice populations may be changing. One year ago, Marymount Hospice relocated to a purpose built facility with significantly improved patient accommodation

facilities. This was actively publicised to increase awareness and promote acceptance of the facilities.

**Objective:** To determine the demographics and patient characteristics of all admissions to a hospice over a two year period. To compare this data prior to and after a geographical relocation.

**Methods:** A retrospective cohort study will be employed. iCARE was used to collect demographics, length of stay, admitting institution and discharge destination. Diagnosis and status of active disease modifying treatment will be obtained from discharge documentation. Period One, September 2010 to August 2011 will be compared with Period Two, September 2011 to August 2012. Data will be entered in Excel and analysed using SPSS 12.0.

**Results:** Data collection on-going.

**Conclusion:** Observational data suggests that the complexity of patients admitted to the specialist inpatient unit is changing with shorter lengths of stay, a younger population and an increase in number of people on active treatment. These changes will have service and staff education implications.

**References:** Health Service Executive (2009). Palliative Care Services - Five Year/Medium Term Development Framework (2009-2013). Health Service Executive

**Abstract number:** P1-314

**Abstract type:** Poster

### Making End of Life Care Services More Accessible to Patients and Carers

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**Aim:** To increase the choice and accessibility of end of life care services for patients and carers.

**Method:** Building on the 35 years of experience in delivering end of life care services from a central hospice base to a patient population of 500 000, over a semi-rural geographical area of over 700 square miles a new model of service delivery was developed. This was driven by recognising that patients are living longer with life threatening conditions, the adverse impact that this is having on both them and their carers, challenging the established paternalistic model of the hospice i.e. deciding who would be best to deliver the care and that some people do not need, or want the intensive and costly specialist interventions traditionally on offer e.g. one to one work with a Clinical Nurse Specialist in the home.

The new service delivery model, formed from the results of focus group interviews with existing patients and carers, members of the public and the local health and social care providers in the hospice catchment area, is based on the principles of offering "more for more" and delivering "lighter touch" services which will complement the specialist palliative care interventions already on offer.

**Results:** The new services are delivered in the local community in centres and satellites that also offer a drop in facility. To date one new larger "Outreach" and three smaller satellite centres have been developed. The Outreach Centre offers a drop in life for information and advice to anyone affected by a life threatening condition. This is facilitated by both volunteers and trained staff. There are also facilities for trialling drop in "wellbeing workshops" as well as running existing patient and carer groups and establishing a base for three of the hospice community teams. The satellite centres have allowed hospice services to be taken closer to patient's communities, working in collaboration with local health and social care providers in each area.

**Abstract number:** P1-315

**Abstract type:** Poster

### Maintaining the Momentum: Sustaining the Gold Standards Framework in an Acute Hospital Trust

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**Aim:** To demonstrate the impact & sustainability of the Gold Standards Framework (GSF) across whole acute hospital, over 3 years.

**Design:** Introduction of GSF in hospital was supported by a wide-reaching education drive aimed at all & reaching approximately one third of all clinical hospital staff. New incentives e.g. End of Life Skillset Challenge education programme & Route to Success for End of Life in Acute Hospitals (TRANSFORM) programme have further embedded GSF within the culture & every day practices of the hospital. Patients' general practitioner are informed of all patients on the hospital held register & encouraged in

turn to add patients known to them. Data collected includes number of registrations, length of stay & length of life from registration.

**Results:** Recorded registrations have increased from 2010/11 to 2011/12 & preliminary figures predict a further rise in year 3. Holding a locality based register within the hospital has enabled identification of 30% of all GSF patients whilst in hospital which better facilitates early co-ordination of care & discharge. The length of stay for GSF registered patients has fallen from an average 11.8 days Sept 2011 to 7.8 Sept 2012. The average length of life from GSF registration is 141 days suggesting that health professionals are accurately diagnosing last year of life & registering patients appropriately.

**Conclusion:** Introduction of GSF into the acute hospital resulted in an increase in numbers of eligible patients recognised & recorded. In addition being recognised as a GSF registered patient has a positive impact upon length of stay. The culture within the organisation is undertaking a monumental shift & has a proactive approach to achieving high quality end of life care. This has been achieved & maintained by the positivity & enthusiasm of all hospital staff & the support of clinical champions. The introduction of GSF has reinvigorated End of Life Care across the Hospital.

**Abstract number:** P1-316

**Abstract type:** Poster

### Transformers: Preparing for Change in End of Life Care in an Acute Hospital Trust

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**Aim:** To prepare the acute hospital & develop the workforce to be able to consistently provide high quality End of Life (EoL) care, by implementation of the Department of Health's Route to Success for Acute Hospitals programme, reviewing and measuring against existing EoL tools from the five key enablers, establishing baseline measurements & inclination for change. The five key enablers suggested are: Liverpool Care Pathway, Advance Care Planning, Rapid End Of Life Transfers, End of Life Locality Based Registers, AMBER Care Bundle. The hospital already has potentially powerful levers such as a well embedded EoL Strategy Group, newly created Transform Facilitator and high profile Palliative Care Team.

**Method:** Audit of current use of EoL tools within the hospital to ascertain effectiveness & productivity, demonstrating continued momentum for change.

**Results:** End of Life register located within the hospital has increased from 2010/11 to 2011/12, with 30% of all registrations originating from the acute hospital, 30% of which are non cancer registrations and the other two thirds being notified by primary care.

Liverpool Care Pathway usage in hospital has increased from 47% of all hospital deaths to 55%. (National average 37%)

Rapid End of Life Transfers increased from 26 in 2010/11 to 72 in 2011/12

Advance Care Planning is still in its infancy, but raised awareness through staff training sessions & a public information drive have increased the profile & recognition of the value of this tool. An information pack demonstrating ways to document preferences is available throughout the Trust.

AMBER Care Bundle implementation is planned for early 2013 & figures for this will be available.

**Conclusions:** With three of the five key enablers already successfully implemented in the hospital, & preparation firmly underway for the use of the other two, it would appear the hospital is a ripe environment to embrace the programme, & prepared to build upon established success.

**Abstract number:** P1-317

**Abstract type:** Poster

### Challenges when Opening a Hospice Casa Sperantei Branch in Bucharest the Capital City of Romania

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Hospice Casa Sperantei is the Palliative Care pioneering organization in Romania. The idea of opening a new Hospice branch came as a response to the great need for palliative care in Bucharest. On planning our work we encountered challenges and barrier from the part of communities and the authorities.

The challenges hospice had along the way included finding the right location, purchasing the land, recruiting well prepared architects with experience in building

hospices, advocating to the public authorities, respect the particularities (in-patient, out-patient units, day centre etc.) of a hospice building and services provided by this institution.

Considering the lack of education in the multiple communities regarding the hospice philosophy and palliative care concept, we've lobbied throughout meetings with companies' representative, communities' leaders, volunteers in order to raise the awareness on the importance of holistic hospice care and of raising funds for building the palliative care facility. One important aspect of hospice care is the team involved and recruitment of skilled and well prepared specialists. Hospice care is based on developing relationships based on trust and respect with other medical institutions, in order to promote the concept and implement total care, for all the patients who need it.

Opening of a new Hospice CS branch in Bucharest will increase the number patients that receive palliative care to over 2000, the number of medical professionals that provide quality palliative care services to incurable ill patients. The following services will be provided: homecare teams, inpatient units, hospital teams, day centers, out-patient clinics, all of them both for adults and children, and educational center for children.

**Keywords:** Planning, challenges, hospice, cultural considerations and legal context.

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### Evaluation of a Macmillan Health Care Support Worker Project Designed to Support Care of Patients in the Community with Palliative Care Needs

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**Aims:** This study reports a descriptive service evaluation of a new role, the Macmillan Health Care Support Worker in one area in Scotland. The service aimed to allow practical support to patients and their families and be part of the team delivering high quality practical care to patients in the community with identified complex care or palliative care needs, therefore, allowing more patients to be supported at home during periods of difficulty and allowing those to die at home if they wish to do so. The HCSW were managed, trained and supported by District Nurses. The overall aim of the study was to evaluate the role of the Macmillan Health Care Support worker in one NHS board area in Scotland.

**Methods:** This was a mixed methods evaluation incorporating a systematic literature review, interviews, participation observation and audit data. The overall design of the evaluation was carried out in liaison with the funders and in particular with local managers and staff of NHS Forth Valley.

**Results:** The findings demonstrated that the role of the Health Care Support worker is flexible and needs driven and highly valued by service users (patients and carers). There were, however, periods when the Health Care Support workers were underused, either because caseloads were quiet regarding palliative patients or because district nurses did not refer appropriate patients. Training was perceived as essential both by professional staff, the support workers themselves, as well as, evidence from the systematic literature review.

**Conclusions:** We make several recommendations based on the findings particularly in relation to mandatory training and a re-evaluation of the coordination of the Health Care Support workers. We suggest that partnership working between health care, social care and the voluntary sector is necessary to deliver effective palliative and end-of-life care in the community. We suggest a move towards a more needs led patient centred service.

**Abstract number:** P1-319

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### Integrating Palliative Care in Lung Cancer: An Early Feasibility Study

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**Aims:** Having a diagnosis of lung cancer has been associated with increased physical and psychological distress when compared to other types of cancer. The aim of this preliminary feasibility study was to evaluate the feasibility of conducting an effectiveness trial of early access to palliative care services through an integrated outpatient model in a Scottish population. The specific objectives of this study

were to evaluate the number of eligible participants, the willingness of participants to participate in a randomised controlled clinical trial, the data collection plan, the response rates to the selected outcome measures, as well as, the adherence/ compliance rates. Newly diagnosed patients with lung cancer receiving palliative intent or best supportive care treatment were recruited over a five month period from one outpatient clinic in Scotland. They were offered a clinical review with a palliative medicine consultant at two time points (baseline and 12 weeks later). Prior to each review they filled in three questionnaires: the Functional Assessment of Cancer Therapy- Lung scale (FACT-L), the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS). During this period, interviews were also conducted with patients to explore their experiences of being involved in the study. Main reasons for low recruitment recorded were patients' condition deteriorating, and not wanting extra hospital visits. However, qualitative data indicated that patients found this extra layer of supportive care useful in identifying and managing their needs, as well as enabling future planning. Taking into consideration findings from this feasibility study, further testing is needed for early access to palliative care services for patients with lung cancer to be integrated in routine practice.

**Abstract number:** P1-320

**Abstract type:** Poster

### Work Is an Important - and Neglected - Issue in End-of-Life Cancer Care

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**Aim:** The importance of enabling people with cancer to remain in work is widely accepted. It is also recognized that the employment support offered is limited. Concerned about deficiencies in services in the UK, the National Cancer Survivorship Initiative funded seven pilot sites to develop local cancer vocational rehabilitation (VR) services. A concurrent evaluation aimed

(i) to identify a model of service delivery capable of being widely implemented;

(ii) to understand patients' perspectives on problems encountered.

**Methods:** Realistic Evaluation was used to develop explanatory accounts of 'what works' in cancer VR. Data sources included:

(i) interviews and focus groups with service providers (n=22);

(ii) pilot sites' records and final reports;

(iii) interviews with service users (n=25).

Quantitative data were analysed using simple descriptive statistics. Qualitative data analysis software (MAXQDA) was used to organise data, which were analysed using Framework. Ethical approval was granted by NHS Central London REC 3.

**Results:** 597 people were referred. It had been anticipated that the focus of service delivery would be on cancer survivors, but a significant number of people referred had advanced disease. Work is not often a topic on the palliative care agenda, but patients identified a range of support needs towards the end of life:

- Support to continue in work as it provided a sense of competence and normality, and a welcome distraction.
- Help with discussing prognosis and reasonable adjustments with employers.
- Information and advice on employment rights.
- Advocacy related to financial settlements and packages.

Patients reported that both they and their employers found these conversations upsetting and difficult, and that very little support or information had been available from their health care teams.

**Conclusion:** There is an urgent need to determine the employment support required by people with advanced cancer and identify the best ways of providing this.

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**Abstract type:** Poster

### Palliative Home Care for the Technology-dependent Patient - a Pressing Health Care Issue

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The number of technology-dependent patients has been increasing worldwide because of medical advantages in the treatment of severely ill patients surviving acute intensive care and due to technological inventions. Many of them are transferred to palliative home care, when an improvement

in the health status of the patient can't be expected and when quality of life and relief from suffering became the main and consented goals of care.

Aim of this preliminary study was to review the present knowledge about palliative home care for technology-dependent patients in Europe and especially in Germany and to work out relevant research desiderata from a health services research point of view. Therefore a comprehensive and systematic literature analysis has been executed and summarized.

As a result of this study the enormous challenges for the future development of the home care system, for conceptualizing palliative care and for the caregiver and care provider involved in palliative home care for the technology-dependent patients became evident. However, little is known yet empirically about concepts, structures, processes, outputs and especially outcomes of a patient-centered palliative home care for this group of patients.

As a conclusion it can be said, that broadening the knowledge base about palliative home care for the technology-dependent patient - especially about the patients and families experiences and perceptions as main unit of care - is strongly recommended to work on this pressing health care issue adequately.

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**Abstract type:** Poster

### Organisation of Community Palliative Care Service in Istrian County

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Organization of palliative care (PC) in countries where there is no national strategy for PC is a challenge for health care professionals and the community. Close cooperation and trust between professionals, associations, population and the local authorities can overcome challenges and establish PC. In this paper we present the way of starting and establishing outpatient PC in Istria County.

Development of PC in Istria was passing through three periods. In the pioneering period were formed the trained volunteers. They organized lectures for health professionals and volunteers. Local population was informed about the need for PC through public media. After 5 years the conditions for professional PC were created. Implementation period started after provision of financial resources, taking into consideration the available human resources. In this period was selected model of providing PC. County of Istria has population of 200,000 at 2800 km<sup>2</sup>. Approximately 2000 people die annually, about half of them at home. It is estimated that about 1500 patients and family members are in need for some aspect of PC. PC for so many patients is possible only in good collaboration with family doctors. We have chosen adapted model of community PC service that would help a family physician in the provision of PC.

Realization of PC is the third period started one year ago. The Palliative care service is established. Within the service is organized Mobile palliative care team. Advisory centers and lending aid services are organized in major cities. Training about PC principles was conducted for doctors, nurses, social workers and volunteers. Initiating a PC service is a huge challenge, but maintaining the model is perhaps a greater demand. This service is established with great enthusiasm of health professionals, good cooperation with family doctors and nurses. However, it is necessary to continuously upgrade the model to achieve the comprehensive palliative care.

**Abstract number:** P1-323

**Abstract type:** Poster

### Evaluating the Need for and Challenges of Providing Community Based and Inpatient Palliative Care for Homeless People in the UK

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**Introduction/aims:** In the UK the average age of death of a homeless person (HP) in the UK is 47 years. Complex care needs are usual in this population due to addiction, multimorbidity, and psychiatric illness. There are a number of barriers to providing specialist palliative care (SPC) to the homeless in the community and in specialist palliative care inpatient units (SPCIU). We discuss these and reflect on our experience of caring for this group of patients, with discussion of a case admitted to our SPCIU. We also assess the prevalence of SPC needs in the homeless.

**Methods:** 47 consecutive homeless patients admitted to a

London hospital were assessed by a multidisciplinary team for homeless persons. Experience of accessing health and social services was discussed with each patient. In addition we describe our experience of caring for a homeless person in our SPCIU.

**Results:** Of the 47 patients assessed, 3 had uncontrolled symptoms warranting SPC input. None had had contact with SPC services. These patients cited addictive behaviours, perceived prejudice from healthcare professionals, transient place of stay and lack of information about services as barriers to receiving required care.

Our experience of caring for a HP with multiple addictive, medical and social issues in our SPCIU highlights the challenges of meeting complex needs and maintaining a safe and therapeutic environment for all patients.

**Conclusions:** The prevalence of persons requiring SPC input is disproportionately high in the homeless population. They may not be identified in hospitals because complex health needs take priority. A hospital homeless team may promote identification and appropriate management. Homelessness is a direct and indirect barrier to accessing SPC. Caring for a HP in a SPCIU is a unique challenge. It requires a flexible team approach and consistent communication. Further investigation of the SPC needs of homeless people would help to develop services that provide for them.

**Abstract number:** P1-324

**Abstract type:** Poster

### Retrospective Survey Evaluating "Open Access" Hospice Admissions for Palliative Patients at Risk of a Crisis at Home

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**Aims:** Palliative patients at risk of an imminent and anticipated crisis at home, were offered "open access" (OA) - an urgent, hospice admission pathway triggered by patients, relatives or health professionals. It aims to enable patients to stay at home for longer, reassured that rapid hospice admission for the anticipated crisis is available 24 hours a day as an alternative to hospital attendance. Pre-assessment means further medical review is not required on admission and instead admission is nurse led, especially relevant when the crisis occurs out of normal working hours. A retrospective survey was undertaken to assess indications for and uptake of OA admissions.

**Methods:** A retrospective survey of the electronic records of patients offered OA from 1st July 2011 to 30th June 2012.

**Results:** Over this period, 12 patients were offered OA. Mean age was 64.3 years and 9 (75%) patients had a cancer diagnosis. The indications for offering OA were:

- Threat of haemorrhage (8 patients, 67%)
- End of life care (3 patients, 25%)
- Breathlessness (1 patient, 8%)

Patient or carer distress was evident in 10 offers of OA. 5 of 12 (42%) patients were admitted to the hospice under OA. 2 admissions occurred out of hours, 1 of which was nurse led. Median time from OA offer to admission was 3 days (mean 5.3 days). 4 patients died during admission. Of patients not admitted under OA, 6 died at home or nursing home and 1 in a hospice.

**Conclusions:** Our survey suggests open access hospice admissions can help manage anticipated end of life crises in the community. Open access is an alternative to hospital admissions which does not impact on hospice out of hours medical staffing. Further evaluation is required to assess the benefits for patients and families.

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**Abstract type:** Poster

### Presentation of a Network Model and Program of Excellence Palliative Care

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**Aims:** A network model of excellence palliative care, with a multidisciplinary palliative care team (EMPT) as a central element, has been in operation since August 1998. A national guide of norms and standards published in 2011 provides a model for palliative care which is similar to our network model focusing on providing access to palliative care support wherever the patient and the family are.

**Methods:** The model sets the standard for palliative care ensuring the efficient transfer of patients and information. The main objectives of the organization are:

- a) that patients always have access to the necessary competence in relation to needs,
- b) that palliative care is given within dynamic and flexible systems across competency levels with clear-cut responsibilities,
- c) to establish better routines for patients in hospital and

primary care,

- d) to better communication between hospitals and primary care,
  - e) that services are based on holistic and interdisciplinary thinking,
  - f) that treatment and care is provided at home or as close to home as possible,
  - g) that the organization promotes further development of clinical practice and research in palliative care.
- Results:** A patient associated with EMPCT has:
- a) continual association
  - b) "Open contact" or "Open return" to a special unit at the hospital
  - c) contact-nurses at the hospital and in primary care,
  - d) the EMPCTs are part of the treatment at the hospital and at home
  - e) access to contact to EMPCT and the hospital unit when necessary
  - f) a form is sent to all involved partners with information of the exact type of association to EMPCT
  - g) a network of nurses with special training in palliative care.

**Conclusion:** The organizational model enables EMPCTs to offer services to patients and their families, hospitals, as well as primary care professionals throughout our area. The central element of the model is that basic care levels have the necessary knowledge of common conditions in palliative care.

**Abstract number:** P1-326

**Abstract type:** Poster

### An Evaluation of an Integrated Specialist Nurse Led Palliative Care Clinic within a General Practice Setting

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**Research aims:** A community nurse led palliative care clinic was introduced at a GP (General Practitioner) practice in the United Kingdom (UK) in April 2012. Whereas previously CNS (Clinical Nurse Specialist) nurses would support their patients by home visits, the fortnightly clinic at the GP practice has now been introduced as an additional complementary resource to consolidate the joint primary care/specialist palliative care approach for this patient group. This study evaluates implementation processes and the impacts of the clinic on patient and professional experiences and practices, uptake of palliative services and the management and delivery of palliative care by the GP surgery and CNS team.

**Study design and methods:** Baseline interviews with GPs (n=5) and the CNS team (n=4) were carried out prior to the set up of the clinics in February 2012. Patient interviews (6-12) and follow up interviews with GPs (6-10) and CNS (4-6) are to be carried out in November 2012. Patient interviews will be analysed using Interpretive Phenomenological Analysis (IPA) methodology, interviews with health professionals will be analysed using Framework Analysis. The evaluation will also report on quantitative data from the palliative care register and patient tracking.

**Results:** Data from baseline interviews suggested some weaknesses at the GP surgery in terms of referral and communication practices, especially for non cancer patients. Aspirations for the clinics were also described which included: earlier referral; improved communication and continuity of care; psychological and practical benefits for patients/ carers and more targeted use of specialist nursing resources. Data from patient and follow up interviews will be reported against these aims, and new themes will also be identified.

**Conclusions:** Conclusions will be drawn on the effectiveness of the clinic and implications identified for palliative care provision in primary care settings.

**Abstract number:** P1-327

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### Development of Out-patient Specialised Palliative Care

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Patients in terminal care often want to stay in familiar surroundings. If they suffer from symptoms like pain or shortness of breath, from vomiting or bleeding wounds, family members and emergency doctors alike tend to recommend hospital admission, even if the patient should be dying.

The team of the palliative care ward analyzed which serious illness managed at home, looking at the patient himself, at his next of kin, asking the General Practitioner and the nurse.

The report describes the development of the project "Brückenteam" from its analyses and dialogues with insurances to the evaluation over two years until today where we work as a regular team taking care of critically ill outpatients.

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**Abstract type:** Poster

### Psychological Empowerment and Self-perceived Effectiveness on Health Professionals Providing Palliative Home Care

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**Introduction:** The literature emphasizes that empowerment is an important component of individual, team and organizational effectiveness. Health professionals are key players in providing quality patient care. Empowerment involves a personal sense of control in the workplace as manifested in four beliefs about the person-work relationship: meaning, competence, self-determination, and impact. Self-perceived effectiveness is defined as the degree to which professionals perceive that they fulfill or exceed work role expectations when providing quality patient care.

**Aim:** To analyze the relationship between psychological empowerment and self-perceived effectiveness on health professionals providing palliative home care services. **Methods:** As part of a larger multicenter survey study, a random sample of 408 health professionals providing palliative home care services in several regions of Spain was selected. The Psychological Empowerment and the Self-perceived Effectiveness Questionnaires were used to measure the major study variables. In the study, the Self-perceived Effectiveness Scale allowed professionals to compare themselves with an "ideal professional". Scales revealed adequate psychometric properties.

**Results:** A series of multiple regression analyses tested the model. As hypothesized, results suggest that higher levels of psychological empowerment resulted in higher levels of self-perceived effectiveness ( $\beta = .81, p < .001$ ) in the workplace. The model accounted for 75% of the variance. **Conclusions:** Health professionals are key players delivering quality patient care. Empowerment in the workplace is an important predictor of professionals' effectiveness in providing palliative home care services. Organizations should develop programs to assess and put in place empowering structures and practices that engage professionals to attain a personal sense of control in the workplace.

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**Abstract type:** Poster

### Building a Palliative Care Consult Service in Long Term Care Facilities: Strategy, Business Model and Outcomes

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**Aims:** Long-term care facilities (LTCFs) in the U.S. have begun palliative care programs for patients not eligible for hospice. Some LTCFs train a full-time nurse and others contract with hospice and palliative care programs for palliative care consult services (PCCS). In 2009 our hospice and palliative care (HPC) program established a PCCS for LTCFs led by a nurse practitioner (NP). The aims of this study are to 1) describe the process for establishing, growing and funding a PCCS in LTCFs;

2) profile PCCS patients, interventions and outcomes; and 3) present LTCF staff perceptions of PCCS services.

**Methods:** This is a descriptive study of the establishment and growth of HPC-LTCF partnerships. The PCCS maintains an Excel database of 600 patients, interventions and outcomes to date. LTCF staff members were surveyed for their perceptions of the scope and quality of the PCCS in their facilities.

**Results:** Working with a steering group and informal network of 40 LTCFs, protocols and a database were developed and four candidate facilities chosen. PCCS referrals grew by 32% the first year and 40% the third year following the hiring of an additional NP, increasing hospice enrollments by a mean of 50 per year. PCCS patients with do not resuscitate (DNR) orders had higher rates of hospice enrollment and lower rates of re-hospitalization. PCCS recommendations for symptom control were effective 66.7% to 100% of the time. LTCF staff reports that palliative care is most helpful for pain management (91%), social/emotional issues (86%), and establishing goals of care (84%).

**Conclusions:** PCCS NPs must establish and maintain credibility through ongoing communication, education, and timely and effective responsiveness to the needs of providers, staff, patients and families. The elements of this presentation provide a practical model for extending palliative care to patients in LTCFs, and the benefits for patients, LTCF staff, and HPC programs. The study was hospital funded.

**Abstract number:** P1-330  
**Abstract type:** Poster

### From Prescription to Patient: The Practicalities of Introducing Nasal Fentanyl to a District General Hospital

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**Introduction:** Despite the proven efficacy of nasal fentanyl in the management of breakthrough cancer pain (BTCP) there are several challenges to introducing it to the inpatient setting. We discuss the practicalities faced by a specialist palliative care team in introducing nasal fentanyl into a district general hospital (DGH).

**Methods:** A multiprofessional group was convened to identify the key areas to be addressed. These included a review of current opioid dispensing for BTCP, liaison with stakeholders and a review of current legislative and political drivers.

**Results:** The following key areas were identified:

1. Ward based response time to delivering BTCP medicine. Barriers to the fast delivery of BTCP medicine included delays in answering patient call bell, finding another colleague to administer controlled drugs (CD), finding the CD cupboard keys and dispensing of analgesia according to CD protocol. In practice, BTCP medication could take over 30 minutes to be administered.

2. Education needs of staff and patients.

The nasal route was unfamiliar to generalist teams. Education regarding the features and management of BTCP was necessary. Prescribing, administration and titration guidance, and patient information leaflets, were needed.

3. Safe/ secure storage legislation of controlled drugs. Current legislation requires CDs to be stored in a locked cabinet. To reduce administration time, self-administration of patient's own medication and a digital safe, attached to the patient's bedside, would allow swift access, within current legislative frameworks.

4. Ongoing review and audit of practice

Process needs to be reviewed with modifications made to practice within real time, in response to any issues raised. **Conclusion:** Barriers to the introduction of nasal fentanyl in a DGH can be addressed by collaborative review of processes, and ongoing monitoring. The impact on health economics e.g. length of stay and preferred place of care, will be presented at a future meeting.

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**Abstract type:** Poster

### Development and Evaluation of a Palliative Care Link-nurse Program in the National Referral Hospital in Uganda

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**Aims:** Palliative care (PC) should be accessible to all patients who need it within the national referral hospital. A needs assessment in 2009 showed that around 40% of patients within the hospital have PC needs. As it is likely the majority of needs can be met at the generalist level a PC link-nurse program was set up in 2011 to increase accessibility of PC within the hospital.

**Design:** Nurses from wards with high PC needs and supportive management, were identified to be trained as link-nurses. A 3-day, followed by a 2-day, training course was provided based on the PC toolkit, alongside mentorship and supervision by the link-nurse tutor, implementation of clinical guidelines and a categorisation system for identifying patients to be seen by the link-nurses and those by the specialist PC service. Basic information was recorded by the link-nurses and an evaluation into the impact of the program is on-going.

**Results:** To date 27 link-nurses have been trained who cared for 629 patients between January-June 2012. 2 link-nurses have completed a diploma in PC and all link-nurses have attended updates through the Palliative Care Association of Uganda. Categorisation of patients and implementation of clinical guidelines has been successful, and mentorship & supervision is ongoing. An evaluation of the impact of the program is underway and results will be shared.

**Conclusion:** Improving accessibility to PC in a national referral hospital through link-nurses has been successful. More patients have access to palliative care and knowledge about PC and the services available within the hospital has increased. Motivation is high within the link nurse team. Lessons have been learnt and the evaluation to date suggests that this is a model that could be utilized elsewhere. *This work has been funded by the Diana Princess of Wales Memorial Fund.*

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**Abstract type:** Poster

### Integrating Palliative Care into a District Healthcare System in Rural Malawi

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**Aims:** In developing countries we see a medical and ethical imperative to integrate palliative care with efforts to prevent, diagnose, and treat chronic, life-threatening illnesses. We describe our initial experience with this integration in rural Malawi.

**Methods:** In January 2012 a nongovernmental health organization began a palliative care initiative in collaboration with the Malawi Ministry of Health at a rural district hospital. Palliative care was integrated with HIV services, diagnosis and treatment of prevalent cancers (Kaposi's sarcoma (KS), cervical), and hospital and outpatient care. Twelve healthcare providers received palliative care training, and a core team comprised of a physician, clinical officer and nurse provided inpatient, clinic and home-based palliative care. An existing network of community health and home-based care workers (CHWs) and a team of social workers offered psychosocial and economic support.

**Results:** The palliative care team followed 63 patients in its first 9 months. Common patient diagnoses were cancer (n=48, 76%), particularly KS (31, 49%) and cervical (7, 11%). Thirty-seven patients (59%) were HIV-positive and 31 (84%) received antiretroviral treatment within the district. Most referrals came from hospital wards (25, 40%), KS clinic (21, 33%), and for home-based patients (7, 11%). The team had 112 patient encounters: 57 (51%) at the clinic; 32 (29%) in the hospital; and 22 (20%) in the patient's home. Twenty-eight patients (44%) entered palliative care on pain medication, and at intake the team adjusted the pain management for 13 patients and started 10 additional patients on pain medication. Thirty-five patients (56%) reported a CHW, and social work referral was indicated for 36 patients (57%). Thirty-six patients (57%) had at least one follow up visit.

**Conclusion:** It is feasible, even in the poorest of settings, to integrate comprehensive palliative care with treatment of chronic disease and community-based support.

**Abstract number:** P1-333  
**Abstract type:** Poster

### Work Experience of Multidisciplinary Team in Rendering of Palliative Domiciliary Care

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Rendering of palliative domiciliary care is new to conditions of Kazakhstan where there are only 6 stationary hospices at the moment for 15,5 million inhabitants. Even without taking into account the features of mentality which are not allowing the majority of inhabitants to send the relatives in hospices and nursing units, it is not enough. Therefore mobile multidisciplinary teams are the optimal solution of this problem.

**Purpose:** To describe experience of multidisciplinary team on rendering of palliative domiciliary care.

**Materials and methods:** In 2011 in Temirtau the first multidisciplinary team in the republic was created, which consisted of the doctor, two nurses, the psychologist and the social worker. This team within half a year provided domiciliary help for people with AIDS.

In 2012 already within the medium-term project this team continued work, serving 20 patients with AIDS and malignant tumors in terminal stages.

**Results:** For operating time of the pilot project the palliative help was rendered to 10 patients being in a terminal phase

of AIDS, all patients noted improvement of the general condition, abort of a pain syndrome, psychological support and social help. Now the help is rendered to 10 patients with AIDS and 10 oncologic patients. The main achievement is complete abort of pain syndrome at one of patients with the 4th stage of oncologic pathology, who against the carried-out treatment could not only get up from his bed but also go to the native settlement. **Conclusion:** Considering features of mentality of citizens of Kazakhstan, rendering of the palliative help by multidisciplinary teams in the form of a hospice domiciliary is the most acceptable both in moral and in economic aspects.

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**Abstract type:** Poster

### A Decade of Prisoners Involvement into Hospice-palliative Care Volunteering in Poland

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Since 2002 in Poland the penal institutions and hospice-palliative care units have been cooperated in a project of voluntary work for the convicted. From 2002 to 2008 in Gdansk prisoners were allowed to work with the patients after the training. Since 2008 the project *Hospice voluntary work as a tool of acceptance and tolerance for people leaving penal institutions* has resulted in 15 care centers in Poland cooperating with penal institutions. In June 2009 Poland was awarded a prize from The Council of Europe for innovative forms of cooperation among prisons and hospice-palliative care units. In 2012 in Poland people serving a prison sentence have been working in 30 hospice-palliative care centers in Poland. After adequate training for hospice volunteers they assist patients as members of care teams.

**Aims:** An initial survey among the sentenced in Gdansk was conducted in 2012 and published in EJPC. Its main objective was to characterize the meaning of life among prisoners doing voluntary work for a hospice, and convicts not involved in volunteering. The comparative survey will be conducted in 2013 in other institutions having prisoners as hospice volunteers.

**Methods:** In the study the PIL (Purpose in Life) questionnaire by Crumbaugh and Maholic were used (Polish adaptation by Pluzek) to examine the understanding of the meaning of life of volunteers.

**Results:** From the results obtained from the pilot study it was found that most respondents have a high level of meaning of life. A qualitative analysis of the data suggests that experiences of hospice volunteering may affect the nature of understanding the meaning of life among the convicts. Pilot study results will be compared with data from other palliative care units.

**Conclusions:** Prisoners not involved in hospice volunteering are more focused on their current situation. Prisoners who volunteer have further time perspectives and use a wider variety of language to talk about life, suffering and themselves.

**Abstract number:** P1-335  
**Abstract type:** Poster

### Outcomes of a Model Regional the Outpatient in Palliative Care Program in Oncology Setting in Rio Grande do Norte, Brazil: The First One Year

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**Objective:** To report on beginning development of an program in palliative care in the outpatient in oncology setting in Rio Grande do Norte, Brazil.

**Methodology:** We are used a descriptive, observational, cross-sectional retrospective study. Data collection was conducted in North Riograndense League Against Cancer (LNRCC), reference institution for cancer treatment in Rio Grande do Norte, Brazil. For the research analyzed the medical records of patients treated in outpatient palliative care in the period between August 2010 and August 2011.

**Results:** During the period were 506 appointments scheduled and attended 182 patients, the mean number of outpatient visits was 2.61 visits per patient. The sample had an average age of 62 years, ranging between 21 and 92 years, and most patients were female (54.9%), unmarried (56%), literate (51.6%), having caregiver (82%). We found that most referrals were made for medical oncology (66%). The predominant reason for referral was the need for analgesia (76%). To assess patients access to the service we measured the average time between referral and first appointment which was 23 days. Since the time between

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diagnosis and death was 2.61 years. The primary site was the most frequent gastrointestinal (26%), which most patients had already metastasized at the time of forwarding (74%), and had undergone surgery, chemotherapy or radiotherapy. The majority (n = 60) of our patients had in-hospital death (33%) and 26 patients (14%) died at home and the minority of patients met diagnostic and prognostic (9%), with another 12 subjects (7%) who do not even know their diagnosis.

**Conclusion:** Our study allowed us to define the profile of patients treated in outpatient palliative care, recently deployed in LNRCC, and open discussion on the impact of this service on our patients contributing to a better structuring of care and planning future strategies coping with the problems that were revealed in research.

**Abstract number:** P1-336

**Abstract type:** Poster

### Individualised, Community-based, End-of-Life Care Reduces Hospital Use, but at what Cost?

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The aim of this study was to evaluate the cost and consequences of an individualised, home-based palliative care model [Palliative Care Extended Packages at Home [PEACH]] designed to expedite discharge and enable patients to remain at home. Incremental resource use, cost and outcomes relative to usual palliative care were assessed over 28 days follow up.

Mean costs and effects were calculated using patient-level data from the PEACH pilot, phase II, parallel, randomised controlled trial (RCT) (n=32), including: days in the community; place of death; costs of the PEACH intervention; specialist palliative care service utilisation; acute hospital and palliative care unit inpatient stays; and outpatient visits. Broadly, patients predominantly diagnosed with advanced cancer were eligible for the pilot RCT if they had complex or unstable symptom management and high care needs. Services were initiated sooner, and more nursing care was provided, in the PEACH versus usual care arm.

PEACH costs (\$3,500) were largely offset by lower inpatient costs (\$2,500) compared with usual care. Over the 28 day follow up PEACH participants had, on average, an extra day at home, but a greater, non-statistically significant, proportion died as an inpatient. The mean incremental cost/extra day in the community was \$1,068 with 95% CI ranging from PEACH costing less but being more effective than usual care to costing more but being less effective.

The findings suggest PEACH could reduce inpatient time and resource utilisation but may reduce the proportion of deaths occurring at home. While promising, high uncertainty around estimates points to the value of an adequately powered, phase III RCT using 1:1 randomisation stratified by recruitment site with longer follow up. Findings support the feasibility of conducting such comprehensive economic evaluations of end-of-life care models. Funding: Australian Government & Flinders University.

**Abstract number:** P1-337

**Abstract type:** Poster

### Integrating Children's Palliative Care into Rural Maharashtra, India

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**Aim of project:** In Maharashtra, certain very backward rural areas exist. In Jawhar Taluka population 1,31,346; 100% tribal Health Indicators poor- malnutrition, low weight, pregnancy before 18, Child Mortality Rate high, Morbidity indicators poor. To implement Palliative care in rural Maharashtra, such a site chosen.

**Concept of project:** Community Based Model integrating Palliative Care into existing public health care system. Existing Doctors, nurses, social workers and ASHA (health care workers) trained initially, 1 doctor and social worker appointed for Palliative care. Repeated visits to site by

mentors and other experts for regular identification and care of children; regular hands on training.

**Results:** Population based model, in place for 12 months. 78 children have been enrolled in the project; 35 with mental illnesses. Symptoms & QOL assessed, care provided at hospital and home, follow up ensured. ASHA (Health care workers) and community nurses form important liaison. Existing CBO's help to improve QOL for the identified families. Challenges include - illiteracy, poverty, unemployment, wide-spread use of traditional medicines, superstitions, cultural and religious beliefs, illiteracy and geographical terrain. Follow up is ongoing- documenting improved Quality of life of these children and their families; along with challenges faced and solutions arrived at.

**Recommendations and conclusions:** This project has helped pick up and care for many children with life limiting illnesses in rural areas. Can be replicated. Long term care for children with life limiting illnesses in remote villages requires-

- 1- Timely needs based assessment and management for every child & family
- 2- Integration into existing specialist services
- 3- Integration with community based organizations and NGO's in field
- 4- Research into the high incidence of certain conditions eg mental retardation- create effective steps for future
- 5- Improve QOL in the community overall, with above interventions.

**Abstract number:** P1-338

**Abstract type:** Poster

### Improving Domiciliary End of Life Care in the UK through the Development and Evaluation of a Specialised Programme for Domiciliary Care Agencies

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**Aims:** Within the UK, there is a drive to reduce the number of hospital deaths leading to an increase in end of life care in the community. However, there has not been a corresponding increase in the numbers of professional health care workers, so organisations such as domiciliary care agencies are bridging the gap and providing more complex care and support for very ill patients in their own homes. This is an emerging role for these organisations so they need development, education and support to provide quality end of life care.

**Methods:** The 'Six Steps to Success' programme was originally developed to enable nursing homes to implement a structured organisational change to enable the delivery of the best end of life care. This programme was adapted for use with domiciliary care agencies, involving a multi agency approach to developing the programme.

A pilot programme with six different organisations was pioneered, with the organisations participating both as learning organisations and evaluation partners. This presentation will provide the first reported evaluation of the pilot programme.

**Results:** The pilot programme was evaluated both pre and post programme using three tools: Quality Markers, After Death Analysis (ADA) and a Knowledge, Skills and Confidence audit. The results have established an increase in the quality of end of life care through a number of means, ranging from early identification of patients at the end of life through to improved communications with other agencies. Qualitative data has also been captured which demonstrates real life impacts and changes.

**Conclusion:** There is a need to ensure that the care provided by domiciliary agencies is able to support the increasing number of patients requiring end of life care in their own homes. Education alone is often not enough to make the changes required within an organisation and this programme can influence more extensive changes through a structured and systematic approach.

**Abstract number:** P1-339

**Abstract type:** Poster

### The Impact of Palliative Care in the Acute Assessment Areas

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**Aim:** To describe the impact of early review by the Hospital Specialist Palliative Care Team (HSPCT) for acutely admitted palliative patients.

**Background:** Over an 18 month period, the HSPCT at a large

University Hospital have attended the Medical Admissions Unit on a daily basis to pick up appropriate referrals to the service, in order to provide early symptom control and treatment advice, and to begin early discharge planning for potentially complex patients. They have attended post-take ward rounds and introduced targeted palliative care teaching sessions within the Acute Assessment Areas (AAA). An electronic flagging system to alert both the admitting team and the HPCT of a patient's palliative status has also been trialled.

**Methods:** A retrospective audit was performed, comparing a one month period of referrals from the AAA to referrals received from general wards within the Trust.

**Results:** Following implementation, on average 25% of all referrals came from the assessment wards, compared to a previous figure of 5%. Patients referred from general wards had a median length of hospital stay (LoS) of 13 days and on average patients were referred on day 5 of admission. Patients referred from AAA however, were all reviewed within 24 hours of admission, and had a LoS of just 4 days.

Fewer patients referred acutely died during the admission (31% vs 37%) and more were discharged home (54% vs 45%). Survival times varied little between the groups (8.8wks AAA vs 9.3wks). However, readmission rates were slightly higher for patients referred from AAA (48% vs 42%).

**Conclusions:** Overall, the service is felt to be of great benefit within the Trust, improving early access to services and advice for palliative patients, and improving clinical relationships. However, further work is required to fully explore the reasons for increased readmission rates in this group, and the overall impact of this for patients and the Trust.

**Abstract number:** P1-340

**Abstract type:** Poster

### A Baseline Audit Evaluating Use of Open Access Hospice Admission Policy: Identifying Potential Problems and Variation in Practice

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**Aims:** Open Access (OA) is an initiative to provide rapid 24/7 hospice admission for anticipated crises that cannot be adequately palliated in the community. Management plan and prescribing occur in advance, allowing immediate initiation by ward nurses. This baseline audit reviews the initial cohort of patients selected as suitable for OA.

**Design and methods:** Retrospective review of documentation to assess utilisation of the policy across three UK hospice sites, comparing practice to current local guidance. Data on circumstances of admissions, clinical indication, length of time patients remained on OA, and plan for review were extracted from notes.

**Results:** Fifteen patients were identified. Reason for use included end of life care, haemorrhage, and other symptom crises. Seven spent ten days or less on OA. Two spent more than 100 days. Review dates were documented for five. Eight patients had subsequent admissions but none followed the OA process completely compared to available local guidance. Variation in uptake and interpretation of the process was evident between hospice sites.

**Conclusions:** This policy has the potential to allow prompt and appropriate crisis management with minimal disruption to current out of hours working patterns. The variations in use and documentation have identified a need for greater clarity amongst staff on the aims and scope of OA. Updated local guidance and recommendations for standardised documentation have been produced. New standards for future audit in line with the NICE quality standards for end of life care have been developed. The process should continue to be monitored with regards to both its utility and resource requirement.

**Abstract number:** P1-341

**Abstract type:** Poster

### Presentation of Experiences Made by a Palliative Team in a Project Conducted in Order to Increase Competence by and Cooperation with the Regional Health Service (RHS)

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**Aims:** Palliative team at a local hospital wanted to intensify their outreach work towards the RHS in order to increase competence within palliation. The project was funded by the hospital.

**Methods:**

1. Ambulant service to patient's home, together with the RHS
2. Outpatients clinic consultations during which RHS

monitor the patient

3. Courses for RHS employees
4. Tutoring in small groups
5. Advising and counselling over the phone.
6. Participate in establishing cancer coordinator in the community.

Team resources: Palliative and oncologic nurses 240 %, physician 60%, physiotherapist 20%

**Results:** Conducted survey in which employees and directors at RHS were asked to evaluate the project according to its aims.

The evaluation showed the following results:

1. The competence within RHS was increased.
2. RHS shows more surety in their treatment of patients with cancer. Stronger focus on palliative patients.
  - Increased knowledge in RHS about pain and symptom management.
  - Medical treatment can be initiated immediately because of close cooperation between the community and the hospital.
3. More time at home for palliative patients
4. Fewer hospital admissions
5. Better cooperation between RHS and Specialist Health Service
6. 3 out of 4 city regions in our sector now have cancer coordinators.
  - 95% of the informants conclude that the treatment of palliative patients has improved during the project period.
  - 100% of the directors at RHS confirm that the competence among staff is somewhat or much better
  - 90% conclude that the cooperation between the local hospital and RHS has improved

The results of the survey will be presented on the poster.

**Conclusion:** The results of the survey show that the project has been highly successful for RHS and palliative patients in the sector. As a result of the efforts of the team the hospital's outreach work has been strengthened after the project period compared to before the period.

**Abstract number:** P1-342

**Abstract type:** Poster

### Results of a Delphi-analysis of Palliative Care in German Nursing Homes

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**Aims:** Based on the results of a series of differently designed model projects in North Rhine-Westphalia a framework programme of palliative care was developed with a remit of the Ministry of Health, Equalities, Care and Ageing (MGEPA) of NRW. The Delphi method was used to find a consensus among experts in all relevant areas.

**Methods:** A total of 129 experts and additionally a group of 30 caretakers were addressed by mail and e-mail. The questionnaire could be filled in by pencil or using the internet. The two rounds of the survey were sent out twice in February and March 2012. An interquartile range (IQR, measure of statistical dispersion) of 2 was introduced as consensus criterion. After the first Delphi round all theses with an IQR $\geq$ 3 were revised. In the second round these revised theses as well as the theses with an IQR=2 were again presented for consensus rating.

**Results:** In the first round of the Delphi process 88 participants answered the questionnaires. For all 21 theses an IQR $\geq$ 3 was found. After the second round (n=51) this was found for nine theses only, and out of these only three theses had an IQR >3. After the first round the mean agreement of all theses was 8.37 and after the second round the overall mean agreement of the revised theses was 8.43.

**Conclusion:** A high consensus and a high consent for the theses were found. However, differences between health and care insurance providers and the medical service for the health insurance funds (MDK, Medizinischer Dienst der Krankenkassen) on the one side and the other groups (project leaders, home leaders, scientists, caretakers) on the other side were explicit.

**Abstract number:** P1-343

**Abstract type:** Poster

### Conclusions of Monitoring and Evaluating Twelve Regional Projects, which Developed Different Models of Palliative Home Care, Funded by the German Cancer Aid (DKH)

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**Aims:** The objective was an improvement of the ambulant care of palliative patients in Germany. The DKH funded twelve regional projects featuring different models.

**Study design and methods:** The funded projects documented all patients using HOPE (Hospice and Palliative Care Evaluation), MIDOS (Minimal documentation system for palliative patients, German version of ESAS) and the Barthel index. Project duration ranged from 18 to 36 months until March 2012. In a final meeting the project managers presented each project in short form, the final statistical analysis of the program was shown and future demands were discussed and experiences exchanged.

**Results:** Data of 3.239 patients were analyzed. In total 85.6% of the patients had a tumour diagnosis, 51.4% were female, 1.9% were younger than 40 years, 21.9% were older than 80 years. The most important problems were weakness (70.7%), no appetite (52.3%), fatigue (52.2%), the need for help with the daily activities (64.8%), family problems (37.0%), pain (35.8%), organisational problems (28.9%), tension (27.1%) and anxiety (25.0%). 60.4% of patients had died. The place of dying was at home in 50.4%, care home in 10.2%, palliative care ward in 16.0%, hospital in 9.8% and inpatient-hospice in 8.9%. All projects implemented a network of close collaboration between primary care providers, social support, ambulant and inpatient specialized services. Almost all projects have contracts with the health insurance system by now. Shortcomings in reimbursement by the health insurance system were described. A necessity for a needs assessment before starting a new palliative care network is seen by all project leaders.

**Conclusion:** The results of the statistical evaluation of the twelve pilot projects show actual data of a high number of patients treated by structurally different palliative care services in different regions of Germany. For all projects the funding by The German Cancer Aid was of tremendous importance.

**Abstract number:** P1-344

**Abstract type:** Poster

### Patients' and Carers' Experiences with Out-of-Hours Palliative Care: Does Information Transfer from the GP to the Locum Make a Difference?

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**Introduction:** Out-of-hours service provision in the Netherlands is now delivered by GP co-operatives, as it is in the United Kingdom, Sweden and Denmark. To ensure good quality of care for palliative care patients, continuity of care is essential. In this study we explored whether patients' experiences were related to the absence or presence of information during out-of-hours care.

**Methods:** We held structured telephone interviews with palliative patients or their carers after all first out-of-hours contacts with the GP co-operative. A trained research assistant held, after given consent, a telephone interview. We compared cases in which information was transferred from the GP to the co-operative or not.

**Results:** We held 324 telephone interviews: 37 with the patients themselves, 190 with a family care giver and 97 with a professional care giver. The locum was significantly more often well informed if information was transferred. When asked if the problem had improved after the action of the locum, 86% said that it did improve. In the group where information was available this percentage was 95%, a significant difference. The locum addressed the reason for encounter also more often in this group, but this result is not significant. No significant difference between the groups was found when asked about the trust in out-of-hours primary care.

**Discussion:** Palliative patients or their carers find the locum more often well informed when information was transferred to the GP co-operative. They also state more often that there was improvement regarding the problem they called for. It is possible that a locum with information on the patient's situation is more able to handle a difficult situation. This confirms statements in literature that improved communication between in-hours and the out-of-hours service was crucial in decision making and symptom control.

**Abstract number:** P1-345

**Abstract type:** Poster

### Barriers and Facilitators to Implementing Quality Improvements in Palliative Care: An Integrative Review

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**Background:** Implementation of change is challenging, in health care settings in general and in palliative care (PC) settings specifically. In order to plan a successful quality improvement project, it is essential to have knowledge about what makes such projects fail or succeed.

**Aim:** The aim of this review was to identify factors that may act as barriers or facilitators for strategies to improve PC in cancer and dementia settings.

**Methods:** Systematic, electronic literature searches were done in the Medline, CINAHL, BNI, and PsycINFO databases. The searches revealed 2379 articles. 144 articles were retained after screening of abstracts according to a checklist. Exclusion criteria: no abstract available, no barriers or facilitators described, not directed at the organization of PC for patients with cancer or dementia, not directed at health care professionals, and pediatric setting. Full-text papers were independently examined by two researchers. Qualitative content analysis was used to identify barriers and facilitators.

**Results:** 87 articles were included. Barriers and facilitators were grouped into the following six categories: Innovation, individual professional, patient/family, social context, organizational context, and economic/political context. Barriers to implementing quality improvements in PC include: Time constraints, lack of knowledge in palliative care, lack of knowledge about quality improvement, and lack of technical support. Facilitators for successful implementation include: Motivated participants, sufficient resources, and leadership support.

**Conclusion:** It is important to anticipate potentially problematic issues when planning improvement projects. The factors reported here should therefore be considered when attempting to change organizations that provide PC. This review was conducted as part of the EU funded IMPACT project (Implementation of quality indicators in Palliative Care sTudy).

**Abstract number:** P1-346

**Abstract type:** Poster

### Dying at Home. But what is Home: A Space, or People? (Seeking an Answer in Two Model Projects of Dying at Home)

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In the Czech Republic, we don't live at home at the end of our lives: 80% people die in institutions. 20% people die at home, most of them suddenly. Palliative care teams care for only 2% of them at the end of their lives (400 people annually). According to an opinion poll (2011), 78% of the population and even 88% of health care professionals believe that the most acceptable place to die at is home. 70% of the population would like to have their close family near them at the end of their lives; 12% people appreciate friends. Only 5% of us would like to have health care professionals at our side at the end. In light of these figures, the situation seems to be rather absurd. Our organisation represents a model project responding to the wishes of the people and at the same time challenges the mainstream system.

The multidisciplinary team of the mobile hospice comes to the patients' homes with a specialized palliative care. The family members take care of them 24 hours a day. Home in this case does not need to be specifically reflected - it is naturally represented both by the space and the people who belong there.

Can home be moved elsewhere? Can we continue only with people, in another space? For people who can't care for their relatives 24 hours a day we have opened a home with hospice care. It is similar to a flat: 4 bedrooms, a living room and a kitchen. The family is replaced by the staff (social workers), and the family members care in keeping with their possibilities. We have been watching what patients and their beloved ones appreciate, what they enjoy, what they need. Relatives and patients consider this place to be safe, enter it like home, cook in the kitchen and sleep there at night. The place isn't very spacious and this fact helps them; more than 6 rooms would already be an institution.

It therefore seems that a home is moveable provided the space resembles a flat, is welcoming, offers intimacy and is inhabited by close persons.

**Abstract number:** P1-347  
**Abstract type:** Poster

## Palliative Care for Cancer Patients in the Emergency Department in Iran

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There is only one public hospital in Iran that provides palliative care services to the cancer patients, who are admitted in the Emergency Department(ED). Between 33%-46% of admissions in the ED are advanced or end-stage cancer patients. For this number of admissions there are only 10 ampules of morphine in the box for their daily needs. They normally stay in emergency for days for management of their symptoms (commonly pain and respiratory distress) or for terminal care.

- Barriers for delivering palliative care services in the ED:
- Traditional attitude among the ED staff that practice life-saving approaches for every patient regardless of their disease.
  - Ambiguous medical rules to protect the ED staff from legal action against them if they refuse to provide futile treatments to satisfy the patients' family with unrealistic expectations.
  - Lack of knowledge about palliative care philosophy regarding the better symptom management and terminal care.
  - Insufficient number of palliative care teams, community care services and hospices as compared to the number of patients who need them.
  - To see the mortality rate as a failure of the healthcare system even for advanced, incurable cancer patients. Some suggestions:
  - Look at the palliative care as a necessity in the national healthcare system that should be addressed urgently.
  - Integration of the basic concept of palliative medicine in educational curriculum of all medical fields and specialties particularly the emergency medicine.
  - Creation of community care services as a priority.
  - Allocation of an oncology unit in the ED for an organized attention to the needs of this group of patients.
  - Regular emergency department visit by palliative care team with the oncology specialists to help a better symptom control, decision-making and future planning.
  - Referring advanced cancer patients to the palliative medicine clinic after discharging them from the ED.

**Abstract number:** P1-348  
**Abstract type:** Poster

## Organising a Children's Palliative Care Program in a Developing Country

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- Aim:** To organise a Children's Palliative Care Program in a developing country.
- Background:** Children's Palliative Care is still not recognised in many countries. Though the need is enormous, there is no policy or strategic planning to provide the services.
- Methods:** The project has been started with National and International Collaborations and mentorship. The aim is to address needs of children with life limiting conditions i.e. HIV/ AIDS, Cancer, Thalassaemia, Neurological disorders and to improve the quality of life of the children and their caregivers. It becomes more essential where poverty, illiteracy, superstitious beliefs, gender differences and social stigma is prevalent in the society. The project is trying to bridge the gaps and overcome the challenges in implementing the Children's Palliative Care Program in three different models. The two sites have already been started, one being at the Paediatric HIV unit at the Urban Public Hospital and the other at a Primary Health Care set up in a remote tribal rural area.
- The important elements of the project are:
1. Advocacy for Children's Palliative Care by adoption of Paediatric Palliative Care Policy by the Government
  2. Education & Training: Awareness to Doctors, Nurses, Social Workers, Volunteers and NGO's in Knowledge, attitude and skill to deliver supportive care to children and to integrate Palliative Care into undergraduate and post graduate medical, nurses/social workers training curriculum
  3. Availability to pain relieving medication like Morphine
  4. Empowerment of children and families to improve their Quality of Life
- Conclusion:** Though there are many challenges in organising a Children's Palliative Care Centre in a developing country, sensitisation of Health Care Professionals and

Advocacy with the Policy makers make a difference in the scenario.

**Abstract number:** P1-349  
**Abstract type:** Poster

## Development of a Fatigue, Anxiety and Breathlessness (FAB) Clinic for Palliative Patients

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**Aims and background:** The development of a fatigue, anxiety and breathlessness clinic evolved from multi-disciplinary discussions around previous Occupational Therapy (OT) and Physiotherapy led clinics. There was recognition of the need for a more holistic approach to these three inter-related symptoms. The aims were to develop a multi-disciplinary (MDT) clinic (Doctor, Specialist Palliative Care Nurse, OT and Physiotherapy), to help people with palliative care needs cope with their symptoms and enjoy a better quality of life. Spouses/carers were invited to participate within the clinic to gain peer support, information and advice.

**Method:** We developed a clinic consisting of weekly 2 hour sessions over a 4 week rolling programme. Suitability criteria for clinic attendance were agreed. Following an initial introduction and assessment, we focus on a different symptom each week within a small, intimate group of four patients plus carers. Weekly symptom diaries and post clinic assessments are also completed. The clinic is reviewed and modified by the MDT on a regular basis.

**Results:** More than 300 patients have been referred over 6 years, with both cancer and non-cancer diagnoses. Qualitative feedback from patients and carers shows evidence of benefit through the holistic approach, access to peer and emotional support, and earlier introduction to the hospice. Quantitative data, collected through validated assessment tools, shows improvement in all 3 symptoms and a positive impact on quality of life for many patients.

**Conclusion:** Attendance at a multi-disciplinary, small group clinic can empower patients and carers to positively manage symptoms of fatigue, anxiety and breathlessness. The FAB Clinic is receiving increasing numbers of referrals for non-cancer patients and is now considered a beacon service within the hospice and locality.

## Policy

**Abstract number:** P1-350  
**Abstract type:** Poster

## Is it Enough or Not Enough Staff Power of Medical Rehabilitation Professionals in Palliative Care Team at Cancer Institute in Japan?

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**Objective:** To investigate staffing about medical rehabilitation professionals including occupational therapist, physiotherapist and speech therapist in palliative care team (PCT) in Japanese regional cancer institute.

**Study design and methods:** To collect data about staffing of medical rehabilitation staffs in PCT each institutes connected by internet on the end of April 2012. Then analysed collecting data statistically.

**Results:** Three hundred ninety-three regional cancer institute were found out by the survey. The size of institute was

1. Under five hundred beds: 208 (52.9%),
2. Over five hundred to one thousand beds: 164 (41.7%),
3. Over one thousand beds: 21 (5.34%).

Number of doctors: 308 (100% of all), Nurses: 392 (99.8%), Pharmacists: 378 (98.5%), Medical social workers: 316 (80.4%), Medical rehabilitation professionals: 231 (58.8%), Clinical psychologists: 214 (54.5%), and Nutritionists (Dietitians): 260 (66.2%).

**Conclusion:** This is a first national wide survey about staffing of medical rehabilitation professionals in PCT in regional cancer institute in Japan. The numbers of medical rehabilitation staffs (231) are almost equal who are staffing in hospice/palliative care unit in Japan (249) by the other survey that has been already reported at 6<sup>th</sup> Research Congress of EAPC in 2010. Although it showed higher than a ratio of medical rehabilitation staffs in PCT to the survey of 2010's (59%/5.6%), only this study told collecting number of staffing in PCT at this time. There were no contents, no quality and no satisfaction of the patient or their family. This is a limitation of this study. We could say not enough staffing in PCT at cancer institute in Japan because of shorter ratio of doctors, nurses and pharmacists. We should need another

survey to say more about quality of medical rehabilitation staffs in PCT in Japan.

**Abstract number:** P1-351  
**Abstract type:** Poster

## Fitting in. What Is the Priority? International Standards or Local Needs?

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Current trends-including palliative care programs- go towards globalization, led by external peer review, international and national directives to determine international standards and norms. A conflict might ensue for policy makers when these contradict the demands of local populations who offer support with effort, time and resources.

**Aims:** To raise awareness to the fact that International standards might be only reliable when they set minimum norms but not so good for maximums in certain areas. To evaluate process, sustainability and impact of programs for niche population in terms of intended and achieved outcomes and perceived quality of care for those unwilling to leave their beloved island to be cared for, to die or -even worse- to accompany a loved one in their last journey beyond the water.

**Method:** Straightforward application of WHO, IAHPAC EAPC recommendations to this island's population and comparison of the figures to real data in the setting; then proceed to analyze why our community needs and complexity seem to escape the sensitivity and specificity of agreed standards challenging them with local evidence.

**Results:** The contexts in which international standards and recommendations are applied are variable. The main bodies offer guidelines to incorporate palliative care services in different settings. None of the recommendations analyzed took into consideration the possibility of establishing maximums. Such lack of extremes inclusions make them impractical to inform strategic planning of advanced societies experienced in the provision of palliative care.

**Conclusions:** Individualized care should be applied to programs and units wanting to offer compassion and care to its population even when it doesn't seem to conform to international standards and norms. Trying to comply with widely accepted standards might keep these organizations from helping their populations achieve their wishes unless a modified versions incorporating their needs are used.

**Abstract number:** P1-352  
**Abstract type:** Poster

## Opinions of University Hospital Health Care Professionals on Existing Palliative Care Practices; Single Centre Survey May Serve as a Model for Palliative Care Consultation Team Start ups

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**Background:** In the Netherlands, the acknowledgement of palliative care as specialized care is a relatively new phenomenon. In November 2011, at Leiden University Medical Centre (LUMC), a fully equipped palliative care consultation team (PCT) was started to improve care. Until then, palliative care was provided on an ad hoc basis, without proper education, knowledge or specialized protocols. To obtain baseline information on existing practices, shortcomings and needs, an internet survey was sent to all LUMC health care professionals.

**Methods:** 400 medical doctors and 1200 nurses received a survey containing 30 questions on prevalence of palliative patients, symptoms, discharge, euthanasia, palliative sedation, use of guidelines, and experienced problems and deficits.

**Results:** 19% responded, representing 75% of all LUMC departments. Prevalence of palliative patients seen by the respondents was low, only 44% considered > 10% of their total in a palliative phase. 80% were cancer patients. Nurses observed more symptoms compared to doctors (median 6 and 4, resp). Deficits were: low level of education, problems regarding timing and communication of transitions from active treatment to symptom control, and absence of integrated care. Only 56% of respondents was aware of the availability of the PCT's special experience.

**Conclusions:** Doctors and nurses in this university hospital do not always recognize that patients are in a palliative phase. This may result in underconsumption of PCT consultations. In the LUMC, growing awareness of palliative care may be enhanced by

- 1) regular education on symptom management and



decision making,

2) tailor made projects for specific departments, and  
3) organizational embedding of the PCCT hospital-wide.  
Survey outcome in this particular hospital of existing practices at baseline regarding palliative care thus appoints specific goals for palliative awareness and care developments. Such an approach may also be helpful for other PCCT start-ups.

**Abstract number:** P1-353

**Abstract type:** Poster

### State Policy on Quality Pain Management and Legislative Changes in Georgia

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**Background:** Quality of pain management highly depends on access to opioids and existence of relevant legislation regulating the rules of prescribing and administration of these medications. Assessment of the National Policy on Opioids, basing on WHO document "Achieving Balance In National Opioids Control Policy" performed by the state authorities in close cooperation with Palliative Care team, have resulted in legislative changes, focusing on all angles of WHO triangle for adequate pain management: Policy, Drug Availability and Education.

**Goals:** Introduction of the State Policy on Quality Pain Management and legislative changes undertaken in Georgia since 2006. The "Law on Regulation of Legal Use of Narcotics" (2007) - commitment undertaken by the State for provision of patients with necessity of opioids both in terms of the quantity and forms; Paragraph concerning inevitability of opioid usage for medical reasons was added to the Chapter, reflecting the main principles and regulation field (2012). The language was refined and confusing terminology and definitions were removed (2012):

- Introduced new definition of dependence "physical dependence"- as sole criteria for dependence diagnose is removed.
- Stigmatizing term "somatocarcinoma" (patient with physical dependence) is removed;
- State Health Program from 2011 provides opioids for noncancerous patients, alongside with cancer patients.

Increasing of opioid supply from 3 to 7 days (2008); Instead of the commission for prescribing the opioids, prescription became one authorized physicians responsibility; Adoption of a new prescription form (2010) - two different kinds or formulations can be prescribed; Authorization on prescription of opioids was passed to PCP-s.

**Results:** Quality pain management became priority of State policy; new legislations ensure balance for medical usage of opioids and preventive measures for diversion; Different formulations and dosage of opioids became available in Georgia since 2008.

**Abstract number:** P1-354

**Abstract type:** Poster

### MRSA in Palliative Care: Should We Be Routinely Screening for it?

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**Aims:** The aims here were threefold.

1. To determine if all patients were being screened as per the specialist palliative care unit's (SPCU) protocol.
2. To determine the success rate of MRSA eradication in the SPCU.
3. To determine the impact of MRSA on length of stay, morbidity and mortality.

**Methods:** In this prospective study, data was collected for all admissions to a 36-bed SPCU over an eighteen month period. MRSA screening data was collected using a proforma developed for this study. All patients were screened for MRSA on admission and one week after admission in accordance with the SPCU's MRSA protocol. MRSA positive patients were managed using the SPCU's MRSA eradication protocol. Mortality, morbidity and length of stay data were also recorded.

**Results:** Admission MRSA screening results were available for 580 admissions (95%). For the 29 patients not screened, 19 were either dying or discharged within 24hrs, and in the remaining 10 the reason was unclear or the sample was lost. A second screen was sent in 294 admissions and a further 11

screens were sent during admission for clinical reasons. For the 74 patients found to be MRSA positive, only 6 (8.1%) successfully completed the eradication protocol, while 46 patients (62.2%) died before its completion. In the remaining MRSA positive patients: 12 were discharged before completing the protocol (16.2%); 7 remained MRSA positive (9.5%); and in the remaining 3 patients the reason for non-completion is unclear (4.1%). There was no significant survival difference in the MRSA positive group, while MRSA positive patients had a significantly longer length of stay (33.7 versus 21.5 days,  $p < 0.01$ ) and more infection episodes ( $p < 0.01$ ).

**Conclusion:** MRSA is prevalent in the SPCU but MRSA eradication success was low. MRSA did not affect survival but was associated with increased length of stay and infection episodes. In light of this, identifying high risk groups may help guide policy development.

**Abstract number:** P1-355

**Abstract type:** Poster

### Revisiting the Definition of Palliative Care: Defining what Palliative Care Is about Rather than Specifying an Agenda for its Implementation

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Palliative Care is a young profession with ancient roots. In its struggle for acknowledgment in modern civilization it is still in the process of establishing a distinct and well defined identity. Formulation of its definition is an important component of this process with far reaching implications for the consolidation of its core features, integration into the health care system and exposition of its role in society. Contemporary approaches to the definition of Palliative Care, exemplified in the formula adopted by the World Health Organization, confound the effort to describe its essence with attempts to specify various aspects of its implementation. Thus, alongside the prevention and relief of suffering, the definition states core policies such as the requirement for a team approach, early intervention, etc. Although such policies may be necessary for the implementation of palliative care, they shed no light on the nature of palliative care, and could apply to many other professions.

The proposed approach considers the distinction between the subject matter of Palliative, and the ever changing agenda for its implementation. It focuses on the definition of a field of activity intent on the fulfillment of the primordial, universal urge to alleviate witnessed suffering originating from medical disorders and their repercussions. The definition in such terms is not exclusive, and accounts for the overlap with neighboring professions that occurs in reality. The agenda for implementing palliative care would be recognized as such rather than mingling into the definition itself.

The reformulation of the definition of Palliative Care is intended to have practical implications. These include enhancing the unique quality of this field of activity in a way that counters claims regarding its redundancy, and the stabilization of its definition by associating it with distinct and constant elements that diminish the weight of policies contingent on transient expert opinion.

**Abstract number:** P1-356

**Abstract type:** Poster

### Setting Policy for Palliative Care Provision at Sub National Level

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In 2009, the Mexican Federal Health Law was amended in order to include Palliative Care (PC) as part of the national services of public health. Because at sub-national level public health services are mainly in hands of each Federal States, some of them have initiated provision of PC without a national framework. Since Veracruz is one of the most populated and largest State in the country, facing growing prevalence both chronic-degenerative and oncological diseases, it has set up a specific strategy to develop a public framework to provide PC. The strategy was formulated by an existing public organization devoted to assistance, support and care for families in social risk.

The strategy was aimed to deliver general information about PC, bearing in mind the dispersion of localities and indigenous population. The social importance of PC was

explained to other institutional bodies and to the Congress. The defined strategy involves health authorities, public universities and some social sector organizations as providers of PC services. Human resources development was considered as a key stone to PC provision. Therefore, a proper training program was implemented.

The aim of this paper is to present the setting policy for PC at sub-national level and the content and stages to develop required PC teams, according to a new official integral model of public health.

**Abstract number:** P1-357

**Abstract type:** Poster

### How Much Does it Cost to Deliver Palliative Care? Preliminary Results of a Pilot Study of Advanced Cancer Patients in Colombia

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**Objective:** The aim of this study is to determine the cost of palliative care provision to patients with advanced cancer in Colombia.

**Method:** A costing model was developed using the cost of medications, medical supplies and medical, nursing, and therapy services per patient based on the cost of health care provision in Colombia as established by the National Mandatory Health Care Plan. The study was approved by the ethics committee at the Universidad de la Sabana in Bogota. A retrospective pilot study to test the costing model was conducted with patients with stage IV gastric cancer admitted to a home care program and died during 2011. Palliative care was identified as services provided to control the most common symptoms in gastric cancer as reported in the literature: nausea, constipation, pain, insomnia, anorexia, and mucositis. Data from the billing and finance department was collected and populated into the cost model. The cost of care was calculated on a daily basis for each case.

**Results:** Seven medical records of patients were randomly selected. The average cost of palliative care in case of control more than 90% of symptoms was US\$90/day per patient. In case of uncontrolled symptoms (10% or less) was US\$898/day. The costliest and least expensive symptoms were persistent pain and controlled mucositis (\$468/day and \$2.5/day respectively).

**Conclusion:** This is the first project developed with the purpose to estimate the cost of palliative care in Colombia. Preliminary data suggest that in spite of the increase need in medicines and care hours, palliative care is cost efficient and that the opposite of not providing symptom control results not only in suffering but adds to the cost of care. Additional studies are needed to measure the cost effectiveness and cost efficiency of other interventions.

**Acknowledgement:** Funding for this study was provided by the Open Society Foundations.

**Abstract number:** P1-358

**Abstract type:** Poster

### National Strategy for Palliative Care in the Republic of Serbia: Where Are We and what Have We Learnt Three Years on?

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**Aims:** A national palliative care (pc) strategy was passed by the government of the Republic of Serbia in 2009 & set out a comprehensive policy to develop pc in Serbia. Prior to this, pc in Serbia was limited. 3 years on, we review how far we have got & what we have learnt.

**Methods:** Work to implement the strategy has been supported by the EU. Following a review, this paper highlights progress in implementation along with lessons learnt. Key areas reviewed include standards & models of care, public & professional education (undergraduate & continuing education), formation of pc teams/units within the health system, legislative provisions & drug accessibility, research & M&E

**Results:** Implementation of the national strategy is ongoing with varying amounts of success including: implementation & development of an accredited multi-disciplinary training programme with over 1000 professionals having been trained to date; PC accepted into the curriculum of the medical schools & in process of being approved by higher nursing schools; 2 hospitals have opened PC units with more under development; legislative changes made to government to increase access to PC including essential

medicines; clinical guidelines drafted & under review; work has begun on translating & culturally adapting an outcome scale for Serbia.

**Conclusion:** Implementing such a strategy on a national scale, takes time, resources & commitment & cannot work without collaboration with partners & the government. The implementation of the National Strategy is moving in the right direction, albeit slowly. PC is further developed in Serbia than in 2009.

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**Abstract number:** P1-359

**Abstract type:** Poster

### Costs in Context: Factors Associated with Health Resource Use at in the Last Year of Life

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**Background:** Understanding health care spending at the end of life helps to plan services and use funds efficiently.

**Aim:** To identify factors associated with individual health care costs in the last year of life (LYoL), in different care settings.

**Methods:** Systematic literature review to elicit health care cost drivers in the LYoL of adults, using a highly sensitive search strategy in EMBASE and Medline (until 8/2012).

**Inclusion criteria:**

- 1) Populations with life-limiting or advanced progressive illness and
- 2) Costs as dependent variable. Results were limited to studies containing original data from multivariate analyses.

Only data applying to the LYoL were extracted from studies covering longer periods. Assessment of the strength of evidence was based on the quality of contributing studies (modified Edwards score<sup>1</sup>), and the number and level of agreement between different studies assessing each cost driver.

**Results:** 21 studies were included. Factors identified were associated with overall or specific types of health care costs: Old age: reduced overall, but higher home care, nursing home and hospice costs

Non-white ethnicity: lower overall, but increased hospital costs

Low socio-economic status: lower hospital, but higher home care, nursing home and hospice costs

Living alone or in urban setting: higher overall costs

Poor functional status, proximity to death, co-morbidities: higher costs across settings

Palliative care: lower costs across settings, particularly in hospital

**Discussion:** Patient-level variables are powerful predictors of individual resource use in the LYoL. There is a dynamic relationship between resource use in different care settings, so all must be considered when measuring economic impact. Although outcomes of care were not included in our review, inequalities in resource allocation should be considered when commissioning end of life services.

<sup>1</sup>Edwards, J Eval Clin Pract, May 2000

**Funding:** Palliative Care Funding Review, Department of Health.

**Abstract number:** P1-360

**Abstract type:** Poster

### Development of an Irish National Guideline on the Management of Constipation in Palliative Care Patients: The Challenges

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**Introduction:** Constipation is a common symptom experienced by palliative care patients. Its impact on quality of life is often underestimated by healthcare professionals.

**Aim:** Create a high quality evidence based guideline on the management of constipation in palliative care.

**Methods:** The guideline was developed using the ADAPTE

protocol, an internationally validated guideline adaptation process designed to foster high-quality guidelines for use in specific regions. This was undertaken by a guideline development group.

**Results:** Following a comprehensive literature review, eleven potentially relevant publications were identified. Five documents were reviewed in detail, having fulfilled the ADAPTE developmental rigor criteria. The process was reviewed by an international external advisory committee of experts in the field. Two documents were selected to form the main foundation of the guideline.

Consensus Recommendations for the Management of Constipation in Patients with Advanced Progressive Illness. The Canadian Consensus Development Group for Constipation in Patients with Advanced Progressive Illness.

The Management of Constipation in Palliative Care: Clinical Practice Recommendations. The European Consensus Group on Constipation in Palliative Care

Challenges were encountered in the process. A poor evidence base meant that expert recommendations informed many of the identified documents. Advisory committee members had contributed to two documents creating a potential conflict of interest.

**Conclusions:** The burden of constipation in palliative care patients is well recognised but often overlooked. The development of a clear practical guideline will assist the management of constipation in this population. Our guideline development process demonstrated that this is not without difficulty. It also highlighted the need for further high quality research.

**Abstract number:** P1-361

**Abstract type:** Poster

### The International Narcotics Regime and Barriers to Access to Essential Medicines

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Fifty years after the formal establishment of the global narcotics control regime, 80% of the world's population has little or no access to medicinal opioids for the relief of pain and suffering, and global problems related to addiction to narcotic drugs remain unsolved. Yet, the regime commands almost universal adherence and billions of dollars in annual funding from the US and other UN member states. UN agencies as well as global NGOs have produced reports detailing barriers to medical opioid access in low and middle income countries and how these might be overcome. This article identifies the significant barriers within the regime itself and locates the source of the misalignment in the "dual obligations" imposed on the Parties by the Conventions.

**Abstract number:** P1-362

**Abstract type:** Poster

### NICE Opioids - A Summary of Guideline CG140

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**Aims:** Misinterpretations and misunderstanding have surrounded the use of strong opioids for decades, which has resulted in errors causing under-dosing and avoidable pain, or overdosing and distressing adverse effects. The UK's National Institute for Health and Clinical Excellence (NICE) developed Guideline CG140, to offer a consistent approach for the initiation of strong opioids in palliative care.

**Methods:** Systematic reviews were conducted to consider the best available clinical and economic evidence. Where minimal evidence was available, the Guideline Development Group's experience and opinion of what constitutes good practice was summarised. A de novo cost-effectiveness analysis was also conducted.

**Results:** The NICE guideline was issued in May 2012. (1,2,3) A number of key areas were addressed: communication, starting strong opioids, management of breakthrough pain and of side effects.

**Conclusion:** NICE is a provider of national guidance on the promotion of good health and NHS organizations aim to comply with guidance as part of clinical governance policy. This guideline takes effect at the point in time when a palliative care patient has moderate to severe pain, which

necessitates commencing strong opioid analgesia. For this abstract, a member of the NICE guideline development group will summarize CG140's recommendations and discuss areas that are of particular importance to palliative care providers and draw parallels to the recent EAPC Guidelines on Opioids in Palliative Care.

Ref:

- (1) Bennett Ml et al. Prescribing Strong Opioids in Palliative Care: summary of NICE guidance BMJ 2012; 344 doi: http://dx.doi.org/10.1136/bmj.e2806
- (2) National Institute for Health and Clinical Excellence Opioids in palliative care CG140 http://www.nice.org.uk/CG140
- (3) Taubert M et al. Opioids in palliative care: Is the new NICE Guideline relevant to specialist palliative care providers? BMJ Support Palliat Care 2012;22:209-212 doi:10.1136/bmjspcare-2012-00013

**Abstract number:** P1-363

**Abstract type:** Poster

### Hospice and Palliative Care in Tyrol, Austria: Development of General and Specialised Palliative Care in the Health Care Systems of Two Model Regions

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**Aim:** In Austria's province Tyrol a three year research project was undertaken with following objectives: To develop a regional specific concept for integrated palliative care; to generate knowledge and foster communication among local actors and stakeholders; to integrate palliative care into the health-care systems; to supervise the integration-processes and consult local health care policy.

**Method:** The multi-level action research project was laid out in three phases: needs assessment, planning of measures and implementing measures. Attention was given to three types of intervention: development of palliative culture in primary care organisations; development and acceptance of specialist palliative care structures; integration and governance of hospice and palliative care plan in Tyrol. Participation was encouraged through collective data collection, needs assessment and evaluation.

**Results:** The action research project offered possibilities to further develop organisational palliative culture processes within different care settings. The participating actors developed plans for necessary measures and steps to further implementation of palliative care in the model regions. On policy and management level a steering committee was established, that brought together all representatives of the commissioning agency. At all levels common goals and interests were discussed, strategic decisions and conceptual suggestions were debated.

**Conclusion:** The project process has enabled the local stakeholders to develop a perspective of an adequate regional palliative care culture. It served to develop sustainable participation, networking processes and establish structures of specialised palliative care services and units. To foster the acceptance of the new palliative care structures in the inpatient area as well as in the home care setting was a major challenge. Finally almost all planned measures could be implemented. This project was funded by the Tyrolean Health Fund.

## Psychology & communication

**Abstract number:** P1-364

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P1-365

**Abstract type:** Poster

### End-of-Life Decisions: A Cross-national Study of Treatment Preference Discussions and Surrogate Decision-maker Appointments

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**Aim:** Making decisions in anticipation of possible future incapacity is part of patient participation in end-of-life decision-making. This study estimates and compares the prevalence of GP-patient end-of-life treatment preference discussions and appointments of surrogate decision-makers in Italy, Spain, Belgium and the Netherlands and examines associated patient and care characteristics.  
**Methods:** A cross-sectional, retrospective survey was conducted with representative GP networks in four countries. GPs recorded the health and care characteristics in the last three months of life, including the discussion of treatment preferences and appointment of surrogate decision-makers, for all patients who died using a standardised questionnaire. Prevalences were estimated and logistic regressions were used to examine between country differences and country-specific associated factors.  
**Results:** 4,396 non-sudden deaths were included. GP-patient discussion of treatment preferences occurred for 10%, 7%, 25% and 47% of Italian, Spanish, Belgian and Dutch patients respectively. Furthermore, 6%, 5%, 16% and 29% of Italian, Spanish, Belgian and Dutch patients had a surrogate decision-maker. Despite some cross-country variation, previous diagnosis discussions, more frequent GP contact, GP provision of palliative care, identification of palliative care as an important treatment aim and place of death were generally positively associated with preference discussions or surrogate appointments. Dementia was negatively associated with preference discussions and surrogate appointments in all countries.  
**Conclusion:** The study revealed a higher prevalence of treatment preference discussions and surrogate appointments in Belgium and the Netherlands. The findings suggest that delaying diagnosis discussions impedes anticipatory planning, whereas early preference discussions, particularly for dementia patients, and the provision of palliative care encourage participation.

**Abstract number:** P1-366  
**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P1-367  
**Abstract type:** Poster

**Decision Control Preferences, Disclosure of Information Preferences and Satisfaction among Hispanic Cancer Patients**

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**Aim:** There is dearth of information about the decisional control preferences (DCP) of Hispanic patients with advanced cancer. We analyzed unreported data of a previously reported study, in this study we aim to describe patient's DCP, disclosure of diagnostic and prognostic information preferences, and satisfaction with decision making among Hispanics from Latin America and the United States. The secondary objectives were to determine the concordance between patients' decision control preferences and their self-reported actual decision making experience related to their cancer care, and disclosure of diagnostic and prognostic information preferences.  
**Design:** We surveyed 387 cancer patients referred to outpatient palliative care clinics in Argentina, Chile, Guatemala, and United States. DCP were measured with the Control Preference Scale. Disclosure preferences were measured with the Disclosure of Information Preferences Questionnaire. Satisfaction with care was measured with the Satisfaction with the Decisions and Care Questionnaire.  
**Results:** Hispanic cancer patients' DCP were 119 (31.2%) active, 182 (47.6%) shared and 81 (21.2%) passive. 345 (92%) of the patients wanted to know their diagnosis and 355 (94%) wanted to know about prognosis. 337 (87%) of the patients were satisfied with the way the decisions were made. Higher educational level was associated with more active decision control preferences (p<0.001). There was concordance between decision control preferences and the actual decision process in 264 (69%) of the patients (Weighted Kappa 0.55). Satisfaction with the way the

decisions were made was associated with older age (p<0.001) and preference for enhanced diagnostic disclosure (p<0.024).  
**Conclusions:** Hispanics in this study did not adhere to a traditional paternalistic decision making model. Patients with older age and those that want to know their diagnosis seem to be more satisfied with the way the decisions were made.

**Abstract number:** P1-368  
**Abstract type:** Poster

**Implementation of New Models for Psychosocial Care. Effectiveness of the Programme for Comprehensive Care of Patients with Advanced Illnesses in Spain**

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**Introduction:** The programme for comprehensive care of patients with advanced illnesses starts in 2008, as an initiative and funding support of "La Caixa" Foundation, with the aim of adding quality and put in value the task of palliative care teams towards individuals (and their families) in end-of-life situation. The program has implemented 29 Psychosocial Care Teams (PSCTs), distributed among Spain, with a minimum of one team per region, and with 120 professionals, mainly psychologists and social workers.  
**Aims:** To create specific psychosocial teams that become referent in their area, adaptable to different situations and environments, with clear orientation towards early intervention, based on the complexity of the psychosocial aspects of patients and their families. The main areas of the program include emotional, social and spiritual support, bereavement and support to teams to prevent burnout.  
**Methods:** The design and implementation of the program was done in 2008. The PSCTs started their task in June 2009. They received specific training meant to achieve a unified work method to generate evidence through systematic analysis of results. A unique registration system was also created so that their interventions could be assessed in terms of effectiveness.  
**Results:** The PSCTs have attended a total of 38.354 patients and 58.344 relatives. During 2012, 109.566 direct visits were undergone. 91.160 out of those were performed at the hospital and 18.406 at the patient's home. As for bereavement, 11.061 individual visits and 688 groups visits were carried out. The study on effectiveness of the program shows a significant improvement in the following variables: emotional unease (anxiety, depression, insomnia) and the variables of spirituality (life significance, peace/forgiveness).  
**Conclusions:** The program for comprehensive care of patients with advanced illnesses has consolidated innovative, specific psychosocial care teams, which have performed effective interventions.

**Abstract number:** P1-369  
**Abstract type:** Poster

**Is Always Palliative Oncology Treatment Permeated with Psychiatric Symptoms?**

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**Objective:** To evaluate the levels of hope, anxiety and depression in palliative cancer patients comparing palliative treatment initiation and evolution over the period of a month.  
**Materials and methods:** We conducted a prospective cohort study, evaluating 40 adult patients of both genders with a diagnosis of advanced neoplasia no possibility of cure, which were assessed at the first time Palliative Care Unit - Barretos Cancer Hospital (BCH). We used the Socio-Demographic Questionnaire, Beck Hopelessness Scale (BHS), Quality of Life Inventory (EORTC QLQ-C30), the Hospital Anxiety and Depression Scale (HADS) and the Inventory of Coping Strategies, which were applied individually before the first appointment and in the next back with doctor (30 days). The scales were compared to the first and second time by the nonparametric Wilcoxon test, p = 0.05.  
**Results and discussion:** Of the 40 interviewed patients, 65% were women. At first collection, anxiety (mean=5.60, ±3.33), depression (mean = 4.73, ±2.78) or hopelessness (mean=3.75±2.76) average rates were lower than the normative average. In the second assessment of these indicators we found then slightly increased: anxiety (mean = 6.10±3.99), depression (mean=5.35 ±3.16) or hopelessness (mean=3, 80 ±2.89). No differences were found between the first and second moment of anxiety scale: (p=0.600), depression scale: (p=0.271) and hopelessness scale: (p=0.897).  
**Conclusion:** The data presented do not meet the related

literature which indicates a higher prevalence of psychiatric disorders in cancer patients, particularly palliative. It is believed that a possible explanation for these findings is associated with the physical structure of BCH humanized and interdisciplinary team work in patient care and following, since their inclusion to palliative care. This context may have enabled patients to develop more adaptive coping strategies to the process of illness and death, protecting them from the onset of diseases of psychic order.

**Abstract number:** P1-370  
**Abstract type:** Poster

**Oncology Patients in Palliative Care: Coping Strategies, Anxiety and Depression**

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**Objective:** To assess the coping strategies used by cancer patients in palliative care and the correlations with indicators of anxiety and depression.  
**Materials and methods:** We conducted a prospective cohort study, evaluating 40 adult patients of both sexes diagnosed with advanced malignancy cancer, which were for outpatient visit for the first time in the Palliative Care Unit - Barretos Cancer Hospital (BCH). We used a Socio-Demographic Questionnaire, the Hospital Anxiety and Depression Scale (HADS) and the Coping Strategies Inventory which were applied individually before the first query and return the first doctor (30 days). To evaluate the correlation between the scales used the Pearson correlation coefficient, the data were tabulated with significance level 0.05.  
**Results and discussion:** There was an inverse and moderate correlation between Positive Assessment Strategies (r = -0.40, p = 0.01) and Problem Solving (r = -0.31; p = 0.05) and depression indicators. However, with anxiety indicators no statistically significant correlation was observed. When assessing the correlations between the different strategies, we found number of significant correlations (N=14), with magnitude ranging between 0.33 and 0.68, which indicates the use of a defensive arsenal, not just specific strategies. We highlight the correlation between social support strategies with Positive Assessment Strategies (r = 0.68, p = 0.001) and Problem Solving (r = 0.50, p = 0.001). So also the Removal Strategy correlated with Acceptance of Responsibility (r = 0.53, p = 0.001).  
**Conclusion:** A positive assessment and the active search for solution of the problems experienced during the situation of illness appear to act as protective factor for no depressive symptoms. Moreover the use of several coping strategies together can ensure a more psychic functioning adjusted to the patient with emphasis on the important role of social support in this process, which seems to contribute to better cope with the disease.

**Abstract number:** P1-371  
**Abstract type:** Poster

**Gender Influence on Coping Strategies in Pediatric Palliative Care Team Members - A Pilot Study**

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**Introduction:** After the death of a child parents nowadays often receive gender specific offers for dealing with their grief. This is based on the insight that grief has gender specific issues. Conversely there are no gender specific offers for members of pediatric palliative care teams (ppct). Especially in context of a more and more financially limited health care system with an increasing number of employees suffering from psychiatric diseases like depression or burn-out-syndrome, a purposeful use of resources should be undertaken in order to prevent these conditions. We conducted a standardized survey among members of ppct, in order to analyze gender specific differences in coping strategies.  
**Materials and methods:** For investigation of coping mechanisms in members of ppct a questionnaire was developed on the basis of Swetz et al. 2009. Further a screening instrument for anxiety and depression (PHQ4) was used, as well as a validated health utility index and an instrument for measuring optimism/ pessimism. The link was sent via email to german ppct. In total 50 questionnaires were completed, 43 by women, 7 by men. The survey involved different specialties like nurses, physicians, social workers, psychologists and pastoral caregivers.

Poster sessions  
— set 1

**Results:** There were no differences between men and women in age and work experience. Both displayed a comparable distribution regarding leisure time activities involving other people or alone. However, there were differences in the total time for talking about stressing events, in the importance of sports, spirituality, supervision, alcohol consumption, remembrance of former patients or realistic expectations.

**Discussion:** Results of this pilot study show differences in coping strategies of male and female employees. These insights can be used for optimizing further studies on gender differences in coping strategies with the long-term goal of improving support strategies. A limitation of the present study is the strong female overlap.

**Abstract number:** P1-372  
**Abstract type:** Poster

### New Guidelines for Breaking Bad News to People with Intellectual Disabilities: Development of Web Resource and Handbook

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**Background:** As a result of a 2 year research study involving over 100 stakeholders, a new model for breaking bad news to people with intellectual disabilities (ID) was developed and presented at the EAPC Congress in 2011.

**Aims:** To make the new model accessible to key stakeholders, including family carers and staff in intellectual disability services as well as generic healthcare and palliative care professionals.

**Methods:** Around 60 stakeholders were asked an open question about their preferred way of accessing information about breaking bad news, during an advisory board meeting, a stakeholder feedback conference and via email. In addition, their opinion was sought on preferred terminology.

**Results:** There was a strong preference among all stakeholder groups (but especially among family carers and support staff in intellectual disability services) to have on-line access to the new model. The word "guidelines" was adopted as family carers did not like the word "model", which they felt indicated a lack of flexibility. Suggestions of different terminology (including "communicating" instead of "breaking" and "significant news" instead of "bad news") were rejected as being too confusing, with family carers feeling particularly strongly that it should be "breaking bad news". As a result, a comprehensive website was developed ([www.breakingbadnews.org](http://www.breakingbadnews.org)), as well as a handbook in plain English.

**Conclusion:** The website went live in October 2012. The use and usefulness of the guidelines, website and book will be monitored during the coming year. Initial feedback is positive.

**Abstract number:** P1-373  
**Abstract type:** Poster

### Analysis of Survey on Psycho-oncology Development in Former Eastern Bloc Countries

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**Introduction:** Psycho-oncology is an interdisciplinary field of medicine. In Europe its development falls in the 1980's, 20<sup>th</sup> century. However, in some countries of the former Eastern Bloc quite a different situation occurs since psycho-oncology, as generally defined, has just come into existence.

**Aim of the study:** Assessment of the current situation with regards to psycho-oncology development in selected countries of the former Eastern Bloc: Belarus, Kazakhstan, Lithuania and Ukraine.

**Materials and methods:** The analysis includes data collected based on survey forms filled in by medical staff representing the selected countries of the former Eastern Bloc and data on psycho-oncology development provided by medical employees from the specific countries. 120 medical employees were asked to participate in the survey that was conducted in the period from January to March 2012.

**Results:** A profession most frequently declared by the respondents was a doctor (from 34.8% in Belarus, up to 63.6% in Ukraine) or a psychologist (from 4% in Kazakhstan to 56.5% in Belarus). The age of the respondents was between 21 and 65 (the average being 40.37). When it comes to the development of psycho-oncology in the selected countries of the former Eastern Bloc, only in Lithuania there is a domestic association in this field, which organizes education for professionals, patients and their families and carries out scientific trials.

**Conclusions:** Psycho-oncology in the countries analyzed is

at its early stage of development except for Lithuania. The main objectives, tasks and principles of psycho-oncology in the selected countries of the former Eastern Bloc are similar to those identified in Poland.

**Abstract number:** P1-374  
**Abstract type:** Poster

### Breaking Bad News: Experiences of Doctors in the Care of Cancer Patients in Mulago National Referral Hospital

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**Introduction:** Breaking bad news is a routine task done by many health professionals and doctors are often involved in giving bad news. However communicating with distressed patients is one of the most important, yet challenging tasks required of the medical profession. Though much has been written about the way that bad news is delivered, the skills needed and the impact of delivering the news on the recipients, the actual experience of breaking bad news has at best received scant attention particularly in an African setting.

**Aim:** To explore doctors' experiences and challenges of breaking bad news to cancer patients to enable future skills development and appropriate support, to improve the doctor - patient communication.

**Method:** It was a qualitative study which used in depth semi-structured interviews to collect data to explore a phenomenon about the doctors' experiences and the challenges doctors face when breaking bad news. 12 respondents drawn from among Senior House Officer from different department of Surgery, Medicine, Gynecology and E.N.T within Mulago National Referral Hospital were interviewed until thematic saturation was reached.

**Results:** The study findings noted the importance the doctors' place on breaking bad news. The circumstances which surround the situation of breaking the bad news either hinder or enhance the doctors' breaking of bad news. When these were unfavorable the emotions the doctors experienced were negative and stressful.

**Conclusion:** Breaking bad news fosters strong relationship between the doctor, patient and family which is required for maintaining a high standard of care for cancer patients.

**Recommendations:** There is need to adequately train doctors to equip them with skills and knowledge of breaking of bad news to patients. These skills will equip them to handle the various responses of the patients and family members.

**Abstract number:** P1-375  
**Abstract type:** Poster

### Evaluating the Effect of Advanced Communication Skills Training (ACST) for Doctors by Patient Reported Outcome Measures (PROM) in Hospital Outpatient Clinics: A Feasibility Study

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**Background:** ACST is currently being proposed to be mandatory in England for all palliative care clinicians. Strong evidence regarding whether ACST elicits noticeable change to patients is lacking. The need for more research using PROM's is evident.

**Aims:** To determine the feasibility of a study to measure a change in PROM arising from ACST for doctors. Specific objectives included the feasibility and acceptability of using Consultation And Relational Empathy measure (CARE) and Patient Enablement Instrument (PEI) as PROM's within secondary care. In addition, to facilitate the design of a larger study, determine the observed difference between doctors on the waiting list (W/L) and those who have already completed ACST (Alumni).

**Method:** Two data collections of 75 questionnaires posted to sequential outpatients following a consultation with a participating doctor. Enabling stability of PROM's to be ascertained in addition to feasibility and acceptability of methodology. Data analysed using descriptive statistics and Mann-Whitney U test for comparison of group medians.

**Results:** Ten doctors recruited (5 in each group). Patients returned over half the questionnaires (802, 53.5%). Respondents were representative of outpatient population with regard age and gender. Majority of questionnaires were valid: CARE 801 (99.9%), PEI 712 (88.8%). Stability of PROM scores over first and second data collection demonstrated: Mean CARE score W/L group overall mean 44.1 s.d. 7.2, median 47 (1st collection 44.0, s.d. 7.6, 2nd collection 44.2, s.d. 6.7), Alumni group mean 46.2 s.d. 5.3, median 50 p=0.000. PEI score: W/L group mean 4.3 s.d. 4.1, median 3.0, Alumni group mean 5.3, s.d. 4.5, median 4.8 p=0.002.

**Conclusion:** Pilot demonstrates the acceptability and

stability of these PROMs in this setting. The results can be used to power a larger study to determine whether ACST does improve doctors' communication skills and lead to greater enablement of patients.

**Funding:** Internal

**Abstract number:** P1-376  
**Abstract type:** Poster

### What Do Inpatients Know and Have Been Told about their Illness? A Cross-sectional Study in a Palliative Care Unit

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**Research aims:** To know how much the patients from a Palliative Care Unit (PCU) say they know about their diagnosis and prognosis and what have been told.

**Method:** The physicians from a PCU were asked to answer if their patients said to know about their diagnosis and prognosis and if the relatives of the patients confirmed that. The attending physician had one week to answer after discussing it with their patients in their clinical practice, and should say the reason when it could not be discussed. Demographic and clinical characteristics of the patients were collected from the clinical chart.

**Results:** 36 patients were in the PCU and were included, media age 73 years old, 21 (58%) men, 32 (89%) advanced cancer patients. The physicians could not discuss with 19 (53%) patients mainly because cognitive impairment 14(73%). Finally 17 (47%) patients were selected. 13 (76%) patients knew the diagnosis, 4 (23%) patients had been told about the bad prognosis, 9 (53%) had been told that the illness is controlled. 10 (59%) patients knew their prognosis and 7 (41%) patients perceived their bad prognosis in spite what been told. 14(84%) Patients wanted to know about their illness by themselves.

**Conclusions:** Physicians could discuss with half of the patients. Most of them knew the diagnosis and half of relatives said patients were not completely informed about prognosis. Almost all patients wanted to know about their illness by themselves.

**Abstract number:** P1-377  
**Abstract type:** Poster

### Toward the Development of a Clinically Useful Index of Prognostic Awareness

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**Research aims:** Clinicians who work with advanced and terminally ill cancer patients often struggle over what, when, and how to disclose prognostic information to their clients. This process is further handicapped by the challenges inherent in determining what clients already know, or understand from their physicians' disclosures. Awareness of one's prognosis has emerged as a crucial variable in guiding both doctor-patient communications, and understanding patient psychological functioning and decision making at the end of life. This study focuses on the development of a clinically useful tool for assessing prognostic awareness.

**Study design:** Individuals with advanced cancer (stage III and IV) were recruited for an ongoing study of meaning-centered psychotherapy. Prognostic awareness was measured using a series of questions targeting patient understanding of the extent and (when accurate) terminal nature of their illness, their anticipated life expectancy, and their perception of available treatment options. Other variables measured in this study included measures of depression, anxiety, hopelessness, and cognitive functioning.

**Results:** Data are not yet analyzed, but will focus on developing an integrated measures that encompasses three axes:

- accuracy of the patient perception of the severity/curability of their illness,
- awareness of their likely lifespan, and
- magnitude of any error in patient perceptions of a and b.

Analyses will focus on the association of these three axes, both independently and when integrated into a single index, with other potential correlates (e.g., psychological distress, cognitive functioning).

**Conclusions:** This presentation will focus on the development of a multi-axis index of prognostic awareness utilizing data from a recently completed study of patients with advanced and/or terminal cancer.

Abstract number: P1-378  
Abstract type: Poster

### Psychosocial Care in Hospices

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Identification of psychosocial problems and needs is an important aspect of palliative care, as emphasized in the definition of the World Health Organization. Many patients in hospices have emotional and psychosocial problems. So far, little is known of the nature of these problems and the professional help that is actually given. We aimed to explore psychosocial problems and needs of patients admitted in hospices and the disciplines involved in psychosocial palliative care.

This study was performed in 4 hospices, and contained 2 parts. First, a selection was made of 80 patient admitted between May 2012–October 2012. All patient files were screened on psychosocial problems and needs and the professionals involved in psychosocial care. Afterwards the Distress Thermometer (DT) was introduced. In the second part, again 80 patient files were screened on the same items and nurses were asked for their experiences with the DT. Fifty-nine (74%) patients (mean age 77 yrs, 48% male) were diagnosed with cancer. Median admission was 16 days. In total, 331 psychosocial problems and needs were identified in the 80 screened patient files. The items 'loss of health' (18%), 'impending end of life' (17%), 'emotional problems' (14%), 'loss of independence' (13%) and 'depressive moods' (12%) were most frequently scored. Of the identified problems, 232 (70%) were met by nurses (n=228) and/or by referral to other disciplines such as minister (n=20) or social worker (n=18). Nurse were involved in almost all problems, whereas ministers mainly focused on existential problems, and social workers on difficulties with spouses. Currently, part 2 of this study is performed; results are expected in December 2012.

**Conclusions:** Nurse are most frequently involved in psychosocial palliative care for hospice patients. However, after introduction of the DT identification of more psychosocial problems and involvement of more disciplines in psychosocial hospice care is expected.

Abstract number: P1-379  
Abstract type: Poster

### Choose Profession and Fear of Death - It Has Connection?

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**Research aims:** The study examined the association between profession and fear of death. Knowing the attitude of healthcare workers towards death is very important, because their efficiency is associated with their fears. Our aim was to explore which attitudes related to death and dying arouse the strongest fear in participants and find out which training or other intervention will help the helpers to make death-related communication more open, decreasing inner anxiety and improving communication with dying patients and relatives.

**Methods:** Our quantitative survey took place between 2006 and 2011 in Hungary. Physicians, medical students and other healthcare workers, priests, psychologists, and non-healthcare workers (N=1062) were asked about their attitude to death by means of the Multidimensional Fear of Death Scale (Neimeyer & Moore 1994, Zana et al 2006).

**Results:** Profession was significantly associated with the total MFODS score ( $p < .001$ ) and with all fear of death factors, with the only exception of the seventh factor expressing fear for the body after death. The only systematic trend that emerged was that priests usually had the lowest scores. A notable exception was the sixth factor measuring the fear of conscious death, for which psychologists had the lowest scores. Further, concerning the second factor expressing fear of the dead, doctors and other healthcare workers did not differ substantially from priests. In this case, these groups showed significantly less fear compared with psychologists and non-healthcare workers.

**Conclusions:** Fear of death seems rather to be present in professions dealing less directly with the dead and dying. Knowledge of the most fearful components helps to find targeted assistance in the work and the daily life, too.

## Research Methodology

Abstract number: P1-380  
Abstract type: Poster

### Needs Assessment of Palliative Care in Ukraine

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**Aim:** Investigate the needs in the services of palliative care for the development strategy for palliative care in Ukraine.

**Methods:** It were tree hypotheses:

1. Primary care has become part of palliative care, have the appropriate skills and knowledge of pain relief and having a license for the use of opioids.
2. The country must increase the number of inpatient palliative care beds and mobile multidisciplinary groups (with public funding) to provide the minimum needs.
3. Ukraine should provide access to pain relief through production and delivery morphine tablets as the most effective and cheap way of providing pain relief for existing conditions underfunding of the health system in this area.

**Results:**

- The primary care doctors should contribute to improving the accessibility of palliative care.
- The existing network of public and private schools does not meet the basic needs of patients in relieving pain.

**Conclusion:** To improve the situation: Develop primary care medical assistance through short term but continuous training, thematic improvement, learning practical skills in palliative care and care, providing opportunities independently and in full to provide relief; ensure increase in inpatient services (hospice and palliative care) and specialized mobile teams to provide qualified assistance in complex cases; ensure broad awareness of patients and their families on how to obtain services of palliative care in existing institutions, public organizations; establish interagency ties (temporarily, to changes in the regulatory framework) institutions MOH and Ministry of Social Policy to coordinate efforts and provide comprehensive services to patients and their families; expand the network of staff psychologists to provide psychological support, supervision and prevention of professional burnout syndrome; provide social support palliative patients and their families to advocate their interests in state government or other public institutions.

Abstract number: P1-381  
Abstract type: Poster

### Recruiting Parents to Paediatric Palliative Care Research: Impact of Low Invitation Rates on Sample Bias

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**Aim:** Recruitment in paediatric palliative care is widely reported as challenging. Low rates of invitation by clinicians are common, but the impact this may have on sample bias is unknown. We aimed to explore this potential bias.

**Methods:** We studied recruitment to a qualitative interview study about parental decision making for children currently receiving palliative care. Clinicians (doctors and clinical nurse specialists) in a specialist palliative care (PC) team were encouraged to introduce the study to parents during routine contact (face-to-face or telephone) during a 9-month period. We used anonymised information from the PC team database to investigate differences between parents invited and not invited, and asked clinicians to provide their reasons for not inviting some parents.

**Results:** 478 live patients were registered on the PC team database, and were eligible for recruitment unless participating in another psychosocial study. Clinicians invited the parents of 25 (5.2%) patients. There was no significant difference between parents invited and not invited in terms of the patient's age, gender and ethnicity ( $p \geq 0.2$ ), but the total family contact time and number of family visits by clinicians during this period was strongly associated with invitation ( $p < 0.0001$ ). The most common reason clinicians gave for not inviting parents was little or no contact with them; others included perceived burden on parents and parents not engaging or communicating with clinician(s).

**Conclusion:** There was no evidence of major demographic bias as a result of low invitation. However, the strong influence of family contact time may have introduced bias

we were unable to measure (e.g. in relation to patient stability and parent-clinician relationships) and warrants further study. Invitation via letter or via additional sources, for example local teams with regular patient contact, might help to boost invitation rates and reduce potential bias. This work is internally funded.

Abstract number: P1-382  
Abstract type: Poster

### Improving Personalized Care in a Hospice: Findings from an Action Research Approach

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**Background:** Patients care is personalized when individual experience and preferences inform the clinical decision-making process and delivery of care. While personalized care is needed to support individuals in the work of living with life-threatening illness, few studies report action research approaches to improve personalized care delivered in hospice.

**Aim:** To develop and to evaluate the impact of an advanced and personalized caring model in an Italian hospice to improve patient centered care.

**Methods:** An action research is being conducted over a 10-month period from June 2012 to April 2013 with a multiprofessional hospice team in Italy. Mixed method data collection strategies to assess current hospice's team caring model are used including interviews, clinical observation and findings from the Frommelt attitude toward the dying scale (FACTOD-A1). Results are being provided by researchers to hospice staff members during focus groups to systematically work together in cycles of "looking, thinking and acting" in order to redesign practice.

**Results:** A synthesis of the most relevant results will be presented within the 13th World Congress of the European Association for Palliative Care including the domains and the first effects of the advanced and personalized caring model as identified and implemented by participants.

Abstract number: P1-383  
Abstract type: Poster

### Developing a Framework for Measuring and Valuing Quality of Life in Individuals without Capacity

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**Aims:** Economic evaluations are essential in decision making within healthcare. For some populations, existing tools for measuring and valuing health related quality of life (HRQoL) are inappropriate. Specific tools should be developed to reflect the needs of particular populations; in this research, we focus on patients with severely limiting advanced dementia. We aim

- (1) to demonstrate how current instruments are inappropriate for use in this population, and
- (2) to propose a new framework for the measurement and valuation of HRQoL that reflects this population's needs.

**Study design and methods:** To show that current HRQoL measurement instruments are not valid in patients with advanced dementia we critically appraise methods used by economists to measure and value HRQoL and the conceptual framework by which these instruments have been developed. We assess the validity of instruments commonly used in research, including the EQ-5D, ICE-CAP and DEMQoL. We propose a novel framework for thinking about quality of life in this population, based on notions of observable patient outcomes and process utility. We are conducting a systematic review to identify the set of possible domains that may be included in a new instrument for measuring HRQoL in this patient group.

**Findings:** Current instruments used in economic evaluation are not suitable in this patient group. We have identified a number of objectively measurable criteria and processes to consider for inclusion in a new instrument. These include markers of general comfort, control of pain and agitation and response to pleasant stimuli such as touch, smell and sound.

**Conclusion:** We have begun the process for development of a new instrument suitable for use in economic evaluations that accounts for the needs of this population. Our systematic review is the first stage of a wider research project to include instrument development and validation, and development of a value set for economic evaluation.

Abstract number: P1-384  
Abstract type: Poster

## The Feasibility of Recruiting People with Advanced Dementia into Research

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**Aim:** It can be challenging recruiting frail older people with advanced disease to research studies. We aimed to test a method of recruiting seriously ill patients with advanced dementia during acute medical hospital admission.  
**Design:** Longitudinal cohort study of pain and behavioural symptoms in people with dementia.  
**Method:** The research took place in 2 large hospitals in the United Kingdom (UK). All patients aged  $\geq 70$  years with unplanned acute medical admission and a diagnosis of dementia DSMIV with sufficient English language to complete study ratings were eligible. Dementia severity was assessed using the Functional Assessment Staging Scale (FAST); 1-5=mild, 6=moderate, 7 and above=advanced. Researchers assessed patients' capacity to give informed consent within 72hrs of admission. For patients without capacity their main carer was approached to give assent. In accordance with the Mental Capacity Act (MCA) 2005, a professional consultee was asked to give their opinion when carers were not available.  
**Findings:** 1162 potential participants were identified, 1382 not eligible. 230 patients recruited, 66% female, mean age 87 (range 75-101). Twenty nine patients (22%) had capacity to consent, of these 90% had mild and 10% moderate dementia. No patient with advanced dementia had capacity to consent. Carers gave assent for 189 patients, of these 29% had mild, 55% moderate and 16% advanced dementia. Professional consultee's opinion was required for 12 patients, 50% mild, 42% moderate and 8% advanced dementia.  
**Conclusions:** Previous and current research has reported that studying disease trajectory and symptoms in people with advanced dementia is a complex and difficult process. We used the Mental Capacity Act to recruit acutely ill older people with advanced dementia, in an acute setting with a limited timescale. This method reduces the risk of bias in this population and may be transferable to other advanced diseases where capacity to consent is impaired.

Abstract number: P1-385  
Abstract type: Poster

## When Is it Acceptable for Palliative Care Patients to Participate in Research? A Comparison of Patients' and Professionals' Views

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**Aims:** There is a need for more robust evidence to guide clinical practice in palliative care, yet recruitment into clinical studies can be challenging. Gatekeeping by healthcare professionals (HCPs) is often cited as a cause of poor accrual, yet the reasons for this remain poorly understood. This study aims to identify the properties of clinical studies that are most and least acceptable to palliative HCPs and patients, and explore the differences between these groups.  
**Methods:** A cross-sectional questionnaire survey in a convenience sample of patients and HCPs from three hospices in Kent, UK. Questionnaires were adapted from a previous Australian study, piloted and revised prior to use. Participants were asked about the acceptability of different types of clinical study and the degree of inconvenience acceptable when participating in research. All questionnaires were completed anonymously.  
**Results:** Questionnaires were distributed to 134 HCPs, (96 responses, 72%), and 120 patients (84 responses, 70%). Both patients and HCPs were willing to be involved in research, with HCPs generally more willing to refer than patients to participate. Examples of some of the differences were: A simple study involving a special mattress: 90% of HCPs willing to refer vs. 39% of patients willing to participate. Trial of oral medication with no side effects: 72% HCPs vs. 24% patients willing. Trial involving at least 1 night per month as an inpatient: 75% HCPs vs. 51% patients willing.  
**Conclusions:** Evidence of gatekeeping was not as prevalent in this group as is often perceived and seemed mainly driven by increasing complexity or invasiveness of study procedures. Reluctance by patients to participate in research may be rooted in different issues to those of concern to HCPs, and researchers should take account of this when designing studies in this patient group. Further qualitative work is needed to identify how misperceptions or fears can be overcome.

Abstract number: P1-386  
Abstract type: Poster

## The Clinical and Cost Effectiveness of CBT Plus Treatment as Usual for the Treatment of Depression in Advanced Cancer: A Randomised Controlled Trial (The CanTalk Study); The Feasibility Phase

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Depression is a prevalent mental disorder in patients with cancer. Cognitive Behavioural Therapy (CBT) has been shown to treat effectively major depression; however there is little empirical evidence of its efficacy for patients with advanced cancer.  
**Aim:** This study (CanTalk, funded by UK National Institute of Health Research Health Technology Assessment programme) investigates whether CBT, accessed through the UK NHS Improved Access to Psychological Therapies Service, is an effective treatment for depression in those with advanced cancer.  
**Study design:** CanTalk is a single-blinded randomised controlled trial (RCT), recruiting from several primary and secondary NHS sites across the UK. Adults with Advanced Cancer (prognosis greater than four months) and depression were randomised to treatment as usual or CBT plus treatment as usual. The treatment phase lasts for up to 12 weeks, with depression, quality of life and economic measures at six-weekly intervals up until 24 weeks post-randomisation.  
**Results:** The feasibility phase measures recruitment and retention rates in a small number of sites so that procedures can be adjusted if rates are not as estimated. Low eligibility rates for the trial and increased risk of attrition because of ill health require a larger population size from which to recruit; this has implications for trial coordination and set up. Gaining NHS permissions in multiple Trusts and support in General Practices is a lengthy process and the reorganisation of NHS services further complicates trial set up.  
**Conclusion:** Recruitment commenced in September 2012. We shall present recruitment, retention, follow-up and attrition data from the feasibility phase. We shall report whether strategies to address the recruitment and retention challenges were successful.

## Non-Cancer

Abstract number: P1-387  
Abstract type: Poster

### End of Life Care for Heart Failure Patients

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**Aims:** Heart failure (HF) is a life limiting chronic disease associated with high symptom burden, 24.7% readmission rate and unpredictable trajectory; making palliative care (PC) interventions appropriate for HF patients. This study compares characteristics and outcomes of HF patients in a large urban, acute care hospital with an established PC program to identify patterns in palliative care consult (PCC) requests and triggers to indicate timely requests for PC involvement.  
**Methods:** This is a retrospective review of hospital data on inpatients with a primary diagnosis of HF who died or enrolled in hospice in 2011 versus HF patients discharged to home, home health service (HHS) or extended care facility (ECF) in the first 6 months of 2011 (matched on age and diagnosis to deceased and hospice patients). Patients were compared by discharge outcomes on demographics, inpatient characteristics, co-morbidities and readmissions. Cross-tabulations and t-tests were conducted in SPSS version 17.  
**Results:** Of the 32 patients who died, 59% had a PCC; there were no significant differences between PCC patients and non-PCC patients who died on any study variables. Compared to patients discharged to home, HHS, or ECF, 1) deceased and hospice patients had a longer mean hospital length of stay and higher rates of acute renal failure and pneumonia ( $p \leq 0.005$ ), 2) patients who died had higher rates of acute respiratory failure ( $p \leq 0.001$ ), and 3) patients who enrolled in hospice (N=15) had higher rates

of dementia and debility ( $p \leq 0.001$ ). Patients discharged to a HHS (N=67) had the highest 30 day readmission rate (10%).  
**Conclusions:** HF patients are referred to PC late in the disease process. Over 40% of inpatients with HF who die do not benefit from PC or hospice involvement. Earlier PC involvement may benefit patients with long-term care needs and those most at risk for acute organ failure by aggressive symptom management and prevention of re-hospitalization. The study was hospital funded.

Abstract number: P1-388  
Abstract type: Poster

## The Supportive Care Needs of Patients with Interstitial Lung Disease

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**Aims:** Interstitial lung disease encompasses a wide range of parenchymal lung diseases. Many have limited or unpredictable prognoses, and there are few evidence-based treatment options. Recent British Thoracic Society guidelines encourage supportive and palliative care involvement in managing these patients, but little is known about their supportive and palliative care needs. The primary aim of this study was to assess whether patients with interstitial lung disease have supportive care needs. The secondary aims were to identify these needs, and establish whether these patients are referred to supportive and palliative care services.  
**Methods:** Patients attending the interstitial lung disease clinic at a regional centre were invited to participate. A holistic needs assessment tool, the Sheffield Profile for Assessment and Referral to Care, was used. Patients' notes were reviewed to identify referrals.  
**Results:** A 54% response rate (n=92) was achieved. 51% were male, and 55% aged under 65 years. There was a high prevalence of needs including physical (most frequently tiredness, breathlessness, and cough), psychological (low mood, anxiety), and concerns about the impact of their illness on others. 36% of patients had needs thought to warrant specialist supportive and palliative care input. 4% had evidence of referral to supportive and palliative care services.  
**Conclusion:** Our study suggests that physical, psychological and social needs are prevalent in patients with interstitial lung disease at a specialist centre. The rate of referral to specialist supportive and palliative care services is low. Further research is needed into how best to support these patients, perhaps through collaboration between respiratory and palliative care teams.  
**Funding:** No external funding was received.

Abstract number: P1-389  
Abstract type: Poster

## Palliative and End of Life Care on UK Stroke Units: A Qualitative Study

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**Background:** Stroke is a leading cause of death internationally, in the UK between 20-30% of people die within 30 days of a stroke. High quality palliative and end of life care are advocated for patients not expected to recover from stroke.  
**Aim:** To explore the perspectives of a range of health professionals regarding the provision of palliative and end of life care on UK specialist stroke units.  
**Design & methods:** Qualitative focus groups and individual interviews were held with 66 health professionals working on UK specialist stroke units. Health professionals comprised medical, nursing and allied health professionals. Data were analysed thematically.  
**Results:** Three themes emerged from the data: (1) Palliative care was recognised as an important component of the care provided to stroke patients; (2) However there was uncertainty amongst staff regarding when and how to initiate transitions to palliative care in stroke; (3) Particular issues were identified with the integration of acute stroke care and palliative care, and perceived conflicts in goals of care were discussed.  
**Conclusions:** The findings provide encouraging evidence that palliative and end of life care have been adopted as key components of specialist stroke care on UK stroke units. However, many patients stand to benefit from earlier identification of palliative care need, and a consideration of quality of life approaches during active care. Encouraging

collaboration and partnership working with specialist palliative care services would optimise management, and may provide patients and their families with greater opportunities for documenting and achieving preferences for care, and achieving a better quality of death.

The study was funded by Collaborations for Leadership in Applied Health Research and Care (CLAHRC) for South Yorkshire.

**Abstract number:** P1-390

**Abstract type:** Poster

### Palliative Care Related Problems among Patients with Heart Failure Attending a Public Hospital in South Africa

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**Background:** Heart failure is a leading cause of death in sub-Saharan Africa. This study aimed to measure the patient-reported affect of palliative care-related problems among adult patients attending a public hospital with stage 3 or 4 NYHA heart failure.

**Methods:** Consecutive patients were recruited from emergency units, cardiology beds, general medicine beds and outpatient cardiology clinics. In addition to demographic, disease-oriented and service use data, patients gave responses to the APCA African Palliative Outcome Scale, a well-validated tool measuring the 3 day period affect of palliative care-related problems.

**Results:** 98 patients participated (response rate 95%). Mean age was 58, n=60 (61%) were male, n=70 (71%) coloured, and only n=16 (16%) in paid employment. The majority (n=76, 77%) were recruited via emergency units. 54 (55%) had at least one hospitalization in the previous 12 months, none had been referred to palliative care. The mean Karnofsky Performance Score was 50. With respect to item analysis, the worst problems (each scored on a scale of 0=worst to 5=best) were pain (median=1, IQR=0-2) symptoms (1, 1-2) and worry (2, 0-2). In multivariable regression analysis with total patient POS score as dependent variable, the following independent variables were not associated with the outcome: age, gender, education, prior hospitalizations. Karnofsky performance status ( $b=-0.264$ , 95%CI -2.245, 0.334,  $p=0.009$ ) was associated with the outcome, with worse performance being associated with worse palliative care-related problem affect.

**Conclusion:** Patients with chronic heart failure in South Africa are most bothered by pain, other symptoms, and worry. The burden of problems is worse with poorer physical performance. Cardiac care must routinely include the palliative care principles of assessment and management of pain, symptoms and psychological problems.

**Funding:** European Society of Cardiology.

**Abstract number:** P1-391

**Abstract type:** Poster

### End of Life Care in Neurodegenerative Conditions: Evaluation of a Specialist Palliative Neurology Service

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The last year of life for people with advanced neurodegenerative conditions (ANC) is often unsatisfactory, characterised by multiple unplanned hospital admissions. Despite this very few patients with ANC access palliative care services.

**Aims:** A unique service led by specialist palliative neurology nurses (PNN) was evaluated against the recommendations of the National End of Life Care Programme (NEOLCP) ANC framework. Additionally, the suggested NEOLCP 7 'triggers' for palliative care referral were assessed.

**Method:** Retrospective observational study of 62 consecutive patients under a specialist palliative neurology service (SPNS). Principle component analysis (PCA) was performed to examine the relationship between triggers and survival.

**Results:** All patients had a key-worker who coordinated care. Capacity was assessed in 95% of cases, for who advance care planning and best interest decisions were documented in 95%. The terminal-phase was recognised in 72.6% and 100% of carers were offered bereavement support.

The median follow-up under the SPNS was 336 days. The mean number of hospital admissions was 0.9 in the last year of life (compared to 3.5 nationally across diagnoses). 56.5% died from pneumonia. 31% of patients died at home (nationally 14% of ANC patients die at home), 26% in hospital (46% nationally) and 24% in hospices (0.03% nationally).

Frequency of triggers increased as patients approached death. PCA found 4 components explained 76.8% of the variance in survival. These represented *rapid physical decline; significant complex symptoms-including pain; infection with cognitive impairment; and risk of aspiration.*

**Conclusion:** This model of service provision investing in specialist PNN has proven to be an effective model in delivering palliative care to this vulnerable patient group and illustrates that the NEOLCP framework is achievable. The triggers for referral require further validation although the derived PCA components do have face-validity.

**Abstract number:** P1-392

**Abstract type:** Poster

### Advance Care Planning in Motor Neuron Disease and Atypical Parkinson's Disease - A Baseline Review of Current Practice in the North West of England

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**Introduction:** The NICE Quality Standard for End of Life Care in England advocates timely identification of people approaching the end of life, allowing opportunities to discuss future support and treatment. Disease-specific guidance for Parkinson's Disease and Motor Neuron Disease highlights the importance of addressing palliative care needs throughout all phases of illness.

**Aims:** To evaluate discussion of prognosis, advance care planning and palliative care referral for patients with Atypical Parkinson's Disease (APD) or Motor Neuron Disease (MND) attending specialist clinics within a tertiary neurosciences centre.

**Methods:** A retrospective analysis of hospital and community case notes for patients known to APD and MND clinics who died between February 2011 & January 2012.

**Results:** 29 patients referred from 10 primary care trusts were included, 52% with APD and 48% with MND. Median time from specialist clinic referral to death was 14 months for MND and 21 months for APD. There was some evidence of advance care planning in 62% (e.g. discussion of prognosis), however documentation of specific decisions for future care was present for 40% of APD and 36% of MND patients. Median time from first advance care planning to death was 4 months (range 2weeks - 29months). Preferred place of death was documented for 11 patients (38%). Specialist palliative care (SPC) referral was made in 17 cases (59%), a median duration of 4 months before death.

**Conclusion:** Evidence of specific decision-making regarding future care needs was present in less than 50% of cases. When carried out, both SPC referral and advance care planning occurred late in the disease trajectory, a median of four months prior to death. In order to improve timeliness of future care planning and palliative care referral, a joint neurology/palliative care group is working to raise awareness of indications for SPC referral and use of advance care planning tools. Audit standards have been set and will be measured against.

**Abstract number:** P1-393

**Abstract type:** Poster

### Developing European-wide Best Practice Guidelines and Core Standards for Palliative Care for People with Intellectual Disabilities

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**Background:** The EAPC Taskforce on palliative care for people with intellectual disabilities was approved in 2012. People with ID make up 2.5% of the population, with numbers rising every year. Those over 50 years old are the fastest growing cohort of the ID population. Increasing numbers of people with ID are developing life-limiting illnesses that require palliative care. In many European countries people with ID live in the community and rely on mainstream services for health care. Meeting the growing

palliative care needs of people with ID thus presents a major challenge. There are no data available around detailing where people with ID are cared for at the end of life, and what conditions they die from. However, there is a small but growing body of research which indicates that there are a range of issues affecting end of life and palliative care for people with ID.

**Aims:** To improve palliative and end of life care for people with ID by:

- (1) identifying examples of good and promising practice across Europe;
- (2) developing consensus guidelines and recommendations for core standards of care, research and education; and
- (3) publishing the good practice examples and consensus guidelines/standards that will be applicable and influential in Europe and beyond.

**Methods:** A Member Group, consisting of experts from different countries, has begun to draw up the initial guidelines and core standards, working mostly through electronic exchange of documents and comments. This will be distributed to a large group of experts from at least 18 European countries, and feedback collected using the Delphi method. Simultaneously, we have invited the submission of examples of best practice.

**Results:** The guidelines/core standards will be refined and presented, along with a range of best practice examples from across Europe. We welcome feedback and comment from EAPC conference delegates. The finalised best practice guidelines and core standards will be published in 2014.

**Abstract number:** P1-394

**Abstract type:** Poster

### Safeguarding Patients with Intellectual Disabilities in General Hospitals against Avoidable Deaths and Inappropriate Commencement of End of Life Care

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**Background:** In response to a string of high profile cases of people with intellectual disabilities (ID) dying in general hospitals in England, an Independent Inquiry (2008) found examples of discrimination and neglect of patients with ID in healthcare services, concluding that there was a high likelihood of avoidable deaths.

**Aims:** To describe the factors that increase and reduce the risk of avoidable deaths and inappropriate commencement of end of life care for patients with ID.

**Methods:** A 21 month multi-method study involving six NHS hospitals in England. Data collection included assessment of policies and procedures; questionnaires to staff (1,018 returned) and carers (88 returned); interviews with hospital staff including senior managers, nurses and doctors (68), carers (34) and people with ID (33); observation of patients with ID on the wards (8); and monitoring of incidents and complaints involving patients with ID.

**Results:** Good practice was haphazard, with both good and poor practice within the same hospitals and wards. As well as many positive examples, researchers found several cases where potentially curative treatment was not initially offered to patients with ID. Analysis of these showed that contributing factors were negative staff attitudes, assumptions about poor quality of life, a lack of staff understanding of the Mental Capacity Act, and diagnostic overshadowing. Contributing factors to good practice included the active presence of an ID nurse for hospital patients, strong advocacy from carers, and good ward leadership.

**Conclusion:** Strong professional advocacy and staff training are necessary in order to ensure that only those patients with ID for whom curative care is not possible are put on an end of life care pathway.

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**Abstract number:** P1-395

**Abstract type:** Poster

### Palliative Management of Symptomatic Refractory Ascites Secondary to Liver Cirrhosis with Tunnelled Peritoneal Drainage Catheters. A Report of Preliminary Experience

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**Background:** End-stage liver disease (ESLD) is an important cause of morbidity and mortality. It is the fifth largest cause of death in the European Union and rates of death are increasing annually in contrast to most other long-term conditions. Refractory ascites (RA), characterised by unresponsiveness to diuretic therapy, is common in ESLD. RA is associated with high rates of mortality and frequent admissions to hospital for percutaneous drainage.

**Aims:** To audit the use of PleurX® tunnelled peritoneal drainage catheters for RA in patients with ESLD reaching the end of life.

**Methods:** Approval for use of PleurX® drainage in this patient group was obtained from the New Clinical Procedures Committee of King's College Hospital, London and an audit of their use was registered. Audit outcomes collected included complication rate, hospital length of stay (LOS), number of days device in situ before removal or death and place of death.

**Results:** Five drains were inserted in four patients. Three patients were male and the median age at insertion was 75y. LOS following insertion was 1d (1-8 days) and patients were discharged home (75%) or to a hospice (25%). The drain remained in situ for a median of 30d (20 - 50d) before removal or death. Those discharged home remained there for a median of 35d before death or admission to a hospice. Two patients died at home and two patients died in a hospice; all died in their preferred place of care. Two patients (50%) experienced complications; one patient required a second drain insertion following accidental removal and one patient required drain removal secondary to leakage at insertion site and non-fatal bacterial peritonitis.

**Conclusion:** Indwelling peritoneal catheter insertion may facilitate terminal care in a setting outside of the acute hospital in patients with end-stage liver disease and refractory ascites. Larger prospective study is warranted.

**Abstract number:** P1-396

**Abstract type:** Poster

## The SPARC-Renal Tool - Development of a Holistic Needs Assessment Tool to Assess the Problems and Issues Caused by Chronic Kidney Disease Stage 5 (CKD5)

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**Aims:** To develop a specific renal module for use alongside the Sheffield Profile Assessment for Referral for Care (SPARC), a tool initially developed to assess palliative care needs in a cancer population which may be useful in supporting health professionals to assess the needs of frail and elderly renal patients. We will ensure an exhaustive list of issues and problems related to renal patients accessing specialist palliative care services are generated.

**Methodology:** The EORTC Quality of Life guidelines for the development of the module were used. As this study is still in Phase 1, a literature search was conducted to identify all studies on care provision to renal patients not eligible for kidney transplantation (managed either by dialysis or conservatively). Each study was independently assessed for eligibility before items on problems and symptoms were extracted. Any items duplicating the original SPARC tool were removed, and remaining items were used to construct the SPARC-Renal list. Six health care professionals (HCP) experienced in managing renal patients will be interviewed to explore the appropriateness of content and the breadth of coverage of the existing SPARC tool and the items generated for the SPARC-Renal module.

**Results:** The literature search identified 532 articles of which 22 were eligible. From these articles, a total of 76 items were extracted, of which 28 were new items not found in the SPARC tool, and used for the SPARC-Renal checklist. Findings with the 4 health professionals already interviewed suggested that 8 items could be removed. More consideration may be needed in incorporating items considering issues around dialysis decision.

**Conclusion:** An initial SPARC-Renal list has now been constructed. Further work is needed to explore the validity of this list in practice and the relevance of both the SPARC and SPARC-Renal with renal patients not eligible for transplantation.

**Abstract number:** P1-397

**Abstract type:** Poster

## Quality of Life and Social Support Family Members Caring for Elderly with Alzheimer's Disease

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**Introduction:** Care about people with Alzheimer's disease in family is very challenging. The care has an impact on quality of life of family members.

**Aims:** The research aimed to identify what are the current levels of quality of life of family members and what factors affect to this quality of life.

**Methods:** Ten women and eight men caring about elderly with Alzheimer's disease were interviewed individually using a semistructured interview guide. The interviews were tape-recorded for subsequent verbatim transcription. The data were analyzed by the author using a qualitative content analysis without any predetermined categories. Both a manifest focus and a latent focus were used. Quality of life was measured using WHOQOL.

**Results:** We found lower quality of life for family caregivers in comparison with the Czech population. The analysis revealed two manifest (descriptive) categories: social support and support from the state. The latent (interpretative) focus was on society valuation. Society valuations are low.

**Conclusion:** This research is a contribution to a description of life situation and position of people taking care for elderly with Alzheimer's disease in family.

**Abstract number:** P1-398

**Abstract type:** Poster

## Living and Dying with Multimorbidity: A Longitudinal Study of Patient, Carer and Professional Perspectives

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**Background and aims:** Many people now die with multimorbidity but little research has addressed their end of life care needs. We aimed to explore the lived experiences of advanced multimorbidity: (living with more than one advanced life-limiting illness) and coordination of care in the last year of life.

**Design:** Ethnographic observations in the acute admissions unit of a regional acute hospital, a large general practice, and a respiratory outpatient service.

Serial longitudinal interviews with patients with multiple advanced progressive conditions recruited from these sites, their family and professional carers.

**Analysis:** Inductive analytical coding, both synchronic and diachronic to construct a model of experiences, attitudes and actions.

**Results:** Ethnographic observations for 18 weeks; 56 patients, 25 family carers, yielding 181 serial interviews. 37 case-linked and setting-linked professionals recruited for qualitative interviews. Patients and carers had many unmet palliative care needs. They rarely received palliative care as professionals failed to identify them for holistic care. Patients and carers lacked knowledge about the possibility of early palliative care. They experienced reactive, unplanned care characterised by uncertainty, health crises and a need to self-manage multimorbidity.

**Conclusion:** Multimorbidity challenges the professional focus on treating a single condition, the generalists who struggle to identify those appropriate for palliative care and to integrate disease-specific guidelines. Therefore patients lack a clear understanding of how their different conditions interact and the implications for their morbidity and mortality. This complex, multi-sited project provides a rare insight into the experience of living with multimorbidity towards the end of life while receiving normal care.

**Abstract number:** P1-399

**Abstract type:** Poster

## End Stage Liver Disease - The Blind Spot of Palliative Care? - A Systematic Review

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**Background:** End stage liver disease is one of the leading causes of death worldwide and incidence rate is still increasing. Despite the established impact of palliative care for patients suffering from other non-malignant life-limiting diseases, there is hardly any guidance for a palliative approach in patients with chronic liver disease to date. We performed a systematic review of literature addressing this topic.

**Design:** Relevant papers published in English, peer reviewed journals from 1950 until July 2012 were retrieved from databases of MEDLINE, the Cochrane Database of Clinical Trials and Systematic Reviews and EMBASE. To conduct a comprehensive analysis articles were selected following the established guidelines for systematic reviews and assigned to different result categories.

**Results:** Electronic search revealed 21 articles meeting the inclusion criteria. Seven of these have been categorized as reviews and four as editorials, nine were clinical trials and one was a case report. Qualitative analysis showed that two manuscripts of the category "editorial" and five of the category "review" dealt primarily with palliative care in end stage liver disease. Three of the studies concerned questions of palliative medicine in ESLD patients. In all other articles, patients with chronic liver disease represented just a subgroup of the evaluated population or palliative care was only mentioned in the margin.

**Conclusion:** This systematic review demonstrates the dramatic lack of studies examining palliative care in patients with end stage liver disease. There is an urgent need for further research in this field.

**Abstract number:** P1-400

**Abstract type:** Poster

## Evaluation of Palliative Care Needs of Patients with Non-acute Stroke in an Internal Medicine Department

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**Background:** Three recent studies concerning acute stroke showed the need to control symptoms, and the importance of PC team support on decisions to suspend futile therapy, in order to improve the quality of medical care, particularly in end of life. There is little information on PC in Non-Acute Stroke (NAS) Patients.

**Aims:** Characterize the symptoms and type of PC care given to NAS patients admitted to an Internal Medicine Department (IMD), considered as requiring PC according to the definition of the NHO.

**Methods:** Prospective and observational study including the patients admitted to an IMD in a 9 weeks period. Selection of the PC patients. Application of a questionnaire and clinical files review, aiming several variables (symptoms and symptom control, special nursing care, mortality).

**Results:** Of the 102 PC patients, 24 had NAS. They all had dementia, 96% were bedridden, 75% had pressure ulcers, 71% were fed by nasogastric tube and 38% presented agitation requiring a mean number of 3 nursing cares. The mean number of symptoms was 3 (dyspnea, constipation and sleepiness were the more prevalent symptoms). Co-morbidities (such as respiratory tract infections that originated dyspnea) and stroke sequelae conditioned the majority of symptoms. Morphine was administered in order to control dyspnea in only 1 patient, receiving the remaining patients basic PC. Mortality rate was 12,5%.

**Conclusion:**

- 1) Symptoms presented by NAS patients were generally associated with co-morbidities and stroke sequelae, originating need of basic (non-specialized) PC and end-of-life care.
- 2) The application of PC philosophy was clearly beneficial to these patients.
- 3) The very dependent NAS patients generally are the object of little interest and investment by clinicians; this study emphasizes that there is much to be done in order to improve symptom control and the quality of life of these patients and their families.



Abstract number: P1-401  
Abstract type: Poster

### Is There Room for Advance Care Planning at a Dialysis Ward?

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**Aim:** Renal dialysis has a tremendous impact on a patient's life and his environment, and recent evolution in dialysis techniques has faded out the gap between life prolonging treatment and palliative care. Therefore, Advance Care Planning (ACP) seems even more important for renal dialysis patients. This study looked at how ACP for them could be organised and what possible barriers are?

**Methodology:** A systematic literature study formed the basis of qualitative research which used face-to-face interviews and a focus group of caregivers for data collection.

**Results:** ACP is a dynamic process that should not be limited to administrative tasks, such as filling out forms. Key elements are: good communication, provision of information at various stages of the illness, and respect for the autonomy of the patient. At a dialysis ward, the nurse has a very important 'signal' function due to the trust relationship with the patient. However, the same relationship can also be a handicap for delicate conversations. Other barriers are the lack of privacy at the ward and the limited time available to caregivers. There is also a lack of attention for the family because they are not allowed on the dialysis ward. The cooperation with general practitioner and home care team can much better. Furthermore, DNR decisions are often discussed too late, and caregivers are not aware of the option of stopping the dialysis treatment which results in patients sometimes being dialysed 'too long'. Finally, it is agreed that one collective medical file accessible to all caregivers, and a regular well organised multidisciplinary team meeting would increase the quality of care.

**Conclusion:** It is recognised that there is a need for a joint vision of the entire dialysis team, support of this team by the mobile palliative care teams, and more communication education and training. The first and most important step seems to be that all caregivers of the dialysis ward should realise the importance of ACP.

Abstract number: P1-402  
Abstract type: Poster

### Identifying Patients in UK Primary Care for Generalist and Specialist Palliative Care

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**Background:** Patients with all types of advanced progressive diseases may benefit from an early palliative care approach. However, current palliative care services largely treat cancer patients in their last months of life, and those with non-malignant illnesses remain underserved. In the UK GPs are reimbursed for keeping local practice palliative care registers. We aimed to document and understand variations in the identification of patients in primary care for palliative care.

**Design:** We carried out a case note review of all patients who had died in nine GP practices over 12 months (684 patients) to examine if and when they had been identified for palliative care before they had died. Semi-structured interviews were also conducted with health care professionals based in these practices. We conducted routine statistical analysis and a thematic analysis of the interview transcripts.

**Results:** 29% of deceased patients had cancer; 25% had organ failure, and 23% had frailty and/or dementia. 75% of patients with cancer were identified for a palliative approach in comparison to 20% of other patients. Patients were identified for palliative care only seven weeks (median) prior to death. Those with frailty and/or dementia were identified significantly later than those with cancer or organ failure. A cancer diagnosis, routine practice multi-disciplinary meetings, and the financial incentive facilitated identification. Having a non-malignant diagnosis, individual (as opposed to team) decision-making, patient's association of "palliative care" with imminent dying, and administrative burden, were barriers to identifying patients for palliative care.

**Conclusion:** Only 20% of patients with organ failure and frailty and/or dementia are being formally identified for palliative care. Across all illness trajectories patients are being identified at a very late stage of illness. Better and earlier identification of patients for palliative care would allow them to access better support.

### Palliative Care in the Elderly

Abstract number: P1-403  
Abstract type: Poster

#### Nursing Home Resident's Wishes for End-of-Life Decision-making - First Results

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**Aim:** Aim of the present study was to investigate Norwegian nursing home residents' wishes for end-of-life decision-making.

**Methods:** Qualitative study with semi-structured interviews of nursing home residents. An interview setting with structured questioning and open interviewing was used. So far 11 interviews of patients who have been included in the study were reviewed and analyzed. Only participants with the ability to give full informed consent were included in the study due to ethical reasons. All interviews were recorded and transcribed verbatim by the researcher himself. Results from the interviews were compared to findings from a literature review.

**Results:** So far 11 nursing home residents were included in the study by nursing home staff. Their age was between 74 - 100 years. One participant had to be excluded by the researcher because of cognitive impairment. The interview duration varied from 12 - 47 minutes.

Important themes and points of view brought up by the participants were about:

- Absence of Advance Care Planning in nursing homes
- Treatment of pain and other symptoms at the end-of-life
- Decision-making by relatives: "They know"
- Problems with shared decision-making
- Residents attitude towards planning their end-of-life

**Conclusion:** Our first results show that Advance Care Planning is absent in many Norwegian nursing homes. Most residents want their relatives to make decisions for them if they would become incapable to decide themselves. Some residents are reluctant to plan their end-of-life. As the study is ongoing, further interviews will help to question our first results and to enrich the knowledge on the resident's views on end-of-life decision-making in nursing homes. This project has been financed with the aid of EXTRA funds from the Norwegian Foundation for Health and Rehabilitation.

Abstract number: P1-404  
Abstract type: Poster

#### Establishing a Method to Identify Older Patients with Palliative Care Needs in the Community

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**Research aims:** The main objective was to determine existing methods or tools in use in other jurisdictions that could be applied in the Irish health care system to support the identification of patients with palliative care needs in general care settings in the community. A significant number of these patients fall into the category of older people whose quality of life would be greatly improved by the application of a palliative care approach. Increasing population ageing as well as increased prevalence of co-morbidities in older people means that it is particularly important that they do not go unidentified in the community and their needs unmet.

**Study design and methods:** A number of potential tools were identified based on review of literature, emerging practice internationally, as well as recent activity in Ireland. The need for a tool to be relevant for all diseases; applicable in a general community setting and have emphasis on palliative need throughout the older patient's journey were key criteria.

**Results:** The Supportive and Palliative Care Indicators Tool (SPICt) tool was identified as the most relevant existing tool that will support GPs and primary care teams identify older patients who have palliative care needs due to the fact that it was user-friendly and designed to be used in all settings, including the community. SPICt acknowledges the

significance of co-morbidities for older people and includes clinical indicators for cancer, dementia, and frailty, as well as liver, respiratory, kidney, cardiovascular and neurological diseases.

**Conclusion:** Further work is required to determine how SPICt will apply to Irish Health systems, and it is planned to pilot this tool in primary care settings. This pilot will include an evaluation that will determine the benefit of the tool for the identification of the palliative needs of older patient.

Abstract number: P1-405  
Abstract type: Poster

#### Where Do We Start with the Improvement of Care for Frail, Older People: Action Points from the Dignity Network Group

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**Aim:** European governments are now preparing for the predicted increase of care needs at the end of life. Meanwhile, quality of care for frail, older people remains poor in practice. We aimed to identify priority areas for the improvement of care for frail, older people and the actions required to achieve this.

**Methods:** An international meeting was organized and participants were selected from an expert network of care for frail, older people. The workshop consisted of presentations on priorities from multiple country and disciplinary perspectives with a focus on Europe, and structured group discussions. Analysis applied standard qualitative techniques.

**Results:** The workshop comprised 20 participants from 9 countries in Europe and Israel. They identified priority areas on:

1. A conceptual level: a. raising awareness to the importance of quality care for older people, and recognising staff's competence; b. developing new care models based on systematic evidence and accurate definitions.
2. A practical level: a. providing care with special attention to access to care, support for care workers, and reduction of regulations; b. facilitating living conditions with available medical provisions in place, avoidance of transfers, personalized care, regard for families and expertise of care for the dying.

They identified mechanisms to increase quality care through structural changes requiring education to raise the level of expertise in caring for older people, and communication between the different parties involved (public, policy-makers, family, staff and family).

**Conclusions:** This meeting identified the limits of current care practices in long-term care and explored the potential for change. Collaborative initiatives between policy, practice and research were planned to realize the conceptual changes which are the driving force to raise societal awareness and achieve changes in the daily care for older people.

**Funding source:** Dignity Centre Bergen and Austrian Red Cross

Abstract number: P1-406  
Abstract type: Poster

#### Significance of Smell and Taste across the Course of Life - Implications for Palliative and Hospice Care

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**Background:** Smell and taste accompany man throughout the whole course of life and affect the essential human functions of eating and breathing. Due to an increasing prevalence of changes of these senses caused by aging and incurable diseases, it is necessary to clarify their subjective significance to patients in palliative and hospice care.

**Methods:** A three step approach was performed.

- (1) A systematic literature review on smell and taste in elderly was followed by a
- (2) qualitative experiment in which fourteen visitors of senior-groups gave feedback on selected smell and taste samples. Their reminiscences of smells and tastes were audio-taped, transcribed and analyzed using a qualitative heuristic research approach and qualitative content analysis. Subsequently a
- (3) review of literature contextualised findings into palliative

and hospice care.

**Results:**

- (1) The subjective significance of smell and taste across the course of life has been rarely explored yet.
- (2) The qualitative experiment and analysis showed that smells and tastes have - throughout the course of participants' lives - individual cultural, environmental and biographical significance. They can function as resources within these three aspects.
- (3) Smell and taste in palliative and hospice is an underrepresented issue, if at all mentioned in the context of therapeutic approaches such as aromatherapy and management of malodorous wounds.

**Conclusions:** Patients in palliative and hospice care might benefit from a raising awareness of the importance of everyday and biography-associated smells and tastes in conceptual and theoretical considerations of gerontological and palliative care practices. Gaining comprehensive knowledge about the individual significance, preferences and aversions of smell and taste of patients is important and should be considered in clinical practice and further research.

**Abstract number:** P1-407

**Abstract type:** Poster

**Elderly Patients with Advanced Heart Failure in Germany: A Qualitative Longitudinal Study on the Patients' Needs and Experiences**

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**Aims:** Heart failure is a major cause of death in Germany and worldwide. In advanced stages it is associated with a high symptom burden and poor long-term prognosis. This study aims, for the first time in Germany, to prospectively explore the experiences and needs of elderly patients with advanced heart failure.

**Methods:** Qualitative longitudinal study with 25 patients with advanced heart failure (NYHA III/IV), aged ≥70 years. Initial interviews were carried out during hospital admission followed by interviews at the patients' home every 3 months for up to 18 months. Interviews were tape-recorded and transcribed verbatim. Qualitative content analysis was conducted across and within the cases.

**Results:** The mean age of the patients (14 female, 11 male) was 85 years (71-98 years). Overall 95 interviews were carried out. Qualitative analyses show that the patients do not focus heart failure as a genuine disease. Moreover, discomforts due to acute crisis or overlapping disease are central, as well as age associated health problems which progressively limit the activities of daily living. The salient loss of familiar concepts such as mental vigour, body image and autonomy matters most. Open questions about emerging needs of support or end of life-issues are recurrently unmet. Although the need for information and dialogue varies depending on changing conditions and individual preferences, a reliable person (e.g. family carer, family doctor) available to address these issues is highly appreciated.

**Conclusion:** The needs of elderly patients with advanced heart failure are various and exceed the capabilities of a single person, e.g. a family doctor. To ensure continuity of care a multidimensional model is required which should be established including both various professions in the community and available family carers. Advanced care planning could be a start to communicate relevant issues of emerging care needs.

**Funding:** Robert Bosch Foundation

**Abstract number:** P1-408

**Abstract type:** Poster

**Analysis of Morbidity Proves the Necessity of Palliative Care in Elders**

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From 2012 Palliative Care services are implemented in 6 from 13 regions of Georgia and capital, Tbilisi. But there are still no special palliative care services available for elders and children. The model of Palliative Care for Elders (PCE), which will be maximally acceptable financially and organizationally for the healthcare system of Georgia and ethnic habits and

psychology of the Country population - currently is under development. To prove the necessity of PCE, the admission of elders (≥60 years) and mean age adults with different disorders to several large hospitals and primary care settings in Tbilisi in 1998 - 2009 was evaluated retrospectively. The effectiveness of drugs administered to these cohorts was also studied. Comparison was done by ANOVA method. 1708 cases (medical records) were studied overall (mean age adults - 18.2%, elders - 81.8%; males - 52%, females = 48%). The admission and morbidity of elders compared to mean age adults with diseases and disorders, advanced stages of which, by international standards require palliative care (cardiovascular diseases, neurological, bone-muscle-connective tissue system disorders and cancer) was significantly higher (P< 0.05). It was also revealed that in these 4 groups of disorders ineffectiveness/less effectiveness of the treatment with standard medications was 7 times higher in elders compared with the same indicator in mean age adults.

The results of survey serve as an additional evidence that:  
1) treatment of chronic conditions in elders is still not standardized and often result in ineffective outcome;  
2) high percent of ineffective treatment in elder patients proves that palliative care, providing symptom management and improving quality of life can be considered as better approach rather than conventional cure.

The acquired result provides additional arguments for implementation of palliative care for elders as specific direction in National healthcare system.

Funded by: IM budget, GNSF grant.

**Abstract number:** P1-409

**Abstract type:** Poster

**Building Consensus and Signposting a Programme of Work for Palliative Care for People with Dementia in Ireland**

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Dementia Palliative Care is a short hand way to talk about ways to meet the end-of-life care needs of people with dementia, their families and carers, reflecting the qualities of person-focused dementia care and the holistic focus of specialist palliative care.

The Alzheimer Society of Ireland (ASI) and the Irish Hospice Foundation (IHF) undertook a six-month feasibility project to build a consensus on the direction of dementia palliative care.

The aim was to gain an understanding of the multiple perspectives involved and identify and signpost a future programme of work.

Through a process of consultation and dialogue with stakeholders-specialists, service providers and family members - a number of issues emerged. The needs of people with dementia and their families can be complex and may cross several service frameworks over the duration of the illness.

Partnerships, networks and shared care models between specialisms and services, based on need and not diagnosis, support end of life care and planning for people with dementia.

In some sectors and services, access to specialist knowledge and advice is not readily available and can particularly impact on end of life care and planning, for example some services have difficulty accessing medical advice about hydration and nutrition and a lack of familiarity with the patient and concerns about outcomes can lead to inappropriate admissions to acute settings.

There are pockets of informal partnerships and networks between services and disciplines that support end of life care for people with dementia. Collaborations across services and disciplines, with a shared vision of person focused care, based on need and not diagnosis, demonstrates the potential to develop integrated partnerships and models of shared care that could form the foundation for a model for dementia palliative care.

**Abstract number:** P1-410

**Abstract type:** Poster

**Nursing Homes Professionals Perspective about End-of-Life Processes**

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**Aim:** To know the perspective of the health-care

professionals that work in Spanish Nursing homes, about end-of-life attention in these centers.

**Methods:** Observational and descriptive study developed in 11 nursing homes in Granada (Spain). An ad hoc questionnaire was developed according to the aim of the study. Professionals rated different aspects of end-of-life process such. For all items 5 was the maximum rating. The results were grouped into broad areas as "psychological" or "social" aspects.

**Results:** Sample was configured by a total of 74 professionals, most of them nurses. Average age was 36 years old. Professionals rated their own practice with end of life patients with a 4,2, their workmates practice with a 4,3 and the institution attention to end-of-life with a 4,2. The less rated areas were "Psychological aspects" and "Ethical aspects" both with a 3. The most rated area was "Physiological aspects" rated with a 4,3. Within "Psychological aspects", monitoring and prevention of complicated bereavement is the worst rated aspect. Ethical aspects such as the use advanced directives are low rated too.

**Conclusions:** Nursing homes in Spain could be a good setting to develop end-of-life care. It's necessary to improve professional's psychological skills in these scenarios. Ethical support should be improved too.

**Abstract number:** P1-411

**Abstract type:** Poster

**Palliative Care for People with Dementia: Gender-narratives**

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**Aims:** Person-centered care as well as palliative care for people with dementia gain importance. Gender-identity is perceived to be a central dimension of being a person. Gender as a social category influences all relationships and has to be acknowledged as relevant aspect in care situations. The aims of the research project presented are:  
1) to generate narratives about gender in care situations involving people with dementia in different care settings,  
2) to contribute to reflection of professionals for gender-sensitive care  
3) to find out „rules of the gender-game“ that support gender-equity in organizational cultures.

**Study design and methods:** Based on a qualitative participatory approach the study design encompasses collaboration with 3 different types of organizations (long term care, home care, acute care) in 4 provinces in Austria. Focus groups (7) with interdisciplinary care teams and expert interviews (10) with management have been conducted. Analyses of the data is undertaken within the research team and validated with gender-experts and practitioners.

**Results:** First results show the diversity of gender as a personal, relational and social category. Themes that emerge within dominant narratives are dignity and appreciation, family dynamics, doing gender while doing care, sexual attraction and intercultural communication. The intersection of gender with other social categories as generation, ethnicity, sexual orientation or social class becomes evident in some situations.

**Conclusion:** Talking about gender-relevant issues in care situations with people with dementia seems to support reflection of professionals and researchers. Gender narratives include different issues and show how doing gender takes place by involving all those who participate in a care situation. Power dynamics interact with doing care and doing gender and have to be followed up in detail to identify gender-equity in organizational cultures.  
(Funded by the Austrian Ministry of Health)

**Abstract number:** P1-412

**Abstract type:** Poster

**Continuous Sedation until Death in Nursing Homes in Flanders, Belgium: A Nationwide Study**

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**Introduction:** Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, has increasingly become a common practice in nursing homes in Flanders, Belgium. Several guidelines on this practice have been published worldwide to ensure the proper use of CSD. However, little is known about the adherence to these guidelines, especially

in nursing homes. Moreover, most of the studies published rely solely on self-reports of physicians' practices. Therefore, we wanted to investigate CSD from both the perspective of the attending physicians and nurses.

**Methods:** All high-care nursing homes in Flanders were included in this study (N = 666). Both the coordinating and advisory physicians, as well as the palliative care nurse of each nursing home, received a questionnaire containing questions on the patient they had most recently treated with CSD (if applicable). The questions addressed patients' characteristics, the indication for administering CSD, the decision-making process, and (clinical) aspects of the course of CSD. The anonymity of the respondents was guaranteed through a careful mailing procedure, involving a lawyer as an intermediary party between respondents and researchers.

**Results:** The general response rate was 70.2% (467 nursing homes participated). We received 431 questionnaires from palliative care nurses (64.7% response), and 380 questionnaires from coordinating and advisory physicians (57.1% response). Cases were reported by 247 nurses (57.3%) and 156 physicians (41.1%). Further results will be presented as the analysis proceeds.

**Discussion:** This is the first study to investigate the practice of CSD in nursing homes from both physicians' as well as nurses' perspectives on a nationwide level. The extensive and representative data provide a solid basis to evaluate the actual practice of CSD in nursing homes in Flanders.

**Funding:** Fund for Scientific Research, Flanders, Belgium

**Abstract number:** P1-413

**Abstract type:** Poster

### Advance Care Planning in Care Homes - It Works!

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**Context:** Advance Care planning is a key part of improving end of life care, especially for the elderly in care homes. Advance Care Planning has been introduced as an integral part of The Gold Standards Framework (GSF) Care Homes Training Programme in end of life care to over 2000 care homes in the UK over the last 8 years. The standard for GSF accreditation that they have to attain is that "every resident is offered an ACP discussion". The GSFCH training programme is a comprehensive phased programme which includes many aspects of end of life care, with over 300 care homes having attained full accreditation.

**Method:** A feedback survey of GSF accredited homes was undertaken.

**Results:** Results showed:

- An increase from minimal use of ACP in care homes to over 90% use.
- Advance Care Planning contributed to an increase in home deaths from 68% to 98%
- Improved communication skills, and contributed to a culture of openness and realisation.
- A growth in confidence in care home staff and use of ACP as a standard part of their care.
- Some additional benefits such as writing of ACP booklet, early discussions with families.
- very positive feedback as to the value of ACP and few reported difficulties.

**Conclusion:** Before the GSFCH Training Programmes, Advance Care Planning in Care Homes was not widespread; this has helped to empower both residents and staff and enable it to become standard practice. This has contributed to overall improvements in care and a reduction in inappropriate hospital admissions. Lessons learnt include:

- Advance Care Planning discussions can be effectively integrated into standard practice within care homes by the staff following training and is integral to quality care.
- Confirmation of the value of introducing ACP discussions in care homes.
- Results from survey & lessons learnt.
- Guidance on use of ACP as part of the wider GSF Care Homes Training Programme.

**Abstract number:** P1-414

**Abstract type:** Poster

### Title: Sustaining Best Practice in Care Homes - Findings from Reaccredited Care Homes Three Years on, Following the Gold Standards Framework Care Homes Training and Accreditation Programme

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**Aim:** To effect organisational and cultural change leading to sustained improvements in End of Life Care for care home

residents.

- Demonstration of successful training and sustained organisational and cultural changes in UK care homes as part of GSF CH Training.

The Gold Standards Framework (GSF) Care Homes training and accreditation programme assesses the care home against 20 quality standards. The accreditation process ensures the standards for quality end of life care are embedded and sustained within the care home, evidenced by portfolio, ADA audit and a robust assessment visit.

Evidence from over 2000 care homes trained, over 300 accredited and the first 100 reaccredited after 3 years reveals sustained improvements in EOLC and ACP, showing a positive impact on the quality of care received toward the end of life and reductions in inappropriate hospitalisation.

Staff have continued to identify and anticipate the needs of the residents as they approach the end of their lives. They have demonstrated continued development and practice improvements through audit and continuous reflective practice. All of these elements have had a direct impact on the reduction of inappropriate crisis hospital admissions toward the end of life.

The portfolios of evidence demonstrate attainment of required standards, feedback from relatives and residents, and whole team involvement. If the work is not embraced by the whole team but undertaken as an isolated project, the impact is reduced and the changes are not sustainable. The reaccredited homes have maintained and improved their standards of care and ACP uptake - not just standard practice but enhanced practice - ensuring consistency and continuity.

**Abstract number:** P1-415

**Abstract type:** Poster

### Care at the End of Life of the Geriatric Patient: Comparison between the Acute Geriatric Unit and the Palliative Care Unit

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**Aims:** To map the Quality of Care (QoC) at the end of life of the geriatric patient using relevant Quality Indicators (QIs). The QoC was assessed both at the Acute Geriatric Unit (AGU) and at the Palliative Care Unit (PCU) of a university hospital in Belgium to identify bottlenecks in the care and to compare QoC between both departments.

**Methods:** The QoC was measured in a retrospective case study by using a set of QIs, collected through systematic literature research and validated via the Delphi method. The target population consisted of patients older than 75 years who had a Do Not Resuscitate (DNR) status and deceased between January 1<sup>st</sup> 2009 and December 31<sup>st</sup> 2010 at the AGU and the PCU and who were hospitalized during more than 48 hours. The Pearson's Chi Square test was used to determine the presence of significant differences between the scores of both departments.

**Results:** A set of 17 QIs was composed. The QIs were related to the principal domains of palliative care. In total, 58 patients were included at the AGU (QI-score generally varying between 0 and 70%) and 59 at the PCU (QI-score generally varying between 50 and 100%). The PCU scored significantly higher for 5 of the 17 QIs, particularly with regard to pain screening, oral care and anxiety screening (all  $p < .001$ ), prescription of rescue medication ( $p < .01$ ) and pain treatment ( $p < .05$ ). Both care units scored low with regard to delirium screening, spiritual care and the involvement of the general practitioner (GP) in the care planning.

**Conclusion:** This study revealed that the palliative approach at both care units could be further optimized. Both departments should perform more delirium screening, should have more attention for the spiritual needs of the patient and should involve the GP of the patient more often in the care planning. For the AGU it is recommended that, if a patient has a DNR status, palliative items concerning pain, oral care and anxiety screening should be routinely added to the patient's record.

### Palliative Care in Children and Adolescents

**Abstract number:** P1-416

**Abstract type:** Poster

### Quality of Pediatric Palliative Care in Lebanon - The Perspectives of Children with Cancer

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**Aims:** The purpose of this study was to evaluate the quality of life (QoL) and symptom management in Lebanese pediatric cancer patients from their own perspectives.

**Design and methods:** The design is cross-sectional and descriptive. The Pediatric Quality of Life Inventory (PedsQL) cancer module and the Memorial Symptom Assessment Scale (MSAS) were administered in Arabic to a convenient sample of pediatric cancer patients over a one year period.

**Results:** A total of 85 patients, mean age 12.5 years, participated in the study; majority came from outpatient clinics. Blood cancer was the most common cancer type with a higher prevalence among the younger age group (7-12 years). Nausea and worry had the lowest scores on the PedsQL indicating poor performance, while procedural anxiety was the highest. A comparison based on age showed significant differences in pain and hurt, nausea, cognitive problems, and global health status/quality of life (GHS/QoL). In children (7-12 years), the most prevalent symptoms were lack of appetite, pain, and nausea while adolescents (13-18 years) experienced mostly lack of energy, irritability, and pain. Most treated symptoms in both groups were pain and nausea. The strongest positive correlation ( $p=0.51$ ) was found between pain and hurt and GHS/QoL.

**Conclusion:** The study group had good performance on the PedsQL subscales except for pain and hurt, nausea, worry, and GHS/QoL. When compared for age, adolescents scored lower on all the subscales. This highlights the impact of age on QoL; where adolescents like children require the same support throughout the disease process. Symptom assessment was adequate yet the treatment received showed lack of proper management. Providing pharmacological interventions with psychological support and assessing their success from the patient's own perspective will alleviate symptom burden and ultimately increase QoL.

**Source of funding:** Lebanese National Council for Scientific Research

**Abstract number:** P1-417

**Abstract type:** Poster

### Interprofessional Information Sharing in Children's Palliative Care How Can We Improve?

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**Background:** Effective children's palliative care requires the involvement of an interdisciplinary team working together towards the achievement of best practice. In Ireland there are approximately 1400 children living with a life limiting condition, the majority of whom wish to be cared for at home. The national policy for the development of children's palliative care names 4 key principles for future developments in children's palliative care - inclusiveness, partnership, comprehensiveness, flexibility. Ineffective communication processes and information sharing have been identified as a block to effective service provision.

**Objective:** To review documentation of end of life decision making and information sharing with professionals caring for children with life limiting illness in Dublin.

**Methods:** A retrospective chart review of a sample of 21 children, known to the Children's Palliative Care services, who were discharged from inpatient care in 2011.

**Results:** 21 discharge episodes reviewed, ten male and eleven female. Age at discharge ranged 2 days-14 years. 8 patients died - 4 died at home, 2 in OLHSC and 2 in other hospitals. Advanced care planning was documented in 16/21 (76%) cases and DNR orders charted in 11/21 (52%). Discharge templates were present in only 4/21 charts (19%). Discharge letters were present in 11/21 charts (52%) and addressed primarily to GP and local paediatricians. Palliative Care was mentioned in 6/11 (54.5%) discharge letters and therefore only 6/21 (28%) of patients known to PCT had this communicated to GP or paediatrician. DNR status was also not communicated to the GP in writing.

**Conclusions:** This review highlights deficits in information sharing between professionals on discharge from hospital of children with life limiting illnesses. This is being addressed in a new discharge template designed by the palliative care team to promote interdisciplinary coordination in provision of palliative and end of life care for children.

**Abstract number:** P1-418

**Abstract type:** Poster

### Promoting Early Childhood Development in Africa - A Vital Aspect of Children's Palliative Care

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## Poster sessions

Every child, no matter what their illness or diagnosis, has the right to play and the right and need to develop to their optimal potential. Ensuring their participation in Early Childhood Development (ECD) programmes is an essential part of children's palliative care in Africa.

For the healthy child, developing physically, cognitively, emotionally and socially requires effort and experience for the smooth transition to the next developmental stage. Consider a child with a life limiting condition who must develop alongside his or her well peers. This child faces all the challenges of a life-threatening illness in addition to growing and developing. Illness and disease affect childhood development for the ill child and often for the siblings as well. This effect differs from age to age but is always detrimental. In response to this need, I was approached by the Hospice Palliative Care Association of South Africa to lead a Task Team to develop guidelines in Early Childhood Development for the use of the hospice services who care for young children and for patients with young children.

The presentation will cover:

- The effect of illness on childhood development
- Assessing the need for the ECD guidelines
- Choosing the optimal team to develop these guidelines
- The process of developing the guidelines
- The topics covered
- The format of the final product
- The dissemination of this information for use by other African and developing countries through the ICPN

Abstract number: P1-419

Abstract type: Poster

### Use of Opioids in a Paediatric Inpatient Population

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**Aim:** Guidelines suggest that morphine, oxycodone or hydromorphone are all appropriate first-line opioids. Every patient on opioids should have doses prescribed as required (PRN) in addition to regularly. As opioid induced constipation is a common and bothersome side effect, all patients prescribed opioids should be on regular laxatives. We reviewed the use of opioids in a paediatric inpatient population to assess compliance with these guidelines.

**Methods:** A cross-section of 73 charts were examined from 5 wards over a 4 month period. Patients were identified using the ward based Misuse of Drugs Act (MDA) records. Hospital records were reviewed and the first opioid prescription for each patient identified. Demographic information for each patient and their analgesic prescriptions were documented.

**Results:** A majority of patients were commenced on morphine preparations including 39 commenced on Oramorph (54.2%), 26 on Morphine Sulphate intravenous infusion (36.1%), 3 on Sevredol (4.2%) and 1 (1.4%) on MST. One patient (1.4%) was started on each of Oxycodone intravenous infusion, oral Oxynorm and Fentanyl intravenous infusion.

Most patients were prescribed other analgesics in addition to their step III opioid with 56 (77.8%) on a step I drug, 41 (56.9%) on a step II drug and 20 (27.8%) on an adjuvant analgesic.

79.2% (57 patients) had a medication prescribed PRN. Only 54.2% (39 patients) were prescribed a laxative on commencing opioids.

Most patients (53 - 73.6%) were not referred to either the acute pain or palliative care teams.

**Conclusion:** Our Lady's Children's Hospital treats many patients who require pain management. The hospital benefits from clinical nurse specialists in acute pain management and palliative care in addition to a paediatric palliative care consultant. Our results show that pain management guidelines are not being followed in all cases. More education is required for staff to manage paediatric pain appropriately.

Abstract number: P1-420

Abstract type: Poster

### Multiple Losses in HIV Positive Children: Interprofessional Palliative Care Can Make a Difference

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**Background:** Martha (10) and her brother Richard (8) stayed with their grandmother (72) in Lesotho after their mother died three years ago of HIV. Both were happy and attended school. Martha was ill for a while and one day when she arrived from school she found her grandmother dead in

her hut. Her father's family came to fetch them and took them to Bloemfontein in South Africa.

Three weeks after the funeral her aunt brought the children to hospital as they were severely malnourished, short of breath and dehydrated. Richard passed away an hour after they arrived at hospital. The diagnosis of pulmonary tuberculosis, chronic diarrhoea and stage-III HIV disease was made and treatment started. The next morning she became acutely psychotic, with auditory and visual hallucinations.

**Discussion:** Previously she lost her mother, her home and her school. Then she lost her grandmother, her friends, her school and then her brother, her health and her mind. Her psychosis resolved on antipsychotic and psychotherapy; her medical condition improved on HAART and TB treatment; and her nutrition improved after she was admitted to the paediatric hospice. She was reunited with her father's family and passed her Grade VI exams as the top student in her class in 2009.

**Lessons learned:** Martha experienced multiple losses on all levels according to Maslow's Needs Triangle, from basics things like housing, family and friends to health, confidence and spontaneity. These losses included the body, mind and spirit. Different members of the multidisciplinary team played an important role in her recovery - children are very resilient and flourish on love and security.

**Recommendations:** Use a multidisciplinary approach to manage each child as an individual, and give them lots of love and encouragement.

Abstract number: P1-421

Abstract type: Poster

### Learning from the First Two Years of Using an Advanced Care Planning Document

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**Introduction:** In 2010, our Health Authority introduced a unified Advance Care Plan (ACP) for children and their parents/carers, providing a framework both for discussing and documenting their agreed wishes. This tool includes: A 'do not attempt resuscitation' (DNAR) instruction, an agreed plan of action to follow when a patient's condition deteriorates, a record of families wishes for place of care, and for other choices during life and after death.

**Aims:** To evaluate the advance care planning tool two years after its implementation, identify levers and barriers to recording preferences and share the learning acquired from implementing this tool.

**Methods:** Quantitative retrospective review of all ACPs made since the introduction of the new tool (2 year period), within our specialist children's hospice, examining: chosen place of care, disease category, and an analysis of the notes of deceased children to assess the impact of the ACP on attaining family's preferred place of care.

**Results:** A total of 62 ACPs were completed (approx 1/3 of case load). Of these 27% died at home, 53% in a children's hospice, and only 20% in hospital. Thus our rate of death outside of the acute hospital was 80%. This is in contrast to the data identified by Craft and Killen (2007) where 74% of children died in hospital.

**Conclusion:** We show the value of ACPs in enabling families to make informed choices about end of life care. The ACP has been well used and has contributed to an 'out of hospital' death rate well above quoted national averages. Also we identified that levers leading to good planning include having a disease for which the management is exclusively palliative or a clear deterioration in a condition for which treatment was previously available (eg relapsed oncology patients). Children with a less predictable course, such as those with a static neurological condition were much less likely to have evidence of good planning, despite being very vulnerable.

Abstract number: P1-422

Abstract type: Poster

### Review of Referral Patterns to a Children's Palliative Care Service before and after the Appointment of a Paediatrician with a Special Interest in Palliative Medicine

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**Background:** The first consultant paediatrician with a special interest in palliative medicine was appointed to a tertiary paediatric centre in Ireland in May 2011. Prior to this, the only Irish children's palliative care service had been led by 2 visiting part time adult palliative medicine physicians. Having a full time palliative medicine paediatrician with an

site has resulted in an increase in the number of referrals to the service. This descriptive study undertakes to compare referral patterns before and after the appointment of the palliative medicine paediatrician.

**Methods:** The medical records of all children referred to the palliative care service from 01/01/2010 to 30/16/2010 and from 01/01/2012 to 30/06/2012 were reviewed retrospectively. Data collected included the number of referrals, diagnoses, referral sources and reasons for referral. SPSS version 18 was used to generate descriptive statistics for both study periods.

**Results:** There were 38 referrals to the children's palliative care service during the first half of 2010 and 56 referrals during the same period in 2012. The most common source of referrals for both periods was medical oncology (27% in 2010; 33% in 2012). In 2012, referrals were received from teams who had not referred in 2010, namely Obstetrics (referred 6 patients), intensive care medicine (7 patients), general paediatrics (4 patients), infectious diseases and emergency medicine (1 patient each). In 2010, 66% of referrals were for symptom control and 9% for terminal care whereas in 2012, 35% of referrals were for symptom control and 36% were for terminal care.

**Conclusions:** Referrals to the children's palliative care service have increased since the appointment of the palliative medicine paediatrician. The pattern of referral sources has changed. The number of referrals for terminal care has increased, which may reflect the fact that new teams are now referring patients. This will help to inform further development of the service.

Abstract number: P1-423

Abstract type: Poster

### Palliative Care Referrals from Neonatal Units: Diagnostic Profile and Outcomes

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**Aims:** There is little data on how palliative care (PC) services can help in managing neonates with life-limiting conditions. We looked to define the population of patients referred from neonatal units to a specialist palliative care service and to analyse their outcomes.

**Method:** A retrospective case series review of the babies referred from neonatal units across London to a tertiary paediatric PC service.

We examined medical notes of babies referred in a 12 month period (October 2011 to September 2012) and extracted the data reported below.

**Results:**

1. Principal life-limiting diagnosis of the patients referred Congenital organ abnormalities with no chromosomal abnormalities 13 (33%)

Chromosomal abnormalities 10 (25%)

Hypoxic ischaemic encephalopathy or cerebral infarct 7 (18%)

Congenital myopathy 4 (10%)

Other 5 (13%): extreme prematurity, mitochondrial disease, epileptic encephalopathy, meningitis

2. Number of babies referred to the PC team in the 1 year period: 39; 2 babies were antenatally referred with confirmed chromosomal abnormalities

3. Number of babies who died on the neonatal unit: 12 (31%)

11 families elected to remain in hospital

1 baby died before she could be discharged

4. Number of babies died after discharge: 13 (33%)

Their place of death: Home 6, Hospice 5

Of note, of the babies discharged from the neonatal unit, only 2 subsequently died in hospital.

Time taken to discharge following referral: Median 3 days, range: same day to 28 days

Time spent out of hospital prior to death: Median 17 days, range: 1 day to 82 days

5. Number of babies still alive: 14 (36%)

1 still an inpatient on the neonatal unit

13 have been discharged.

Time taken to discharge after referral to the PC team: Median 28 days, range: same day to 159 days

**Conclusion:** A specialist PC service can help facilitate rapid discharge and gives parents real options in deciding their preferred place of care and death for their baby.

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Abstract type: Poster

### Maltese Paediatricians' Experience of Paediatric Palliative Care Provision

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Paediatric palliative care (PPC) figures in every paediatrician's daily practice. During its provision, paediatricians may experience both distress and satisfaction with the care provided.

This phenomenological study explores Maltese paediatricians' (MPs) experience of PPC. It elucidates how Maltese paediatricians (MPs) define PPC, identifies any difficulties encountered during paediatric palliative care provision (PPCP) and interventions that may aide them to optimize their provision of PPC.

In-depth, face-to-face, semi-structured interviews were carried out with 11 MPs from a Maltese institution. The transcribed interviews were analysed using interpretative phenomenological analysis. This analysis, apart from MPs' construct of PPC, resulted in three main emergent themes: 'struggling', 'emotional responses' and 'responding to needs'.

MPs feel that PPC aims at improving the quality of life of children and families living with a potentially fatal illness. It should be instituted at diagnosis of the illness, irrespective of the outcome and involves interprofessional, holistic care. MPs encounter several barriers to PPC, including uncertain illness trajectories, parental opposition and organizational barriers. These barriers result in distress for MPs, as they are seen to impede them from providing adequate PPC. PPC results in strong emotional responses. Although burdened with their grief response to a patient's death, MPs derive satisfaction with the knowledge of having provided adequate PPC. The participants voice their need for education and training to counteract feelings of incompetence and further advocate for a team approach both as a personal support mechanism and to enhance quality of care.

Whilst supporting an integrated model of PPC, MPs experience both personal distress and satisfaction through PPC. Implementing facilitators to PPC may help MPs improve care provision, resulting in less personal distress and greater satisfaction.

Abstract number: P1-425

Abstract type: Poster

### Symptoms and Pharmacologic Management among Patients in an Outpatient Cancer Rehabilitation Clinic

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**Context:** The burden of cancer-related symptoms among patients undergoing cancer rehabilitation in an outpatient setting has not been investigated formally.

**Objectives:** To identify symptoms experienced by cancer patients in an outpatient rehabilitation clinic and to document the medications and physiatrists' interventions used to manage symptoms and address other rehabilitation needs.

**Methods:** A retrospective chart review of consecutive patients who visited an outpatient rehabilitation clinic (N=200) in a tertiary cancer center. The main outcome measures were Edmonton Symptom Assessment Scale (ESAS) scores during outpatient care; medication lists; and clinic notes.

**Results:** Patients' median age was 55 years (range, 15-93y), and 52% (103/200) were female. According to a mean ESAS visual analog scale score  $\pm$  standard deviation, the most intense symptom reported during outpatient rehabilitation clinic visits was fatigue (4.11 $\pm$ 2.84), followed by sleep disruption (3.52 $\pm$ 2.96), pain (3.29 $\pm$ 2.9), and diminished appetite (3.09 $\pm$ 3.03). The most common problems addressed by physiatrists in the clinic were mobility (95%), medical issues (63%), symptoms (44%), and issues related to brace/split/durable medical equipment (DME) (25%). A pain score of  $\geq 3$ , but not other symptoms' score  $\geq 3$ , was associated with the physiatrist's addressing pain in the clinic notes ( $p < 0.001$ ). Symptom scores of  $\geq 3$  for pain, nausea, depression, or shortness of breath were significantly associated with use of medications targeting these symptoms.

**Conclusion:** We found significant symptom burden in cancer patients during their visits to the outpatient rehabilitation clinic. Although the physiatrist's primary role is to address mobility-related issues, addressing cancer-related symptoms is also important and needed in this cancer patient population.

Abstract number: P1-426

Abstract type: Poster

### The Spectrum of Symptoms and its Management in Children with an Incurable Brain Tumor; Insight in the Palliative Phase

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**Introduction:** CNS tumors involve 25% of pediatric oncology patients leading to death in 30%. The aim of this study is to gain insight in the variety and extend of symptoms during the palliative phase, their treatment, and what course can be expected.

**Methods:** We retrospectively reviewed all medical charts of patients from the Emma Children's Hospital who died of a brain tumor between May 2005 and September 2012.

**Results:** 34 children with a brain tumor (medulloblastoma/sPNET 8, ependymoma 4, ATRT 5, pontine glioma 5, glioblastoma multiforme 7, other 5) aged 0.4-17.2 years at time of death were included. After 0-2480 days from diagnosis (median 168) infaust prognosis was evident with death following after 1-603 (median 68 days). Palliative anticancer treatment was given in 68%, comprising chemotherapy solely in 11 (32%), and radiotherapy solely in 5 (15%) patients, while 6 (18%) received a combination of both. Symptoms were categorized in 17 groups of which most frequently occurring were pain 79%, reduced mobility 74%, change of appearance and disturbed cognition both 62%, seizures 53%, somnolence and vomiting (both 50%). Cranial nerve symptoms recorded were reduced vision 47%, squint and facial asymmetry both 44%, balance/hearing loss 41% speech problems 32%, dysphagia 21%. Admission days were 0-31 days/patient, median 5. Pain was treated satisfactory in 96%, requiring systemic morphine and sedation eventually in 38% and 15% respectively. A do-not-resuscitate code was discussed with all parents at 0-576 days before death, median 50. 28 (82%) patients died at home in nonolent state. 6 patients were admitted for systemic anticonvulsants, pain medication and sedation until death.

**Conclusion:** A diversity of symptoms occurred during the palliative phase of a brain tumor necessitating intensive symptom management, mostly conducted at home. This knowledge enables advanced palliative care planning and helps to prepare parents and professionals to optimize palliative care.

Abstract number: P1-427

Abstract type: Poster

### Withdrawing Ventilatory Support in Children and Young People, Outside the Intensive Care Unit - Is this a Feasible Option?

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**Aims:** Offering choice in place of end of life care is a key factor in palliative care provision. In the UK, many Intensive Care Unit (ICU) deaths occur after planned withdrawal of life-sustaining ventilation (WLSV) when continued treatment is deemed not in a child's best interests. As timing of WLSV can be identified, this study aimed to explore the feasibility of offering choice in place of extubation.

**Methods:** A 10-year retrospective case note review identified families who elected for WLSV outside ICU. Symptom management, staffing requirements and practical issues were identified to determine overall feasibility of the process.

**Results:** 18 families chose for their child to undergo WLSV outside ICU. Five went home, 8 to a children's hospice, 1 to another hospital ward, 1 to a residential school and 3 died before transfer. (Ages 1 month to 16 years). Symptom management plans (SMP) were devised in anticipation of agitation, seizures, breathing changes, pain, secretions and fluid requirements. No child required additional medication beyond that anticipated in the SMP. Time until death ranged from immediate to 5 days (1 child survived long-term). Practical considerations included access to the property, transfer timing, health professional availability to manage transfer and extubation and support in the home. Long-term care arrangements for the child and family were essential, given the uncertain duration of survival. 24-hour nursing was not available in the home but community nurses and/or family doctors could attend if required. Families were trained to deliver their child's care and medication and 24-hour palliative care support was available via telephone. Of those surviving to discharge, no transfer failed and no child was readmitted to hospital.

**Conclusion:** Withdrawal of life-sustaining ventilation outside the ICU is feasible but requires robust planning. We believe that palliative care and ICU teams should be providing this service if WLSV is planned.

Abstract number: P1-428

Abstract type: Poster

### Experiences of Brazilian Families in Care Delivery to Children and Adolescents with Cancer in Palliative Care

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**Aim:** Understand family members' experience in care delivery to children and adolescents with cancer during the palliative care phase, particularly in end-of-life care.

**Method:** Descriptive and exploratory field study with qualitative data analysis. Participants were 14 families of children and adolescents with cancer, accompanied at the Pediatric Oncology sector of a teaching hospital in São Paulo state, who died between July 2010 and June 2011. Data were collected through interviews at home, together with the application of the genogram and ecomap, addressing questions about the care experience, needs during this phase and the family's organization for care. To complement this phase, clinical data were surveyed in the patients' medical records.

**Results:** The results were organized around three themes: the impact of the worsening of the disease on the family dynamics; home care and the family's experience in view of palliative care. The relatives manifested themselves about painful feelings, uncertainties and conflicts when confronted with the cancer diagnosis, which demanded family restructuring. The worsening of the disease was identified through the observation of signs and symptoms that did not respond to the treatment. It was observed that the family experience during end-of-life care was marked by the acknowledgement of the disease's severity, accompanied by the search to maintain a normal daily life. The health team was mentioned as an important element, as it was responsible for support during treatment and in the palliative care phase. The study participants considered that the families were active caregivers during treatment, even in the palliative care phase. They highlighted that open communication and daily information are fundamental, but these were not systematic practices.

**Conclusion:** The results contributed to understand the care process for children and adolescents with cancer in the light of palliative care principles.

Abstract number: P1-429

Abstract type: Poster

### Advance Care Planning in Pediatrics: The Care Providers' Perspective

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**Background and aims:** Advance care planning (ACP) is increasingly regarded as the gold standard in the care of patients with life-limiting illnesses. Research has focused on adults, but ACP is also being practiced in pediatrics (pACP). Health care providers may have to deal with unknown diagnoses and prognoses, patients without decision making capacity and a complex social network. However, research on pACP has widely neglected the professionals' perspective. Our aim was to investigate the experiences and needs of both the facilitators and the recipients of pACP.

**Methods:** We conducted 16 semi-structured personal interviews with experts in the care of severely ill children and adolescents. Interviewees were from different professions, settings and institutions. The interviews were evaluated using qualitative content analysis, and categories were constructed out of the material.

**Results:** Pediatric ACP is perceived as important by all care providers. Important pACP-elements are: Repeated discussions with the parents, clarifying the treatment preferences for emergency situations in advance, and better cooperation of clinicians with non-medical care providers in the community. An advance directive (AD) should be individualized, completed with the treating physician and validated by his signature (shared decision making). Conflicts may arise between intensive care/emergency physicians and social-educational institutions without clinicians: The former have difficulties in accepting a child's AD that limits therapy and feel that in such cases they should not be called in, whereas the latter have difficulties in following a child's AD without the presence of a physician and will therefore routinely call the emergency service to assist them.

**Conclusion:** This is the first European study that investigates

## Poster sessions

the perspective of professionals on pACP. There is a need for pACP, but the perspectives differ between care providers. A pACP-program should account for those differences.

**Abstract number:** P1-430  
**Abstract type:** Poster

### If Palliative Care Is a Children's Right, Why Do So Few Children Receive it?

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**Aims:** To identify successful methods to increase access to palliative care for children and young people globally. To recommend further activities to accelerate development of children's palliative care.

**Methods:** Development of palliative care for children has been effective in some countries and regions, but very slow in most parts of the world and especially in poorly resourced countries and regions. A global movement has mapped development worldwide, and identified effective activities that influenced development in both the public and private domain. Challenged by conflicting palliative care priorities and with minimum funding, palliative care activities for children have nevertheless increased worldwide through education, advocacy, dissemination of information, mentorship and support from model programmes both in care and education. sharing of expertise and knowledge, across borders and continents, has supported this development.

**Results:** The project has identified the effectiveness of sharing of experience and expertise and using model programmes as exemplars and supportive resources within countries and regions. Education with mentorship has been more effective in stimulating development than advocacy, however a combined approach working alongside national palliative care associations, has shown to be most effective.

Regional education teams of practitioners willing to travel to train and to accept professionals for clinical placements have been established to provide a regional resource for further training and mentorship.

**Conclusion:** Growth of services for children and young people is dependent on effective networking and partnerships. To rapidly scale up development of palliative care for children, further resources should be dedicated to education, strengthening model sites for mentorship, and building regional resources; Advocacy initiatives must include national associations and champions to strengthen the right of life-limited children to palliative care.

**Abstract number:** P1-431  
**Abstract type:** Poster

### Accessing the Right to Palliative Care for Children in 3 Countries in Sub-Saharan Africa

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**Aims:** To increase access to palliative care and pain relief for children and adolescents in 3 countries in sub-Saharan Africa with limited palliative care development for this age group, through education, advocacy, model programme development and mentorship.

**Methods:** HIV and Palliative care programmes were assessed for suitability for development as Beacon Centres for palliative care for children. Programmes selected in 3 countries all had strong infrastructure, management support and access to pain-relieving drugs including opioids.

A curriculum for a six month certificate course for health care professionals, a textbook for Africa and other relevant materials were developed. Training of health care professionals at certificate level and introductory level was completed, and community care workers received a modified training. All three centres were developed into centres of excellence for palliative care for children in their countries.

A web-based Virtual Resource Centre was initiated for the dissemination of information and to encourage discussion. Two external evaluations were carried out  
**Results:** 208 professionals completed the Certificate course and passed the final examination.

A Diploma in Children's Palliative Care has been developed and is waiting for final accreditation. This will be available for all East African countries.

Training was expanded to many institutions in each country. Advocacy has increased awareness in their countries.

The Beacon centre organisations have included services for children into their long-term strategies

Support from management and involvement of the national palliative care association was essential for success.

Students identified communication skills and pain management as most important. Play and early childhood development were identified as new knowledge by many.

**Conclusion:** Developing the 3 Beacon centres has strengthened services to children in the sub-Saharan region through sharing of lessons learned and education.

**Abstract number:** P1-432  
**Abstract type:** Poster

### The Course of Decision-making Regarding Ventilator Support in Families with Spinal Muscular Atrophy Type 1 and Respiratory Failure

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**Introduction:** Spinal muscular atrophy type 1 (SMA 1) is an inherited neurodegenerative disease presenting in the first year of life. Without ventilation support death occurs within the first two years of life. Even with intensive treatment the majority of children die in early childhood. There are regional differences in physician recommendation for ventilator therapy ranging from respiratory support, non-invasive ventilation (NIV) to tracheotomy and mechanical ventilation.

**Material and methods:** We retrospectively analyzed the courses of decision-making regarding respiratory therapy in nine infants with SMA 1. Our pediatric palliative care team (PCT) cared for them between 2001 and 2012. All discussions about decision making regarding respiratory care were analyzed on the basis of the PCT documentary charts.

**Results:** In their first year of life n=5/9 patients (pt) died, in their third year n=3/9 pt and n=1/9 pt is still alive at the age of 18 months without ventilation therapy. n=3/9 had NIV (died in the mean age of 24 months), n=6/9 had supplementary oxygen (two pt died suddenly at a mean age of 4 months, three pt died at a mean age of 6 months). In this cohort no family decided on tracheotomy.

In all nine families the discussions about ventilation options were primarily lead by the physicians of the PCT. It was always an ongoing process with recurrent discussions. The physicians have never foisted the family on a decision and the PCT always supported the choice of the families.

**Conclusion:** Physicians of a PCT looking after children with SMA 1 should be familiar with all options regarding respiratory support. Care options should be presented in an open and balanced way. The decision making process should start as early as possible in the course of the disease and may last until the end of care. The physician should accept either decision of the family particular as no international guidelines exist regarding ventilation support in children with SMA 1 so far.

**Abstract number:** P1-433  
**Abstract type:** Poster

### Challenges in Provision of Pediatric Palliative Care in a Developing Country (Kenya)

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Palliative care has fully been integrated into existing health services yet there are pediatric patients who would benefit tremendously from it. Health workers site lack of knowledge and skills, staff shortages and lack of proper equipment and drugs to care for these patients.

5 rural hospitals will be reviewed with an aim of uncovering the bottle necks that hinder provision of pediatric palliative care services. It is hoped that this review will enlighten the administration and service providers on the challenges and help them come up with solutions that will enable them provide pediatric palliative care services.

## Advocacy & Media

**Abstract number:** P1-434  
**Abstract type:** Poster

### Think Ahead as Self-advocacy Tool for the Public in Discussing and Recording their Preferences around End of Life

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**Research aims:** Think Ahead is the 'flagship project' of the Forum on End of Life in Ireland. Think Ahead is also a public awareness initiative and empowers people to become self-advocates in their care.

A number of pilots were carried out with the aim of gauging public responses to Think Ahead and what might prompt people to participate with the project, as well as engaging the medical and legal professions and community leaders that people may choose to assist them in having important discussions.

**Study design and methods:** A wide range of consultation processes have been engaged in, including focus groups with the public, as well as a baseline survey and consultations with stakeholders from representative medical and legal organisations, NGOs, and statutory bodies. 58% of respondents to a survey in 2010 said that they would be interested in availing of a service like Think Ahead and the focus groups and baseline survey in 2011 sought to discover if this was still the case.

Two GP pilots were carried out in 2011-2012, involving 120 patients. Two regional pilots began in counties Limerick and Louth in September 2012 and will run until November 2012 with a view to a national launch in 2013.

**Results:** The majority of participants in the focus groups in September 2011 and respondents to the baseline survey in December 2011 considered Think Ahead to be a welcome initiative, in particular in its capacity to initiate conversations. Results from the GP pilots have been analysed and report very positive outcomes for both patients and GPs. These findings are due to be published in the Irish Medical Journal by the end of 2012.

Data is being gathered from the regional pilots and will then be analysed.

**Conclusion:** Further work is required to fully evaluate Think Ahead as a tool for people to become self-advocates but these findings show significant potential in the area of public empowerment.

**Abstract number:** P1-435  
**Abstract type:** Poster

### Public Advocacy Activities for Palliative Care System Creating and Palliative Care State Policy Shaping in Ukraine

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**Urgency of an issue:** Executives and members of NGO 'All-Ukrainian League of Palliative and Hospice Care' are aware that the problem of palliative care in Ukraine is vital. Every year about 2 million cancer patients, elderly people with severe incurable chronic diseases, patients with AIDS and TB, children and their families need palliative care (PC).

**Description of the situation:** Unfortunately, PC system is not yet created in our country. There is a great need in specialized palliative care institutions. There are about 20 inpatient hospice and palliative care units in hospitals, although mobile teams are virtually absent, there is lack of funding, equipment, well-trained professionals. Ukraine has not yet developed volunteerism, which has long been the norm in the civilized world.

Another major problem is lack of access to modern effective anaesthetic, too complicated procedure for PC at home, unnecessarily limited total daily dose and range of pain reliefs. Ukraine is the only country in Europe, where tablet morphine, syrups and transdermal therapeutic system are not used yet.

**Goals and activities of the league:** We actively conduct advocacy activities to improve the situation given. League's Experts elaborate Palliative Care Development State Program Draft; take part in the drafting law of the Cabinet of Ministers of Ukraine to improve the availability of opioid analgesics for PC patients, directions of Ministry of Health and Ministry of Social Policy of Ukraine, National Standards for PC, clinical protocols and guidelines for PC professionals. The Ukrainians as European nation should implement European standards. These are democracy and prosperity, human rights and freedoms guarantee, consolidation of public, state and society efforts.

Abstract number: P1-436  
Abstract type: Poster

### Global, Regional and National Advocacy on Palliative Care: Sharing Lessons on Influencing the Non-communicable Diseases Agenda

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**Aims:** The aim of this presentation will be to highlight the process, successes, challenges and lessons learned on global advocacy on palliative care by international pan-national and national organisations in relation to the Non-Communicable Diseases (NCDs) agenda.

**Methods:** Organisations have worked together to influence the decision making to ensure the inclusion of palliative care within NCDs documentation at the global, regional and national level. This has been done through coalition building, the development of consultation responses, supportive materials for national palliative care associations, attendance at UN meetings and engaging with governments and decision makers. Through a survey of organisations, a review of published literature on this topic and through interviews with key participants, we will look at the challenges and successes of this work as well as the importance of national and local involvement.

**Results:** In 2011, palliative care was referenced throughout the UN Political Declaration on NCDs and in 2012 and an 'Access to Palliative Care indicator' was included in the draft monitoring and evaluation framework on NCDs.

**Conclusion:** Palliative care has to date been well included within the global discussion on Non-Communicable Diseases but there have been challenges along the way. Collaboration, consultation and consensus building are key components of successful advocacy at all levels but they also bring challenges. To ensure success, palliative care organisations need to work together, as well as to build coalitions with non-palliative care specific allies.

Abstract number: P1-437  
Abstract type: Poster

### The Advocacy Campaign for Access to Adequate Pain Relief in Armenia

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**Background:** According to international human rights law, countries have to provide pain treatment medications for patients suffering from chronic and life-threatening diseases as part of their core obligations under the right to health; failure to take reasonable steps to ensure that people who suffer pain have access to adequate pain treatment may result in the violation of the obligation to protect against cruel, inhuman and degrading treatment.

Over 3000 people need daily palliative care in Armenia, 70-80% of them need pain relief and still only about 200 patients have access to opioids. Although the oral morphine is the 'gold standard' for palliative care, in Armenia it is still available in injectable form only. There are no pain control policies in the country. Patients have limited access to opioids in outpatients care. Patients do not have access to the opioids because of lack of regulations related to that. Physicians as well as patients yet have opiophobia, concerning about the addiction and legacy issues. The country does not have "The Law on The Rights of Patients".

To develop Patient Advocacy in the country, and to promote the improvement of healthcare legislation there was initiated the "Life Without Pain" Campaign in Armenia to raise the awareness about the access to adequate pain relief for suffering patients as a basic human right. Many volunteers, celebrities as well as the artists joined to support the "Life without Pain" Campaign in Armenia. Press conferences, interviews for TV and radio, round tables with physicians and health care seniors were provided to get them involved into the Campaign. As part of a nation-wide campaign on Access to Pain-relief, a series of street actions and info-fairs were held in different parts of Yerevan to get people have signed the petition for pain relief. The torture chair was presented as a symbol of the untreated pain.

Abstract number: P1-438  
Abstract type: Poster

### We Have Right to Pain Treatment - Human Rights NGOs Report in Ukraine

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**Situation:** There is no developed palliative care system, that corresponds to the world standards. Lack of such system leads to violation of the fundamental human rights. Hospices are established in some regions of Ukraine, but they are isolated entities located on a big distances from each other. "Palliative care" definition itself is a very abstract category even for healthcare professionals, most of them associate it with just hospices. While overwhelming majority of patients who need palliative care, stay at their homes. The real situation is that a patient is able to get a required dose of opioids, when other analgesics do not control pain any more, only while staying at healthcare facilities. After the discharge from the hospital a terminally ill patients with chronic pain syndrome has to deal one on one with prohibitive and hyper-controlling system of handling opioids.

**Methodology:** The given report was drafted on the basis of in-depth - interviews with cancer patients and their relatives, people living with HIV/AIDS, healthcare professionals, including oncologists, AIDS Centers' staff, social workers as well as administrative staff of hospitals and state-run healthcare system servants.

The interviews were conducted in Mar.2010 - Nov.2012. The patients were city residents or dwelled in rural locations while being treated at hospice either or at home. The interviews were conducted at patients' homes or at a hospice upon patient's consent and consent by their family members.

**Lessons learned:** The problem is that the Government fails to fulfill the obligations imposed by some international treaties, including human rights standards applied in the area of palliative care. The most severe and prevalent violations of human rights among palliative care patients were observed and documented among the patients living at their homes, in rural regions, at a considerable distance from district healthcare facilities.

## Spirituality

Abstract number: P1-439  
Abstract type: Poster

### Hospice Patients' and Caregivers' Perspectives on Spiritual Concerns

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**Aim:** Hospice providers must assess and respond to spiritual pain and symptoms as well as physical pain and symptoms. The aim of this study is to determine whether or not patients and their caregivers recognize spiritual pain or symptoms, and how such inquiries might lead to more successful assessment and treatment of them.

**Methods:** This is a pilot, qualitative study of 15 caregivers and hospice patients who were physically and cognitively able to consent and participate in an interview. Consent forms and semi-structured interview schedules were created for patients and caregivers. A hospice physician interviewed patients and a psychologist interviewed caregivers. Interviews were audio-taped and analyzed according to methods of grounded theory.

**Results:** All patients had well-controlled pain and symptoms and did not openly express spiritual concerns. Four common themes were identified across patients and caregivers:

- 1) connectedness to others,
- 2) religion,
- 3) personal concerns, and
- 4) dying.

Both patients and caregivers mentioned exchanging caregiving roles, patients focused on concern for the caregiver while the caregiver focused on the closeness and meaning of family relationships. Both tended to equate spirituality with religion; if they did not define themselves as religious they did not define themselves as spiritual. Patients were concerned about future pain and loss of control and functioning and caregivers about their ability to meet the patients' needs. Both relied on past experiences with death to help them cope.

**Conclusions:** Although spiritual issues were revealed in their narratives, patients and caregivers did not name them as such. Future study of how patients and caregivers define and describe non-physical pain and symptoms may lead to better assessment of spiritual pain and symptoms. The Summa Foundation funded this study.

Abstract number: P1-440  
Abstract type: Poster

### EPIONE: Spanish Association for Palliative Care Project to Assess and Promote Spiritual Resources in Patients: Preliminary Results

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*Suffering and spirituality* are core topics in palliative care. Arising from the Spirituality Task Force from (BLINDED) works, we elaborated and validated a measure for patient's spiritual needs and resources appraisal, aiming to provide some spiritual care guidelines for clinical use. The 8 item likert-scale questionnaire explore three related dimensions: Intrapersonal (meaning or coherence); Interpersonal (love, harmonic relationships) and; Transpersonal (legacy, hope and belonging).

**Design & analysis:** Correlational study on a sample of 121. Descriptive, bivariate and multivariate statistics on socio-demographic, clinical, spirituality, depression, anxiety, symptoms, and resilience variables are performed. **Results:** Confirmatory factor analysis supported the three-factor structure with an underlying second-order factor named spirituality construct. Every indicator loaded significantly ( $p < .05$ ) and high on the three hypothesized first order factors, giving support to the overall spirituality approach. The three first order factors also loaded significantly ( $p < .05$ ) and high in second order hypothesized factor.

Adequate reliability and criterion validity results were found: Positive and high relations with other spirituality measures, FACIT-Sp, were found: .64 ( $p < .001$ ) with meaning; .32 ( $p = .001$ ) with peace; and .32 ( $p = .001$ ) with faith. As regards predictive validity, spirituality performed as expected, spirituality general factor correlated: -.45 ( $p < .001$ ) with depression; -.26 ( $p = .006$ ) with anxiety; -.18 ( $p = .06$  m.s.) with symptoms; and .33 ( $p < .001$ ) with resilience.

Clinical applicability of the questionnaire was also good in terms of acceptance, comprehension and perception of the benefits for the patients.

**Conclusions:** The new GES measure of spirituality based on a solid empirical research and *bedside* experience shows good psychometric properties and clinical applicability.

Abstract number: P1-441  
Abstract type: Poster

### Counting on a Miracle: Palliative Care Doctors' Clinical Encounters with Patients at the End of Life who Hope for a Miracle

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**Background:** The delivery of palliative care should incorporate impeccable assessment which should include spiritual needs. Patients who continue to hope for a divine miracle at the end of life present challenges to health care professionals, hampering discussions on care planning.

**Aims:** To explore UK palliative care doctors' experiences of caring for patients with a terminal illness who continue to hope for a miracle at the end of life, and examine how well these complex situations are negotiated.

**Methods:** Qualitative interviews among palliative care consultants and associate specialists purposely selected from three palliative care units. Transcribed interviews were analysed using the framework approach.

**Results:** 5 female and 1 male doctors consented to interview. Four themes were identified:

- (i) 'The driving force behind belief' which referred to the source of patients' beliefs;
- (ii) 'Approaching patients and their family' which included reference to timely and open discussions and acknowledgement of patient-held meanings of religion and faith;
- (iii) 'Personal impact' which refers to the effects of caring for this patient group and;
- (iv) 'The centrality of teams' which refers to the supportive environment of the clinical team when caring for this group of patients.

**Conclusion:** This study identifies that increasing social diversity brings with it patients who hold views which at times may be considered idiosyncratic or anti-therapeutic and therefore challenge open and timely communication. However, we also identify that non-judgemental listening skills and open support from other clinical team members are essential in order to provide culturally relativist and effective care.

## Poster sessions

Abstract number: P1-442  
Abstract type: Poster

### Can a Palliative Care Program Fully Supported on Electronic Records Incorporate Adequate Provision for the Spiritual Aspects of Palliative Care?

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Needs centered Palliative Care (PC) requires knowledge, commitment and robust documentation. Information accessible to professionals helps match complexity to level of intervention and promote comprehensive and multidisciplinary approach raising awareness of PC resources. Single point of entry at referral impulses timely PC access. Suffering is acknowledged as complex, nebulous and often difficult to assess. It has physical or psychological manifestations: feelings of hopelessness and worthlessness, sense of meaninglessness. It may exacerbate, and be exacerbated, by psychosocial and physical disturbances. Systematic assessment and approach to these needs ought to be incorporated into general systems.

**Aims:** To improve accessibility to holistic PC decreasing uncertainty and variability in care, reducing the intricacy of the PC care process by a systematic approach. To ensure spirituality is an integral part of assessment, management and multidisciplinary treatment plans. Its outcomes systematically measured. To determine whether Electronic Palliative Care Records (EPCR) are practical in reference to it. **Method:** Working with primary care and with good coordination among all professionals, we defined standard criteria for the PC process. Single referral, clinical history MDT plan and discharge documents incorporating Spirituality were created.

**Results:** quantitative and qualitative data from the analysis of spiritual assessment, identified needs, responses and outcomes extracted from all patients referred the regional specialist PC program EPCR in a 16 month period are presented. 3000 referral documents, over 2000 assessments, Multidisciplinary (MDT) plans protocols as well as over 24000 contacts to the regional 24h service.

**Conclusion:** Data relating to spiritual needs and evolution and holding the multidisciplinary plan of action in MDT protocols can be accessed via EPCR and supports continuity of care by earlier identification and spiritual needs registering

Abstract number: P1-443  
Abstract type: Poster

Abstract withdrawn

Abstract number: P1-444  
Abstract type: Poster

### Evaluation of Spiritual Assessment and its Challenges in Georgia

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**Research aims:** Georgia is the Former Soviet Country with population of 4.5 million. Approximately 42,000 death cases are registered annually in Georgia, approx. 25,000 patients require Palliative Care (PC) and pain relief. Given that at least 2 family members provide care for terminal patients, significant improvement of approximately 75,000 people overall can be achieved through PC service annually.

The aim of the study was to evaluate of spiritual care assessment, its place, role and challenges in patients whole care in Georgia.

**Study design:** The interviewing of 128 patients, their care givers and health care professionals was performed. The level of their competence, experience, knowledge and tools using for assessment were evaluated by specially designed questionnaires. The respective database was created and analyzed.

**Results:** The primary spiritual assessment in palliative care settings done mostly by health care professionals in Georgia. This is related with lack of multidisciplinary teams and missing the spiritual counselors in multidisciplinary teams. Practically in some cases in medical documentation is missing the spiritual assessment and there is the still in numerous of cases spiritual care is equal with religion. Problem becomes more problematic when patient is not

informed regarding the disease and prognosis.

**Conclusion:** Spiritual assessment is essential and non-separate part of patients' whole assessment. It should be done by professionals and knowledgeable persons having the special skills. Spiritual assessment has to be noted in medical documentation properly.

The challenges of presentation of spiritual assessment should be caused by:

Lack of spiritual counselors in multidisciplinary teams;  
Lack of multidisciplinary teams taking care of the patients;  
Lack of evaluation tools; Lack of information and problems of shearing bad news with patients and their caregivers;  
Lack of communication and challenges of team playing.

Abstract number: P1-445  
Abstract type: Poster

### Beyond 'the Gate': Comparison of the Impact of Two Versions of a Course Designed to Raise Spiritual Awareness for Health Professionals

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**Background:** The established 'Opening the Spiritual Gate' education programme, used across cancer networks in the North West of England increasingly over the last 6 years, is designed to help the health & social care workforce to increase spiritual awareness & improve the confidence of staff in assessing & meeting spiritual & religious needs of patients & families. The course includes recognising spiritual distress, the religious needs of different faith groups, communicating where there are no answers, recording & reporting spiritual conversations and resources and support. **Method:** Evaluation of the pilot had already demonstrated significant change in confidence in those undertaking the course but the face to face and online study had not been compared. As part of an evaluation of the course, pre & post course confidence scales relating to assessment of spiritual & religious needs, providing spiritual & religious care, & the need for further training were completed by individual health professionals, who had undertaken the face to face study day or the four week online facilitated version of the same course. These were analysed to evaluate the impact of the face to face study compared to the online course on participants.

**Results:** Both the face to face study day and the online learning produced significant improvement in the confidence of participants and the poster demonstrates how these compare.

**Conclusions:** Both face to face training and a facilitated online course can be utilised to help to increase awareness of the spiritual and religious needs of patients and families, dependent upon the learning preferences and work needs of health professionals.

Abstract number: P1-446  
Abstract type: Poster

### Spiritual and Religious Needs of Chronically Ill Patients in Poland. Validation of the Polish Version of the SpREUK Questionnaire

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**Aims:** The SpREUK (acronym of "Spiritual and Religious Attitudes in Dealing with Illness") by A. Büssing has been created in Germany. Author with collaborators have started to test the SpREUK in predominantly Catholic Poland. Polish religiosity displayed an extremely "Church oriented" structure, and church affiliation was and still is an important indicator of national identity.

**Methods:** Participants: All individuals were informed of the purpose of the study, were assured of confidentiality, and gave informed consent to participate. The patients were recruited consecutively by a psychologist and educators in various hospitals, nursing homes and hospice-palliative care units.

**Measures:** All items of the respective instruments were translated by a bi-language scientist, and critically discussed with a committee of Polish psychologists, theologians and medical doctors, and the primary author of the SpREUK.

**Results:** The SpREUK was primarily designed to be used in secular societies with both religious/spiritual and secular patients. However, the Polish sample consist of 100% Catholics, and thus there was less variance among the different patients which would regard themselves as religious (85%) rather than spiritual but not religious (2%) or neither religious nor spiritual (13%).

**Conclusions:** Although Polish religiosity displayed an extremely "Church oriented", in the past decades it has been changed. People stay religious; many become engaged in more private and more intrinsic (as opposed to extrinsic) ways of religiosity. In many cases, however, people's religiousness does not include the Church as an indispensable element. Consequently there is a need of further research regarding spiritual needs of all the patients - those who are still religious and the growing number of those who do not find help in traditional rituals during chronic illness or towards end of life.

Abstract number: P1-447  
Abstract type: Poster

### Research Priorities in Spiritual Care: Views of European Experts

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**Background:** Spiritual care is an essential component of palliative care, but one that is often neglected in clinical practice and research.

**Aim:** To identify research priorities in spiritual care, to take forward the provision of spiritual care across Europe.

**Methods:** The Halley Stewart Trust Symposium on Spiritual Care in Palliative Care was convened at King's College London, UK, on 23 October 2012. Invited experts included researchers and clinicians recruited through the EAPC Spiritual Care Taskforce and patients and carers identified through the local Symposium Advisory Group. First, state-of-the-science presentations covered three priority areas identified in the 2012 Taskforce spiritual care survey:

(1) effectiveness and interventions;  
(2) conversation models and staff attitudes; and  
(3) assessment and screening. Second, delegates (in three groups) listed, discussed and prioritised research questions using a Nominal Group Technique approach. Thematic content analysis was used to explore group members' lists of research priorities.

**Results:** 39 delegates attended from the UK, Ireland, Netherlands, Belgium, Spain, Sweden, Denmark, Poland and USA, including 7 patients and carers, researchers (e.g. from sociology, ethics, palliative care, theology), clinicians (nurses, doctors, social workers, chaplains) and policy experts. The priority research questions in the three domains related to: (1) the objectives of spiritual care; (2) barriers to staff-patient communication; and (3) understanding diverse populations (e.g. culture, language, faith, diagnosis).

**Discussion:** This landmark Symposium was the first of 3 annual meetings to establish an agreed research agenda and consensus to progress the development of patient-centred spiritual care in Europe. Findings will be used as a spring-board for future focussed research and debate.  
Funder: Sir Halley Stewart Trust

Abstract number: P1-448  
Abstract type: Poster

### Implementing the Ars Moriendimodel in Palliative Home Care: A Pilot Study

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**Background:** Assessing the spiritual well-being of palliative patients is often perceived as difficult by professional care givers. Previous research showed that they would appreciate a directive for spiritual conversations, if this tool would be not too structured, not too religious and useful in clinical practice.

**Aim:** To investigate the experiences of general practitioners, district nurses and patients with the Dutch ars moriendimodel as a directive for spiritual conversations in palliative home care.

**Method:** Qualitative semi-structured interview pilot study in Flanders.

**Results:** All professional care givers (n=7) experienced the ars moriendimodel as a useful directive to talk about spirituality at the end of life. They stressed the importance of adjusting the questions to each patient, and of spreading the spiritual conversation over several contacts. The palliative patients (n=4) appreciated the conversation and advised the care givers to show an open attitude, to spend enough time on their spiritual well-being, and to follow them in their spiritual process. Both care givers and patients emphasized the importance of a trusting relationship to establish spiritual conversations.

**Conclusion:** Flemish professional care givers experienced



the ars moriendi model as useful for supporting spiritual conversations, provided that the model is used in a spontaneous and intuitive way, according to the needs of the patient. Palliative patients are stimulated by the questions of the model to think about their spiritual needs and resources.

**Abstract number:** P1-449

**Abstract type:** Poster

**Spiritual Care and the Ars moriendi Model (AM-model)**

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The AM model of Leget (2008) provides a framework for patients and care professionals to enter into a dialogue about life questions.

**Aim:** To study how palliative patients experience an invitation to discuss spiritual questions with the help of the AM model (Leget, 2008), which helps them to organize and verbalize their needs. This study also focuses on gaining insight on the items palliative patients would like to discuss with a professional caregiver, whether palliative patients benefit from written information about the AM model and whether they think this model with the five themes: Farewell, Suffering, Autonomy, Guilt and Hope, should be extended.

**Method:** In a qualitative descriptive study, in-depth interviews with 10 palliative patients were held. For validity and reliability different methods were used: e.g. topic list, methodical accountability, peer debriefing and a structured analysis of data using a sw-program Kwalitan 6.0.

**Results:** The five themes of the AM model have significance for palliative patients. It helps to consider and organize their life questions and they find it useful to discuss this with a nurse, NP, spiritual caregiver or physician. 4 of the 5 themes are recognized by all palliative patients. The theme Autonomy is not known or difficult to understand for 40% of the patients, however, they talk about life questions within this theme. Not all the 5 themes are applicable to all palliative patients.

Some palliative patients think that the graphic design of the AM model does not represent the dynamic dimension of the themes. It is meaningful also to offer written information about the AM model.

**Conclusions:** The AM model by Leget helps palliative patients to organize and express their life questions. Written information about the AM model facilitates this process. The 5 themes of the AM model are helpful, and they find it meaningful to discuss them with a nurse, a NP, spiritual caregiver or physician.



# Poster sessions – set 2

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Pain  
Other Symptoms  
Assessment & measurement tools  
Audit & quality control  
Basic & translational research  
Bereavement  
Education  
End of Life Care  
Epidemiology  
Ethics  
Family & Care Givers  
Medical Sociology  
Organisation of Services  
Policy  
Psychology & communication  
Research Methodology  
Non-Cancer  
Palliative Care in the Elderly  
Palliative Care in Children and Adolescents  
Advocacy & Media  
Spirituality

Pain

Abstract number: P2-001  
Abstract type: Poster

**New Experience with Oral Morphine for Cancer Pain Relief in Republic of Moldova**

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**Introduction:** Oral Morphine has been introduced for treatment of the chronic cancer pain in Republic of Moldova from February 2012.

**Aim of the study:** To evaluate the pain relief and side effects after medication.

**Material and methods:** In study were included 45 patients with chronic cancer pain and duration of treatment with oral morphine was 30 days.

A high percentage of pain relief was achieved at the end of the second day of titrated therapy; relief was maintained at satisfactory levels throughout the study period in a majority of patients (90%). Interruption of oral morphine administration was necessitated in two patients because vomiting. The majority of patients (89%) did not manifest any side effects.

**Conclusion:** Oral morphine therapy for cancer pain offers effective pain relief with minimal side effects in the majority of patients.

Abstract number: P2-002  
Abstract type: Poster

**Dose Conversion when Switching between Oral Morphine and Oxycodone**

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**Background:** Indications for opioid switching include inadequate analgesia and intolerable side effects. Dose conversion ratios guide prescribing, however it is known that there is wide inter-individual variation in dose requirements when switching from morphine to oxycodone.

**Aim:** To explore the opioid doses required when switching from morphine to oxycodone and vice versa.

**Methods:** A randomised controlled trial of morphine versus oxycodone for cancer-related pain was conducted. Doses were titrated according to response using the immediate release preparation. Where inadequate analgesia or intolerable side effects, patients were switched to the alternate opioid, and re-titrated. The dose conversion ratio of morphine: oxycodone, 2:1 was used in both directions. Doses were recorded at the points of clinical response or non-response. Conversion ratios were individually calculated.

**Results:** Per protocol analysis showed 50/165 patients required opioid switching. In those taking morphine first-line the median pre-switch dose was 60mg (range 30-360mg) and median post-switch dose of oxycodone was 50mg (range 15-130mg). In those taking oxycodone first-line the median pre-switch dose was 60mg (range 15-240mg) and the median post-switch dose of morphine was 180mg (range 60-300mg). Subgroup analysis of those whose pain was controlled at switching was done to estimate dose conversion ratios (n=14). Wide inter-individual variation in dose requirements was observed. When switched from morphine to oxycodone the median (range) dose conversion ratio was 1.3 (0.4-4.0), and from oxycodone to morphine was 0.5 (0.3-1.5).

**Conclusion:** There is substantial inter-individual variation in patient response to and dose requirements of morphine and oxycodone when switched between the two drugs. Variability in dose ratios was observed, including the need for up and down titration in each direction of switch. An immediate release preparation allows greater flexibility within this process.

Abstract number: P2-003  
Abstract type: Poster

**A Palliative Care Intervention for Pain that Is Intractable to Cordotomy**

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**Background:** Interventional pain management alone will not treat total pain in cancer patients. We describe a patient

who experienced intractable pain and unsuccessfully underwent cordotomy, but responded to the interdisciplinary (IDT) palliative care approach in the acute palliative care unit (APCU).

**Case:** A middle age female who has been recently diagnosed with ovarian cancer metastatic to the left psoas muscle, supraclavicular and retroperitoneal lymph nodes. She complained of severe left thigh and flank pain and was admitted to the hospital. She had been unsuccessfully treated with morphine, methadone, hydromorphone, hypogastric nerve block, epidural steroid injection, and Cordotomy. The Palliative care team was consulted while awaiting a placement of an intrathecal pump by the chronic pain service and resulted in transfer to the APCU for symptom management and transition to hospice. She was placed on an intravenous hydromorphone infusion. Her morphine equivalent daily dose (MEDD) was 680 mg. Our IDT recognized and addressed the psychosocial and spiritual causes for her total pain expression. She came from an extremely poor family and worked multiple jobs to financially support them. She was a newlywed. There was a considerable amount of spiritual distress associated with not having attended her religious congregation in recent years. Meanwhile she still hoped for a miraculous cure from her cancer. Our IDT focused on frequent counseling, improving her function, provided medication education, discussed goals of care and educated about hospice. She was discharged to hospice care with good pain control and an MEDD of 95 (88% reduction). She did not require an intrathecal pump.

**Conclusion:** An APCU approach involving the IDT alleviated the need for invasive interventions by diagnosing and treating the psychosocial, emotional and spiritual distress contributing to the patient's total pain expression.

Abstract number: P2-004  
Abstract type: Poster

**Psycho-oncological and Pharmacological Pain Management Therapies for Lung Cancer Patients with Anxiety, Depression and Breakthrough Cancer Pain (BTCP)**

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The psycho-oncological approaches to pain management ensures patients the most effective options to treat their pain in the palliative care setting. Emotional (i.e., anxiety, depression) distress have been linked to greater mortality related to cancer. Studies by Temel et al. and Bakitis et al. showed preliminary evidence for a survival benefit in patients who received palliative care. (Bruera and Yennurajalingam, 2012).

**Method:** It was conducted one observational study on lung cancer patients in advanced stage, with chronic pain controlled by at least 3 days with Targin® (Oxycodone-with-naloxone controlled-release tablets). As regards the BTCP therapy, all patients were treated with oral transmucosal fentanyl citrate. All subjects have compiled the HADS (Hospital Anxiety and Depression Scale). Within individual psycho-oncological psychotherapy, patients treated by dealing with the emotional experience of their illness and demands of treatment. Pain assessment is used the numerical scale from 0 to 10 (NRS). The effectiveness of rescue medication is evaluated as PID (pain intensity difference) and the subjective evaluation of efficacy as GI (General Impression).

**Results:** From April 2011 to July 2012 were taken 35 patients with advanced non-small lung cancer which showed moderate-severe intensity pain in 80% of cases (28 patients) with 17 patients (60%) demonstrating BTCP. Clinically levels of anxiety (HADS anxiety  $\geq 11$ ) in patients without and with BTCP were 22%, and 63% respectively, while, depressive symptoms were (HADS depression  $\geq 11$ ) 18% and 76% respectively. Fentanyl is effective in reducing any intensity of pain.

**Conclusion:** This study confirms the high prevalence of anxiety and depression in patients with BTCP and that the application of the guidelines of European Association of Palliative Care in a model that integrates psychological approach into cancer pain management allows an effective control of cancer pain.

Abstract number: P2-005  
Abstract type: Poster

**Palliative Care for 21 Japanese Patients with Bone and Soft Tissue Sarcoma**

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**Aim:** There have been few studies on palliative care for patients with bone and soft tissue sarcoma (BSTS) due to its low prevalence. No case study on adult patients with BSTS has been reported by palliative care physicians in Japan. The aim of this study is to retrospectively investigate into clinical features and palliative care intervention by palliative care team (PCT) in 21 patients with BSTS who was hospitalized for chemotherapy. The ultimate purpose is to disclose the current status of palliative care for patients with BSTS and to utilize it for the improvement for future palliative care.

**Method:** We retrospectively reviewed all medical records of 21 patients with BSTS who received palliative care interventions by PCT during their hospitalization from January 1, 2010 to November 30, 2011 at our hospital.

**Results:** 21 patients (male 7, female 14) were reviewed in this study. The median age was 50 years (23-87). The histological subtypes included leiomyosarcoma (n=8), gastrointestinal stromal tumor (n=3), Ewing sarcoma (n=2), other (n=8). The median number of chemotherapy regimens was 3 (0-5). The most common life-threatening complication was respiratory failure (n=6), followed by bleeding of the tumor (n=4), others (n=3). Reasons of consultation were intractable pain (n=8), psychological support (n=7), lymphedema (n=6).

**Discussion:** 13 patients (62%) had life-threatening complication, and the outcomes of 10 patients of them (77%) were death. The major cause of complications was most likely due to organ compression by tumor since the symptoms improved by size reduction of tumor. Patients with BSTS tended to be highly distressed by the lack of information about their disease and available treatment. Therefore the PCT was consulted frequently for psychological support in early stage.

**Conclusion:** Psychological support was highly needed in early stage of BSTS

Progression of organ compression by tumor was thought to be correlated with poor prognosis in BSTS.

Abstract number: P2-006  
Abstract type: Poster

**Two Year Case Series of 88 Patients Using Sublingual Fentanyl for Breakthrough Cancer Pain**

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**Aims:** To assess the dose required, the effectiveness and the tolerability of sublingual fentanyl and to investigate the relative frequency of the types of breakthrough pain in a specialist palliative care practice.

**Methods:** A data capture form was completed for patients who had breakthrough cancer pain and were given sublingual fentanyl.

**Results:** Over a two year period between 1st April 2010 and 31st March 2012 the data capture form was completed on 88 patients (50% males). The median age was 71 years with a range between 22 and 94 years. All but two of these patients had malignant disease. 37 patients had bone metastases and 16 had liver metastases. The mean opioid dose prior to introduction of sublingual fentanyl was equivalent to 180 mg of morphine per day and the median dose was 120mg/d. Patients were started on 100mcg of sublingual fentanyl and titrated to the effective dose. Only a few patients required the higher doses of 200mcg(13) 400mcg(8), 600mcg(4) and 800mcg(3). The commonest type of breakthrough pain was spontaneous idiopathic breakthrough pain(42) followed by predictable incident pain(32). There were 12 cases of unpredictable incident pain and 5 of procedural incident pain. Nearly all patients reported sublingual fentanyl to be effective or very effective. None reported it to have exacerbated their pain. Most reported it effective within 5-10 mins. Sublingual fentanyl was tolerated well by all patients in this case series. No adverse effects were noted.

**Conclusion:** This two year case series has allowed us to monitor our use of this medication locally as well as providing some useful data about our patient population. The commonest type of breakthrough pain occurring was spontaneous idiopathic breakthrough pain. The 100mcg

dose proved adequate for most patients. Sublingual fentanyl has been found to be reliably effective, rapid in onset and well tolerated across the whole range of our adult palliative care population.

**Abstract number:** P2-007

**Abstract type:** Poster

### A Method for Switching from Fentanyl Patches Changed Every 24 Hours to Continuous Intravenous Infusion of Oxycodone in Japanese Patients with Cancer

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**Objective:** We studied appropriate methods for switching from fentanyl patches changed every 24 h (Ftd24) to continuous intravenous infusion of oxycodone (Oxyciv) on the basis of plasma drug concentrations that were calculated from the plasma half-life of each drug in Japanese patients (7 per drug).

**Methods:** Four methods for switching from Ftd24 to Oxyciv were studied.

Method 1) Treatment with the equivalent dose of Oxyciv (total dose) is started 12 h after patch removal.

Method 2) Total dose of Oxyciv is started 24 h after patch removal.

Method 3) One-half of the equivalent dose of Oxyciv is given from 0 to 24 h after patch removal, and total dose of Oxyciv is started after 24 h.

Method 4) One-half of the equivalent dose of Oxyciv is given from 0 to 48 h after patch removal, and total dose of Oxyciv is started after 48 h. The plasma Ftd24 concentration before switching was considered equivalent to the plasma Oxyciv concentration after switching (steady state) = 100 (%). Plasma concentrations of each drug were estimated from 0 to 96 h after switching.

**Results:** The percentage of time that concentrations were outside the optimal range of 80% to 125% and the maximal plasma concentration-minimal plasma concentration (%) were as follows:

Method 1) 52 and 153-77;

Method 2) 50 and 139-59;

Method 3) 38 and 141-100; and

Method 4) 0 and 125-85.

The percentage of time that optimal concentrations were outside the upper limit-lower limit of the 90% confidence interval of the half-life of each drug (%) and the maximal plasma concentration-minimal plasma concentration (%) were as follows:

Method 1) 82-23, 158-58;

Method 2) 78-22, 148-34;

Method 3) 81-0, 152-84; and

Method 4) 43-24, 135-61.

**Conclusions:** Our results suggested that the best method for switching from Ftd24 to Oxyciv is Method 4. Our results can be applied to switching from fentanyl transdermal patches changed every 72 h (Ftd72) to Oxyciv as well as to switching to morphine or fentanyl injection.

**Abstract number:** P2-008

**Abstract type:** Poster

### Oxycodone/naloxone Prolonged-release Tablets (OXN PR) Are Well Tolerated and Efficacious in Long-Term Treatment of Cancer-related Pain

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**Background:** Opioids are recommended for treatment of cancer pain however a common side effect is opioid-induced constipation (OIC). OXN PR tablets contain oxycodone and naloxone in a 2:1 ratio for the treatment of pain and to counteract OIC.

**Aims:** To demonstrate long-term tolerability (n=92) and efficacy of OXN PR, subgroup analyses were performed focusing on patients with metastasis pain of different cancer origin (n=84) supported by data from two specific cancer indications, i.e. lung (n=40) and/or breast cancer (n=39) with and without metastases.

**Methods:** Long-term safety/efficacy of OXN PR was assessed in a randomized, double-blind (DB), 4 weeks study (OXN PR vs oxycodone PR (OxyPR)) and 6 months extension phase up to a maximum daily dose of 120/60 mg OXN. Post-hoc subgroup analysis includes assessment of pain, bowel function and Adverse Events (AE).

**Results:** At randomisation mean (SD) pain intensities were comparable between both treatments in all subgroups

(metastases OXN PR 4.8 (2.1), OxyPR 4.1 (2.0); lung cancer OXN PR 4.4 (2.1), OxyPR 4.2 (1.6); breast cancer OXN PR 4.3 (2.0), OxyPR 4.2 (2.0)) and improved similarly throughout DB phase in all subgroups. Mean pain values remained low and stable throughout extension phase with OXN PR (metastasis 4.0 (2.26), lung cancer 4.2 (2.1), breast cancer 3.4 (2.1)). During DB phase a clinically relevant improvement in BFI scores was demonstrated for subjects receiving OXN PR (ΔBFI metastases: -17.1, breast cancer: -25.3, lung cancer: -15.9) which was maintained during long-term treatment. 40 (43.5%) of 92 subjects receiving OXN PR throughout DB and extension phase had related AEs. Only 7 (7.6%) subjects experienced 10 related SAEs. As expected for opioids and the assessed patients common AEs were reported for gastrointestinal and general disorders.

**Conclusion:** OXN PR is efficacious and well tolerated during long-term treatment for cancer-related pain of different origin.

Study was funded by Mundipharma Research

**Abstract number:** P2-009

**Abstract type:** Poster

### A Description of Symptom Prevalence and Intensity in Adolescents and Young Adults (AYAs) Diagnosed with Cancer on Referral to a Palliative Care Service

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**Aims:** Despite the recognition of AYA as a distinct oncological entity, there remains a paucity of literature describing the pain and symptom burden in the AYA population as research has only examined AYAs in either paediatric or adult contexts. Our aims were, 1) To obtain a reliable estimate of the prevalence, severity and mechanism of pain and other symptoms in AYAs on presentation to a palliative care service, 2) To compare symptom burden with an adult cohort matched for diagnosis.

**Methods:** Retrospective observational study of AYAs (age 15-25) and a randomly matched cohort (age >25), referred between July 2010-June 2012. Eligibility was determined by completion of Edmonton Symptom Assessment Scale and Edmonton Classification of Cancer Pain. Descriptive statistics and Wilcoxon rank sum non-parametric tests were performed.

**Results:** 33 of 42 screened AYA patients were eligible. The median survival of the AYA group was 14 months versus 9.8 months in the control group. The most common malignancies were sarcoma (52%) and haematological (21%). The median ESAS scores on initial assessment were Pain: 6, Fatigue: 3, Nausea: 1, Appetite: 2, Wellbeing: 3. 77% of AYAs reported moderate to severe pain. There was no significant difference in symptom intensity. 100% of AYAs subsequently reported pain syndrome on ECS-CP compared with 85% of controls (P=0.018). There was a noted trend toward more AYAs diagnosed with neuropathic pain (59% vs 39%, P=0.053) and a high prevalence of incident pain (40% vs 61%).

**Conclusion:** Our limited data suggests no significant difference in symptom burden in AYA patients though they may exhibit a higher prevalence of pain syndromes. Further studies are warranted to assess the perceived symptom distress in this population and its potential link cancer treatment and survival.

**Abstract number:** P2-010

**Abstract type:** Poster

### Therapeutic Decisions Made by Palliative Medicine Physicians in Poland Related to Managing and Modifying Pain Therapy and Factors Affecting Them

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The study's aim was to identify the therapeutic decisions made by palliative medicine physicians who conduct and modify pain management, in particular the difficulties in conducting therapy, the perceived pros and cons of drugs, and the factors affecting their choice.

**Participants and methods:** The study consisted in thirteen group interviews with palliative care specialists (qualitative part) and an analysis of questionnaires (quantitative part). The study showed that difficulties in pain treatment were both medical and non-medical, related to financial factors, lack of control in home palliative care teams, and resistance

of patients and their families. Also, patients were referred to palliative care too late and their previous pain therapies were inappropriate. In approx. 50% of cases, on admission to palliative care, pain therapies had to be modified, which involved changing the dose, form, and frequency of administration and adding or discontinuing certain analgesics. The choice of opioids was influenced by the patients' condition, social support and care arrangements, and psychological factors. According to the respondents, more patients took strong opioids orally (44%) than transdermally (37%). One of the most common side effects of opioid analgesics is constipation (62% of patients). Prophylaxis of constipation primarily involved irritants and hyperosmotic agents, but also a changed diet and fluid intake.

The final selection of the opioid is difficult because not all of the substances are available in each formulation.

**Conclusions:** The three main factors that affected the choice of the opioid were the patients' status, their social support and care arrangements, and the psychological factor. The respondents identified constipation as one of the most common side effects of opioids.

Research was supported by Mundipharma Polska Sp. z o.o.

**Abstract number:** P2-011

**Abstract type:** Poster

### The Cross-roads of Interventional Palliative Care: Advancing Interdisciplinary Care for Patients with Refractory Cancer Pain

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**Objectives:**

1. Provide a literature-based review of interventional procedures for refractory cancer pain.
  2. Identify the benefits and barriers to successful collaboration between palliative care and interventional pain practitioners.
  3. Discuss models of practice integration to improve interdisciplinary care of patients with cancer-related pain.
- Pain is one of the most commonly experienced and feared symptoms faced by cancer patients. Palliative care teams are able to control symptoms of pain with pharmacologic therapies in most circumstances. However, the literature suggests that up to 24% of patients with cancer pain may have inadequate analgesia and/or intolerable side effects with systemic modalities. For these patients, minimally-invasive interventional pain therapies can be significantly beneficial.

Neuraxial analgesia delivers pain medications directly to the spinal cord, resulting in greater potency and fewer systemic side effects. Likewise, image-guided neurolytic blockade can allow for improved analgesia with associated reductions in opioid consumption. However, despite these benefits, a number of studies demonstrate a lack of collaboration between palliative care and interventional pain providers, resulting in fewer patients receiving potentially beneficial interventions.

In this interactive discussion, we will highlight the growing clinical role of interventional pain procedures for patients with cancer pain. We will discuss the mutual benefit to patient care that can occur through effective collaboration between palliative care and interventional pain practitioners. Through interactive case studies and small group discussions, the attendee will understand the role of interventional therapies, identify patients that may benefit from early involvement with such therapies, and appreciate various models of collaboration that may be incorporated into their own clinical practice.

**Abstract number:** P2-012

**Abstract type:** Poster

### The Relationship between Subjective Assessment of Pain and the Objective Assessment of Gait and Physical Function in Patients Receiving Radiotherapy for Painful Bone Metastases

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**Introduction:** An objective measure of pain relief is desirable, particularly when evaluating treatments. The aim of this study was to determine whether objective measures of gait and/or physical activity could act as biomarkers for subjectively rated pain relief, in patients receiving radiotherapy (XRT) in cancer induced bone pain (CIBP).  
**Material and methods:** Patients with CIBP were assessed with the Brief Pain Inventory (BPI), the GAITRite™ electronic walkway system (measure of gait), and the activPAL™ ambulatory physical activity meter (measure of general function) at baseline and after XRT. Pain was evaluated using the BPI items worst and average pain, total functional interference score, and walking interference score. For the GAITRite, velocity (cm/second), cadence (steps/minute), and functional ambulatory performance score were used. For the activPAL the number of steps, time spent walking, standing, and sitting/lying were analyzed. Baseline and follow up were compared using Wilcoxon signed rank test. XRT responders and non-responders were compared using Mann-Whitney U test. Pearson correlations between the GAITRite and activPAL parameters, and BPI items were examined.  
**Results:** Sixty patients were assessed at baseline and 42 patients at follow up. BPI worst pain, average pain, walking interference and total functional interference all improved ( $p < 0.001$ ). The GAITRite and activPAL parameters did not change following XRT ( $p > 0.05$ ). An improvement in BPI (functional interference) correlated with aspects of gait (cadence = 0.341,  $p = 0.03$ ) and aspects of function (daily hours standing  $r = 0.469$ ,  $p = 0.002$ ). In responder analyses there were no differences in GAITRite and activPAL parameters between responders and non-responders ( $p > 0.05$ ).  
**Conclusion:** The study indicates that assessment of gait and physical function allow for a good characterization of the functional aspects of CIBP, but not in the evaluation of the effect of XRT.

**Abstract number:** P2-013  
**Abstract type:** Poster

### Assessment of Analgesic Efficacy, Safety and Quality of Life During Treatment with Controlled-release Oxycodone Formulation in Cancer Patients Receiving Palliative Care with Chronic Moderate to Severe Pain Intensity: A Multicenter, Non-interventional, Observational Study. Study Code: PMS-PL-OXY-2011-02

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**Aim:** Aim of the study to assess analgesia, safety, quality of life (QOL) and compliance during treatment with controlled-release (CR) oxycodone formulation.  
**Patients and methods:** Cancer patients with moderate to severe pain from 123 palliative care units were treated with oxycodone CR alone or in combination with adjuvants, non-opioids or other opioids for 21 days. Pain intensity and pain interference with QOL (activity, mood, relations with other people, sleep) were assessed by NRS (Numerical Rating Scale: 0 - no pain /no pain interference with QOL; 10 - the most severe pain / complete pain interference with QOL).  
**Results:** Among 783 patients of age 64 (+/-1.1) the final analysis was conducted on 771 patients. Pain intensity decreased from 6.6 (+/-1.72) at baseline to 2.5 (+/-1.72) [ $p < 0.00001$ ] after 21 days of the treatment along with significant decrease in pain interference with QOL. Mean daily doses of oxycodone CR increased from 35 mg at baseline to 56 mg on day 21. Among patients studied 45-48% received concurrently another strong opioid, 43-50% non-opioids, and 30-31% adjuvants. The mean percentage of oxycodone CR doses omitted since the last visit was 2.0% within the first three days, 2.3% since day 4 till day 7, 1.6% since day 8 till day 14 and 1.9% since day 15 till day 21. At baseline 47% patients complained on constipation, 35% on nausea, 15% on drowsiness; during treatment these symptoms intensified or appeared for the first time in 3% of patients.  
**Conclusions:** CR oxycodone administered alone or in combination with other analgesics in cancer patients was safe and effective opioid and significantly improved patients' QOL.

**Abstract number:** P2-014  
**Abstract type:** Poster

### The Role of Alfentanil for Opioid Switching in Cancer Pain

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**Background:** Alfentanil is a mu opioid receptor agonist metabolized in the liver to inactive metabolites. It is used parenterally for cancer pain and as an analgesic in end-stage kidney failure. The evidence to support its use in opioid switching (os) in cancer pain is limited.

**Aims:** To establish:

1. Indications for os to alfentanil (al) in a specialist palliative care unit (SPCU)
2. Pre-switch opioid
3. Renal function
4. Relative analgesic ratio used
5. Effect of os on pain
6. Researcher's assessment of global benefit to patient

**Methods:** Using a literature review and SPCU guideline, a data recording sheet was developed. A retrospective review of the health records, of patients prescribed al over a 12 month period from June 2011 to June 2012, was undertaken. 10 records were selected randomly from the SPCU controlled drugs database. Pain was assessed using a numerical rating scale (NRS) and the number of rescue doses required. JMP software was used for statistical analysis.

**Results:**

1. Indications for os:
  - a) Poor pain control and opioid toxicity 6/10
  - b) Poor pain control 3/10
2. 5/10 switched from hydromorphone; 4/10 from oxycodone.
3. 4/10 had renal failure.
4. Relative analgesic ratio of subcutaneous morphine to al was 15:1 (100%). A dose reduction was used in the setting of opioid toxicity.
5. NRS pre and post os was documented in 4/10. Post os NRS was lower in 2/4; higher in 1/4. 24 hours post os, rescue doses increased in 6/10; reduced in 2/10.
6. Researcher interpreted a global benefit to patients in 5/10. No clear benefit 5/10.

**Conclusion:** Improved NRS documentation would assist future interpretation of benefit from os using alfentanil. Despite increased rescue dose use post os, the researcher's interpretation of health records was that 50% benefited globally from alfentanil. It was employed 3<sup>rd</sup> or 4<sup>th</sup> line for cancer pain. The benefits of switching earlier to al could be considered? These results will inform development of clinical pathways for os and direct future studies.

**Abstract number:** P2-015  
**Abstract type:** Poster

### Aberrant Drug-related Behaviors in Patients Prescribed Opioids for Cancer Pain Syndromes

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**Background:** Addiction of opioid analgesics is rare in cancer patients. But, little is known about other problematic behaviors with opioid analgesics in patients with cancer pain syndromes.

**Aim:** The aim of this study was to clarify the prevalence and characteristics of aberrant drug-related behaviors (ADRBs) among patients prescribed opioids for cancer pain syndromes.

**Method:** We retrospectively studied the medical records of all hospitalized adult patients prescribed opioids for cancer pain syndromes who supported by palliative care teams between 2004 and 2011. Information was collected regarding age, sex, history of psychiatric disorders, and ADRBs (detected using the model by Passik and Portenoy and classified in four categories consisted of addiction, pseudo-addiction, chemical coping, and diversion/forgery). In ADRBs patients excluding pseudo-addiction, we assessed types of opioid analgesics associated with ADRBs and the

association between ADRBs and other variables. The date was statistically analyzed with Fisher's exact test.  
**Results:** 15 out of 477 patients (3.1%) had ADRBs with prescription opioids, consisted of 1 addiction (0.2%), 8 pseudo-addiction (1.7%), and 6 chemical coping (1.3%). All 7 patients excluding pseudo-addiction were male and younger, and had ADRBs with intravenous injection of fentanyl. No association was found between ADRBs and history of psychiatric disorders.  
**Conclusion:** These results may indicate that intravenous injection of fentanyl have higher risk for ADRBs than other opioids in hospitalized cancer inpatients confronted with "total pain", and that male and younger age is risk factors for ADRBs in patients with cancer pain syndromes as well as patients with chronic non-cancer pain.

**Abstract number:** P2-016  
**Abstract type:** Poster

### Assessment of Cancer Pain Management by Services Non-specialized in Palliative Care According to Recommendations of the European Association for Palliative Care (EAPC)

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Recently, the EAPC has published recommendations for cancer pain management.

**Objective:** To determine the degree of analgesia adjustment according to the EAPC recommendations, before intervention of palliative care services.

**Method:** A descriptive, retrospective study, based on review of medical records. Care setting: Palliative care home program (PCHP) in urban area (admits advanced cancer patients coming from hospital services and primary care) All cancer patients with pain, visited in period July 2011-July 2012, were included. Data analysed, recorded at first visit of PCHP: demographic data, clinical characteristics, analgesia before admission to PCHP, and adjustment of analgesia according to EAPC criteria.

**Results:** N=103. Mean age 75.4 (SD: ± 12.68; 98-38). Females were 59%. The most frequent primary cancer was colon-rectum (23.3%). Pain types: visceral 44.7%, somatic 39.8%, mixed pain 15.5%. Edmonton Staging System Cancer Pain: 32.0% stage II. Analgesia: 5.8% no analgesics, 32.0% non-opioids analgesics (WHO step I), 18.4% weak-opioids (step II), and 43.7% strong-opioids (step III). Seventy-one patients (68.9%) met EAPC recommendations. Discordances with EAPC criteria: no association of first and second WHO step drugs when adequate 15.3%; no routine laxative use 9.7%.  
**Discussion:** Most patients received adequate pain treatment before admission to PCHP. However, one third of patients had an analgesic treatment which did not meet all the EAPC recommendations. Of note, that a relevant number of patients had no analgesia despite having cancer pain. The main discordances with the EAPC recommendations were:  
a) Lack use of the association of non-opioid and weak opioids, when adequate;  
b) Lack of routine use of laxatives for reduce opioid-induced constipation.

**Abstract number:** P2-017  
**Abstract type:** Poster

### Pain Control in Patients with Terminal Illness in Ghana

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Many Ghanaians continue to experience pain associated with life threatening diseases because palliative care has not been integrated into the health care system. In 2006, African Palliative Care Association was inaugurated and soon after that palliative care was introduced into the undergraduate nursing curriculum in Ghana. Fortunately, between 2011 and 2012 there have been series of workshops for other health workers like doctors, pharmacists clinical psychologists and nurses on Palliative care. Central University College, a private Christian institution has embarked on the training of nurses in palliative care, with practical components in the community. This year, 2012, 80 nurses are undertaking home-based Palliative Care Nursing. The study will explore the care provided with emphasis on symptom control, pain measurement and pain management. A total of 80 home-based-care notes will be evaluated and individual patient's demographic data, disease history, symptoms and pain control modalities will be examined. The findings will be presented at the conference.

Abstract number: P2-018  
Abstract type: Poster

### Usefulness of Rikkosan, a Traditional Japanese Medicine, for Intolerable Oral Pain in Cancer Patients

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**Aims:** The oral mucosal damage caused by chemotherapy, radiotherapy and the invasion of head and neck cancer generates intolerable pain and eating disorders, which possibly leads to reduced quality of life(QOL) in cancer patients. Rikkosan is a traditional Japanese medicine, which consists of Glycyrrhizae radix, Asiasari radix, Cimicifugae rhizoma, Saposhnikovia radix, and Gentiana scabrae radix, was reported to be effective for toothache and periodontitis. We recently developed an ice ball and a freeze cotton swab containing rikkosan for cancer patients with intolerable oral pain causing difficulty in taking medicine. We investigated the efficacy of rikkosan in those patients.

**Methods:** With an IRB approval, six patients with severe oral pain was retrospectively investigated. Their age ranged from 62 to 90 years and male / female was 4/2. The causes of oral pain were oral mucosal invasion in patients with mandible or the right palate cancer, side effects of chemotherapy and radiotherapy in those with hypopharyngeal or kidney cancer, and a gum swelling and bleeding in those with hematologic malignancy. As oral pain was failed to be relieved with NSAIDs, the gargle or the spray of diclofenac sodium or lidocaine, and narcotic dose increase, rikkosan was given before meals and on demand. Honey, which had an anti-inflammatory effect, was added if necessary.

**Results:** An ice ball and a freeze cotton swab containing rikkosan were kept in an oral cavity more than 5 minutes. Patients with hemorrhage were relieved pain with gargle. Pain was successfully relieved with 1-3 times of rikkosan administration in five patients, who became able to conduct mouth care and oral food intake. Pain was enhanced in spite of taking rikkosan because of an enlarged tumor exposing in the oral cavity in the remaining one.

**Conclusions:** Rikkosan is a useful option of medication for oral pain control in palliative care, especially given in a cold form with honey.

Abstract number: P2-019  
Abstract type: Poster

### ATOME Project and Turkey

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**Aim:** The main objective of ATOME is to improve the access to opioid medication in Europe as well as to evaluate the legislation of all 12 countries. This research is to present opioid use and barriers and legislation in Turkey.

**Method:** To identify legal and regulatory barriers to opioid medication was used for Turkey. We analyzed and calculated the average ME/mg per person (1980-2009) (PPSG).

**Result:** Turkey places 46th in global morphine consumption (in 154 countries) When looked at all the countries, the increase use of transdermal fentanyl caused the decrease in use of morphine (2000). The 1961 Single Convention, 1971 and 1988 contains stigmatizing language. Barriers in prescribing, language use and dispensing was recorded of opioid. There is also a big concern of potential opioid abuse regarding doctors, patients and the public. In 2008 the Turkish "Pharmaceuticals Track and Trace System" defined the infrastructure. In 2012 electronic prescription has started. In 2009, the accessibility of opioids have been increased with new legislations.

It was detected that Turkey is the only country within Europe that does not have access to IR morphine. Methadone and Oxycodone is also not available.

**Conclusion:** Current legislation and laws are still improving. With ATOME's aim to awareness the Turkish government has started to use new terminology, prescriptions in order to improve access and availability of opioid. Even though awareness has been increased there is still a barrier when it comes to the knowledge of opioid use by physicians.

**Recommendations:** All forms of opioids should be available. An education for opiophobia is necessary for physicians, pharmacies, nurses and lawyers. Education should start at the school, before not after residency. Behind closed doors and hidden in locked drawers, opioids are available but not accessible and can be considered as a crime when it is not used. We can make a difference and challenge this issue to improve quality of life.

Abstract number: P2-020  
Abstract type: Poster

### Predictors of Overall Survival Following an Opioid Rotation (OR) in Cancer Patients Presenting to an Outpatient Supportive Care Center (SCC) of a Tertiary Cancer Hospital

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**Background:** Limited data exist on cancer outpatients undergoing OR. Results of a previously reported study showed a 65% success in OR. We now report the analysis of predictors of overall survival following an OR of this previously reported study. The aim of this study was to compare the patient characteristics and survival of patients with and without follow-up after OR, and survival in patients with successful and unsuccessful OR

**Methods:** We reviewed consecutive patients in the SCC in 2008 for an OR. Demographics, Edmonton Symptom Assessment Scale(ESAS), Memorial Delirium Assessment Scale(MDAS), pain characteristics, opioid use, indications for OR, and outcomes were collected. Successful OR was defined as 2 point or 30% reduction in ESAS or resolved opioid-induced neurotoxicity and continuation of new opioid at follow up.

**Results:** The median age was 55 years, 56%(106/190) were male, 72%(136/190) were white, median(Q1-Q3) ECOG performance status (PS) was 2(1-3), most common cancer type was gastrointestinal 24%(45/190) and 86%(163/190) had advanced disease. Of 190/938(20%) patients who underwent OR, 120/190(63%) had a follow-up visit. OR was successful in 79/120(66%). Follow-up visits occurred in patients with localized disease 89%(24/27; P=.0023), history of substance abuse 100%(12/12; P=.0085), PS ≤ 2, 66%(97/146; P=.0002), absence of delirium 67%(118/177; P=.002), uncontrolled pain as reason for OR 66%(97/146; P=.036), patients with higher ESAS scores of fatigue(P=.0036), and appetite(P=.025) and lower MDAS score(P=.0009). Both following up after an OR (P<.001) and successful OR (P=.012) were predictors of longer overall survival with a difference in median survival of 4.3 and 3 months respectively.

**Conclusion:** Patients who followed up after OR are more likely to have localized disease, better PS, history of drug abuse, uncontrolled pain, better MDAS scores and longer overall survival. Successful OR is a significant predictor of longer overall survival.

Abstract number: P2-021  
Abstract type: Poster

### The Estimate of Fentanyl Buccal Tablets in Breakthrough Pain (BTP) Treatment of Palliative Care Patients

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**Aim:** BPT is a crucial clinical problem in advanced cancer patients, as it affects 50% of total. The aim is to assess effectiveness and attempt of the standardization of indications for fentanyl buccal tablets in the BPT treatment.

**Method:** Retrospective study, 20 (8 male and 12 female) patients hospitalized at the Dept. of Palliative Medicine (2011-2012 due to severe cancer pain).

Basic problem: pancreas cancer - 8, cervix uteri cancer - 3, ovary cancer - 2, sarcoma - 2, breast cancer - 1, stomach cancer - 1, others - 3.

All patients were treated with high doses of opioids (over 60mg in terms of morphine), due to basic pain and episodes of BPT. Varieties of BPT: visceral pain - 5, bone pain - 1, neuropathic pain - 6, mixed pain - 8.

The pain score was measured in NRS scale before and after using buccal tablets. The starting dose was 100mcg, for all the patients. The effectiveness of treating episodes of BPT was judged. The patients were supervised in order to notice any side effects.

**Results:** 1 person maintained the 100mcg dose, 7 patients needed 200mcg dose, 3 - 400 mcg, 1 - 800 mcg, fentanyl buccal tablets was not beneficial in 5 cases, in 1 patient experienced only partial effectiveness of the treatment (neuropathic pain). They had to be given additional painkillers and/or alternative techniques. In 2 patients medication was stopped due to side effects: 1 patient experienced vomiting and partial occlusion of oesophagus, 1 patient did not tolerate the opioid (dizziness).

**Conclusion:** Rescue drug dose is not adequate to the basic opioid dosage. Fentanyl buccal tablets did not control BPT of neuropathic character.

Additional methods and aid drugs were necessary.

The fentanyl buccal tablets are the most effective in BPT episodes, especially in case of nociceptive pain (visceral, bone pain).

Abstract number: P2-022  
Abstract type: Poster

### Efficacy of Pregabalin for Neuropathic Pain in Cancer

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There are many kinds of adjuvant analgesics that treat neuropathic pain. For neuropathic pain, evidence-based guidelines suggest gabapenoinoid or antidepressant first. There few evidence for cancer-related neuropathic pain. Pregabalin titrates faster and more easily on onset than gabapentin. So we researched efficacy of pregabalin for cancer-related neuropathic pain.

**Methods:** We reviewed the records of patients who were administered pregabalin from Oct of 2011 to Sep of 2012. The cause of pain, dose of pregabalin, other pharmacotherapy or treatment, pain score of numerical rating scale (NRS) before and after pregabalin administration, side effects, changed medication were also investigated. The patient's prognosis was under 1 month were excluded.

**Results:** 38 cancer-related neuropathic patients were administered by pregabalin. The dose of pregabalin was 50mg to 600mg. Causes were 19 of bone metastasis, 10 of neuropathy from chemotherapy or radiotherapy, 6 of tumor invasion or compression and 3 of others. Opioids were already prescribed to 18 patients. NRS changed from 6.4 to 4.2 after pregabalin administration.

While cancer itself or cause of pain was managed by radiotherapy or chemotherapy, pregabalin's dose and pain score were stable. But NRS increased when radiotherapy and/or chemotherapy's efficacy was limited. 10 were switched to clonazepam and 9 to ketamin from pregabalin with opioid's dose set up by palliative care team consultation.

**Conclusion:** Pregabalin is effective for cancer-related neuropathic pain while cancer is in controlled radiotherapy and/or chemotherapy. For advanced pain, it was suggested that another strategy like adjuvant switch is needed by expert opinion.

Abstract number: P2-023  
Abstract type: Poster

### Outpatients with Cancer in a Multi-centre Study - Who Is in pain?

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**Background:** Pain is a major health care problem for patients with cancer. This is the first multi-centre study to explore prevalence of pain in patients with cancer in Dutch outpatient departments, in all cancer stages.

**Aim:** To explore prevalence, the pain intensity, treatment adequacy and interference of pain with daily activities in outpatients with cancer.

**Study design and methods:** A descriptive, multi-centre, cross-sectional study was conducted in patients with cancer visiting one of the seven outpatient departments of regional general hospitals. During five consecutive working days, patients visiting the oncology outpatient department were asked to participate. Patients were eligible if they were diagnosed with cancer and 18 years or older. Exclusion criteria were severe cognitive dysfunction or no ability to understand the Dutch language. Descriptive statistics and subgroup analysis were conducted. Subgroups will be classified by: age, gender, tumor type, treatment intention, education, metastasis.

**Results:** Four hundred twenty-eight out of 629 patients (68%) completed the questionnaire, of which more than one out of three reported pain (39%). Twenty-six percent of patients in pain, experienced their pain as moderate (5-6) and 23% of patients as severe (7-10). Pain treatment was inadequate in more than one out of two patients with pain (62%). Additionally, 89% of patients in pain, experienced pain-induced interference with one or more activities in daily life.

**Conclusion:** A substantial proportion of patients with cancer in Dutch outpatient departments has pain and are inadequately treated, compared with previous studies in Europe, which varied from 27%-68%. This illustrates that

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pain is still a problem in Dutch outpatients clinics. This study explored the current situation to improve pain management in outpatients with cancer in the future.

**Funding:** Dutch Cancer Society and Bergh in het Zadel (Dutch Association that funds research).

**Abstract number:** P2-024

**Abstract type:** Poster

### Abstract withdrawn

**Abstract number:** P2-025

**Abstract type:** Poster

### Postoperative Analgesia for Opioid-dependant Cancer Patients

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**Background:** Post operative pain management for the patient with chronic opioid-dependant cancer patient is a challenging task.

**Methods:** We have been using our institutional pain management protocol for chronic opioid dependant-cancer patients. With approval of IRB, we conducted retrospective chart review in opioid-dependant adult cancer patients having undergone surgery.

In brief, our pain management protocol consisted of the following policies such as 1) Maintenance of preoperative baseline opioids, 2) Epidural analgesia if applicable, 3-A) Additional opioid by epidural morphine 3 - 4 mg/day or intravenous fentanyl patient-controlled analgesia (PCA) at basal rate of 0.4 - 0.6mcg/kg/hr in patient receiving preoperative lower-dose opioids (less than 210 mg/day of oral morphine equivalents), 3-B) Additional opioid by 30% of baseline opioids in patients receiving preoperative higher-dose opioids (more than 210 mg/day). The purpose of this study was to evaluate the validity of our protocol. We defined as an unsuccessful pain control when patients received more than 2 rescue-opioid or needed to increase the basal dose within the first 2 postoperative days.

**Results and discussion:** Between April 2008 and November 2011, 44 cases out of 58 opioid-dependant patient surgery cases completed the protocol. No severe opioid-related adverse events and symptoms suggesting opioid withdrawal were documented. Patients received wide-range of preoperative baseline opioids (15 to 1800 mg/day, median: 60 mg/day). Pain management was unsuccessful in 18 patients according to our definition. In most of the unsuccessful pain controlled cases, the pain was controllable with increase of the basal rate of PCA. Our protocol tended to succeed in patients with epidural analgesia, and those who had smaller dose of opioids preoperatively. In very high dose opioid dependants, we might need to modify the protocol.

**Conclusion:** Our current pain management protocol is clinically acceptable.

**Abstract number:** P2-026

**Abstract type:** Poster

### Do the Assistance of an External Advisor Improve the Performance of Full-time Hospital Palliative Care Team? A Prospective before-after Study

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**Background:** Japanese authorities mandate the cancer care hospitals to establish the hospital palliative care teams (PCTs) for official registration. While patients with refractory pains or in severe conditions tend to be referred for the teams in the setting, the number of palliative care specialist physicians falls far short of the domestic demand, thus the majority of the teams should need to step up the performance. External advisors (eg, academy authorized instructors) might help them to meet the challenges. The efficacy of having external advisors is unknown, and thus, should be examined.

**Methods:** We assessed the effect of the external consultation service by the change in pain intensity of the

referred patients during the first week under a full-time PCT involvement. An external palliative care specialist provided three-day on-site supervision followed by four weekly-teleconferences, using the protocol derived from the WHO-guideline (presented at the 12th EAPC Congress) as a main material. The pain intensity was measured with Numeric Rating Scale (NRS) of 0-10 of average pain in the last 24 hours. We compared the trend before the service (observed for 7 weeks) with the one after the services (supported for 5 weeks).

**Results:** Consecutive 22 were enrolled: 11 as group A before the service, 11 as Group B after the start of attending. Our analysis on average pain showed no significant difference in pain intensity at referral, age and gender between the two groups. NRS in group A did not change through the 1<sup>st</sup> week period (3.3±2.0 on day 1~2.6±2.1 on day 7). On the other hand, NRS in group B significantly improved compared with the intensity of 4.3±2.1 on day 1: 2.3±2.0 on day 3 (p=0.026)~1.9±1.2 on day 4 (p=0.018)~1.3±1.3 on day 5 (p=0.012)~2.1±1.1 on day 6 (p=0.035)~2.0±1.1 on day 7 (p=0.033). And 2 or more points improvement found in day 4~7 compared to the referrals.

**Discussion:** The sustainability must be confirmed and utilized to other teams in Japan.

**Abstract number:** P2-027

**Abstract type:** Poster

### Pain Prevalence and Management in a University Hospital

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Aims were to explore pain epidemiology and management practices in a University hospital. This was a descriptive, point prevalence study. Participants were >18 years, hospitalized on medical or surgical services for >24 hours, and able to participate. The American Pain Society Patient Outcome Questionnaire, assessing pain severity was administered. Data regarding pain medications and documentation were collected from medical charts. The response rate was 77%. Participants (N= 368) mean age was 67.6 (SD=17.4) years, range 18-100; 51% were women. Pain prevalence in the past 24 hours was 80%. The mean worst pain (0-10) was 4.5 (SD=3.2); 51% of participants reported moderate to severe pain (>4 out of 10). Pain was more prevalent on surgical services (91%) compared to medical (76%),  $\chi^2=9.504$ ,  $p<0.05$ , in women (87%) compared to men (78%)  $\chi^2=4.384$ ,  $p<0.05$ , and in patients aged 18-74 (87%) versus >75 (78%),  $\chi^2=4.468$ ,  $p<0.05$ . Mean worst pain severity was 1.1 point higher in surgical patients than medical,  $t=-3.259$ ,  $p<0.05$ , 1.2 points higher in women than men,  $t=-3.508$ ,  $p<0.05$ , and 0.8 points higher in patients <75 years compared to >75,  $t=2.308$ ,  $p<0.05$ . Most (68%) participants had been prescribed pain medications in the past 24 hours —non-opioids for 20%, weak opioids for 22%, and strong opioids for 26%. Seventy eight of those in pain had no pain medications ordered. According to the pain management index, treatment was insufficient in 37% of participants. Pain assessments using standardized methods had been performed in 12% of patients. The mean worst pain severity was 1.9 points higher in patients assessed by standardized methods  $t=-3.488$ ,  $p<0.05$  than in those not assessed. Pain was common in the hospital and many patients reported severe pain in the past 24 hours, notably surgical patients, women and younger patients. Pain management did not always follow established guidelines and needs to be improved. The study was sponsored by the Icelandic Research Fund.

**Abstract number:** P2-028

**Abstract type:** Poster

### Hyperalgesia and Propofol Terminal Sedation in a Patient with Neuropathic Cancer Pain

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**Introduction:** Patients suffering from terminal cancer could develop multiple and complex symptoms. If the normal therapeutic approach is unable to control these symptoms, palliative sedation (PS) can be used.

**Case report:** A 22-year-old woman with a multirecipient Ewing's sarcoma (EWS), with a Psoas Malignant Syndrome because of a huge right pelvic mass was evaluate in our inpatient palliative care unit (PCU) for pain control. She was

transfer due to an Acute PCU in which opioids switching was done in two times 1<sup>st</sup> morphine iv to methadone and 2<sup>nd</sup> methadone to oxycodone. She started hyperalgesia because of a rapid scale of oxycodone 600mg/day. We start Ketamine and decrease oxycodone using other adjuvant drugs as gabapentin, corticosteroids and diazepam. 3<sup>rd</sup> switch to morphine 300mg/day dose presenting better pain control, but started fever in the next 24hours and new acute pain, EVA: 10/10, because of probably infection of the tumoral mass, we start antibiotics and finally 4<sup>th</sup> switch to fentanyl iv and started PS, 1<sup>st</sup> with midazolam iv increasing to 10mg/hour and finally started propofol iv 2mg/hour because of important nasal bleeding.

**Discussion:** Propofol is an anaesthetic drug for intravenous administration, which is used to induce and maintain general anaesthesia: when other drugs, as midazolam fails. The administration of this drug usually takes place in-ward, due to the need of both an intravenous access and the continuous presence of trained staff.

**Conclusion:** Successful strategies that may decrease or prevent opioid-induced hyperalgesia include the concomitant administration of drugs like NMDA-antagonists or opioid switch. Propofol may be considered as a further option, perhaps its under-usage due to the limited experience that palliative care specialist have with this drug.

## Other Symptoms

**Abstract number:** P2-029

**Abstract type:** Poster

### Home Comforts

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**Aims:** Hospice at Home service works with other community services to fill gaps in end of life care for patients, whose preferred place of care is home. A twenty four hour / seven days a week sitting service is delivered predominantly by trained Healthcare Assistants (Aides), who recognised that anxiety and breathlessness might benefit from immediate, simple non pharmacological interventions.

**Methods:** Similar interventions are provided by appointment at the hospice and the Hospice at Home team were trained in simple skills and techniques (basic hand and foot massage, the importance of touch, and anxiety and breathlessness management). Regardless of the severity of condition, touch can always be safely administered and studies show massage as the second most commonly administered non-drug strategy to reduce symptoms. Hospice at Home Aides were encouraged to use these skills and techniques with patients, and teach them to families and informal carers where appropriate.

**Results:** We present audit and survey results of this positive partnership between hospice, Aides, complementary therapists, families and community services.

**Conclusion:** Families described better outcomes, empowered by doing something practical instead of feeling inadequate and helpless. Patients' symptoms were relieved immediately in the home instead of waiting to attend the Hospice, and confidence levels and job satisfaction increased amongst the Hospice at Home staff because they could respond immediately by providing a non-pharmacological technique for these distressing symptoms in the patient's place of choice - home. A cost effective, one stop shop!

**Abstract number:** P2-030

**Abstract type:** Poster

### Is the F.A.B (Fatigue and Breathing Clinic) Clinic Really Fab? An Evaluation of a Novel Clinical Service

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**Aims/introduction:** Fatigue and breathlessness are distressing symptoms experienced by over 50% of patients with malignant and non-malignant disease. Specific programmes for managing cancer-related fatigue or breathlessness can lead to improvements in patient functioning. The aim was to evaluate an innovative clinic combining management of both patient fatigue and breathlessness.

**Methods:** A joint Occupational Therapist/Physiotherapist led fatigue and breathlessness clinic (F.A.B) was introduced in a hospice day therapy unit. The clinic includes 7-weekly sessions covering breathing techniques, exercise, energy conservation, sleep, nutrition, relaxation, challenging negative thoughts. Patient data collected as part of the service includes: brief fatigue inventory (BFI), numerical rating scales for breathlessness (completed at course start



and end), a fatigue diary and a service evaluation. Summary statistics are used to describe data, paired t-tests to evaluate change in fatigue and breathlessness scores.

**Results:** 22 patients were enrolled into service (mean age 72.6 years, (range 47-89), 16/22 (73%) male, 15/22 (67%) had malignant disease (prostate cancer most common in 6/22). 9/22 patients completed course (6 too unwell, 2 undergoing treatment, 2 died, 2 social reasons, 1 felt too well). Mean BFI fatigue score at baseline was 6.1 (SD 1.6) and at end 5.4 (1.4) (t=0.9, p=0.18, n=9). Mean breathlessness at worst was 8.6 (SD 2) at baseline, and 7.3 (1.9) at end of course (t=1.9, p=0.09, n=9). Course participants reported satisfaction and benefits from the course, in particular exercises and breathing techniques.

**Conclusion:** Preliminary results suggest the combined FAB clinic as a practical way of helping fatigue and breathlessness. However it needs to be appropriately timed as many participants were too unwell or undergoing treatment, which prevented completion of course. Data from further participants will be available.

**Abstract number:** P2-031  
**Abstract type:** Poster

**Frequency of Risk Factors of Depression from EAPC Guide in Oncologic Palliative Patients Home Care Setting**

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The EAPC Guide for the management of depression in palliative care gathers some factors that increase the risk of developing depression. However, we feel that those factors are too frequent in our population to serve us as screening. Our hypothesis is that one or more of these factors are present in more than 80% of our patients.

**Methodology:** Descriptive cross-sectional retrospective study in palliative home care settings from San Juan de Dios Hospital in Navarre during a year. Inclusion criteria: >18 years, advanced cancer. The social-demographic variables were sex, age and location of primary tumor. We also collected the EAPC guide risk factors, to which we added the awareness about diagnosis and prognosis, and cognitive impairment. Statistical analysis was made comparing variable by means of chi-square. Authorization of the Ethical Committee was received.

**Results:** Among the 414 patients, we randomly selected a sample of 156 (37%). The standard patient was a man of 74 years with gastro-intestinal neoplasm (see table 1 for descriptive results). 85% of our patients presented at least 1 risk factor among the described in EAPC guide (53% >=2, median=2; 92.3% including PPS< 50% and < 60 years). People < 60 years were more aware of diagnosis (OR 9,46 p< 0,0001) and prognosis (OR 2,013 p=0.034), as well as greater perception of lack of social support (OR p=0.048). 70% with advanced cancer at diagnoses presented worse functional status than those localised at the beginning (OR 2,35 p=0.011). In this, 55,2% suffered from poor symptomatic control versus 36,7% in the others (OR 2,13 p< 0,024).

**1. Descriptive results**

AWARENESS OF DIAGNOSIS (ADX)	78.8%
AWARENESS OF PROGNOSIS (APX)	50%
COGNITIVE IMPAIRMENT (CI)	17.9%
ANTECEDENT OF DEPRESSION (AD)	12.8%
RELATIVE ANTECEDENT OF DEPRESSION (RAD)	-
DISTRESSING EVENT (DE)	1.9%
PERCEPTION OF LACK OF SUPPORT (PLS)	17.9%
ADVANCED AT DIAGNOSE (AAD)	61.5%
POOR SYMPTOMATIC CONTROL (BSC)	48.1%
PHYSICAL DISABILITY (PD)	14.1%

**2. BIVARIATE ANALYSIS**

	ODDS RATIO	p value
AWARENESS OF DIAGNOSIS (ADX)	AGE <60=95.2% 9.46	AGE>60=67.7% <0.0001
AWARENESS OF PROGNOSIS (APX)	AGE <60=60.3% 2.013	AGE>60=43% 0.034
PERCEPTION OF LACK OF SUPPORT (PLS)	AGE <60=33.3% 3.73	AGE>80=11.8% 0.048
POOR SYMPTOMATIC CONTROL (BSC)	AAD YES=55.2% 2.13	AAD NO=36.7% 0.024
PPS<50%	AAD YES=68.8% 2.35	AAD NO=48.3% 0.011

**Discussion:** Results confirm our hypothesis that the EAPC risk factors of depression are very common in our population. This leads us to believe that they are not very useful for screening. We have observed some associations that could serve to detect situations of greater vulnerability. More research is needed to study in depth which of the risk factors are specific to our population.

**Abstract number:** P2-032  
**Abstract type:** Poster

**Drug Therapy for Delirium in Terminally Ill Adult Patients: A Cochrane Systematic Review**

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Delirium is a syndrome characterised by a disturbance of consciousness (often fluctuating), cognition and perception. Although under-recognised it is in terminally ill patients a common cause of healthcare admission. It is distressing for families to witness and challenging to treat; it may arise from any number of causes and treatment should be directed at addressing these causes rather than the symptom cluster. In cases where this is not possible, or treatment does not prove successful, the use of drug therapy to manage the symptoms may become necessary.

**Aim:** To evaluate the effectiveness of drug therapies to treat delirium in patients in the terminal phase of a disease.

**Method:** We searched five citation databases. Trials with/without randomisation or blinding were included.

**Results:** One trial was identified. It included 30 advanced AIDS patients receiving chlorpromazine, haloperidol or lorazepam. The trial under-reported methodological features. It found overall that patients in the chlorpromazine group and those in the haloperidol had fewer symptoms of delirium at follow-up (to below the diagnostic threshold using the Diagnostic and Statistical Manual of Mental Disorders) and that both were equally effective (at two days mean difference (MD) 0.37; 95% confidence interval (CI) -4.58,5.32; between two and six days MD -0.21; 95% CI -5.35, 4.93). Chlorpromazine and haloperidol were found to be no different in improving cognitive status at 48 hours but at subsequent follow-up cognitive status was reduced in those taking chlorpromazine. Improvements for patients randomised to lorazepam were not apparent and all developed adverse effects, including increased confusion, leading to trial drug discontinuation.

**Conclusions:** There is insufficient evidence to draw strong conclusions about the role of drug therapy in the treatment of delirium in terminally ill patients. Practitioners should continue to follow clinical guidelines, but further research is essential.

**Abstract number:** P2-033  
**Abstract type:** Poster

**Psychoneurological Symptom Profiles of Breast Cancer Women at Diagnosis Predict their Quality of Life Two Years after Diagnosis**

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**Research aims:** Cancer patients often experience multiple symptoms before and during treatment. This study was aimed to identify latent subgroups of breast cancer patients using five frequently reported psycho-neurological symptoms assessed at diagnosis and to examine the predictive effect of group membership on quality of life at 2 years after diagnosis.

**Study design and methods:** The data were drawn from a large longitudinal study of symptoms after breast cancer surgery. Severity of five symptoms (i.e., cognitive dysfunction, fatigue, sleep disturbance, depression, and anxiety) assessed before breast cancer surgery (n = 198) were used to explore subgroups of patients using latent class analysis. Among the 198 women, 98 were available for assessment of quality of life at 2 years after surgery. General linear model was used to examine the group difference on quality of life.

**Results:** Four distinct patient subgroups were identified. Group A was characterized with low cognitive dysfunction and fatigue but borderline sleep disturbance, depression and anxiety. Group B was characterized with borderline cognitive dysfunction, fatigue, depression and anxiety but moderate sleep disturbance. Group C had a very low severity on all symptoms. Group D was characterized with moderate cognitive dysfunction and fatigue but severe sleep disturbance, depression, and anxiety. The group differences for each of five symptoms were all significant (p < 0.001). After adjusted for covariates, the quality of life scores at 2 years after diagnosis were significantly different among four groups (P = 0.002). Post-hoc comparison showed that scores in Group D were significantly lower than that in Group C (P = 0.002).

**Conclusions:** Symptom profile at diagnosis has a long-term predictive effect on quality of life for breast cancer women. Routine assessment of patients' symptom profiles before treatment is suggested for identifying the high risk group.

**Abstract number:** P2-034  
**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P2-035  
**Abstract type:** Poster

**Levomopromazine for Nausea and Vomiting in Palliative Care - A Systematic Review**

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**Aims:** Nausea and vomiting are common symptoms of patients with incurable disease. Patient assessment allows clinicians to choose an appropriate first-line antiemetic based on the presumed underlying cause of nausea and vomiting. While this is a widespread approach there is little evidence from randomised controlled trials for many of the drugs used for these symptoms in this patient group. Levomepromazine is a neuroleptic agent which is commonly used to relieve nausea and vomiting in palliative care settings. We conducted a systematic review to evaluate the efficacy and adverse events associated with the use of levomepromazine for the treatment of nausea and vomiting in palliative care patients.

**Methods:** We searched electronic databases using relevant search terms and synonyms. Selection criteria specified that studies had to be randomised controlled trials of levomepromazine for the treatment of nausea or vomiting for adults receiving palliative care or suffering from an incurable progressive medical condition.

**Results:** The search strategy run in September 2011 identified 421 abstracts. None of the studies met the criteria for inclusion and all were excluded from the review. Some of the studies identified provide support for the use of levomepromazine as an antiemetic in patients with advanced cancer although none were randomised controlled trials. We found several studies assessing levomepromazine use in the prophylaxis of chemotherapy-induced vomiting but the results are not directly applicable to a palliative care setting.

**Conclusion:** There is a lack of evidence from randomised controlled trials in palliative care, particularly due to the difficulty of conducting such studies in this setting. Further studies of antiemetic agents are needed to provide better evidence for their use in palliative care. However, levomepromazine remains widely used by palliative care physicians despite the lack of data from randomised controlled trials.

**Conclusion:** There is a lack of evidence from randomised controlled trials in palliative care, particularly due to the difficulty of conducting such studies in this setting. Further studies of antiemetic agents are needed to provide better evidence for their use in palliative care. However, levomepromazine remains widely used by palliative care physicians despite the lack of data from randomised controlled trials.

**Abstract number:** P2-036  
**Abstract type:** Poster

**Management of Oral Mucositis with a Muco-adhesive Oral Rinse, a European Clinical Experience**

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**Introduction:** Radiotherapy/chemotherapy induced oral mucositis represents a major therapeutic challenge encountered in cancer patients.

MuGard® is an innovative ready-to-use, viscous, muco-adhesive oral rinse which forms a protective hydrogel coating over the oral mucosa.

**Patients and methods:** Patients either began using the oral rinse prophylactically or after the onset of mucositis. Health care professionals were proposed to consider OMAS (Oral Mucositis Assessment Scale) and/or EORTC scale for the evaluation of changes in lesions and symptoms of OM. 129 cancer patients undergoing RT/CT used this rinse either in prevention or treatment of oral mucositis.

**Patient anamnesis:** Clinical use and patient acceptance of the oral rinse for the treatment of oral mucositis (73% of the patients) and prevention of oral mucositis (27% of the patients) were assessed in 129 adult cancer patients undergoing radiotherapy and/or chemotherapy, and therefore at risk of developing oral mucositis.

**OMAS AND RTOG/EORTC scores, treatment phase, endpoint analysis**

MuGard significantly improved or stabilised lesions in 76% of patients: [change from baseline (Wilcoxon signed rank test): p = 0.0052 (OMAS scale), p = 0.037 (RTOG/EORTC scale)].

Use of analgesics: decreased from 67% (baseline) to 53% (final) of patients in the treatment group. Relapse of OM: in 9/129 (7%) patients. Treatment acceptability: Good /Very Good: 111/129 (86%) patients. Main reasons: burning, nausea/vomiting, reduced general condition related to the underlying disease.

**Conclusion:** The use of the oral rinse with esp. MuGard® in cancer patients provides an improvement and/or

stabilisation of the lesions and symptoms of OM in more than 3/4 treated patients. These results are combined with 52% significant reduction in oral discomfort (oral pain and swallowing ability) in patients with pre-existing lesions of OM. It is well accepted by 86% patients, as reported in this assessment program.

**Abstract number:** P2-037  
**Abstract type:** Poster

## Impact of Opioid Dose on Frequency of Constipation

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**Background:** Opioids are one of the most frequent etiological factors of constipation in palliative care patients. However information on the relation between the daily dose of opioids and the frequency of constipation is scarce.  
**Aims:** In this cohort study we observed the frequency of constipation depended on the dose of daily opioids used in the last 7 days.  
**Study design and methods:** Constipation was defined as frequency of complete spontaneous bowel movements < 3 per week or Bowel Function Index > 3. Morphine equivalent doses (MED) were taken according to EAPC 2012 guidelines. The analysis was performed in 3 groups of patients:  
1. non-opioids,  
2. low-dose opioids (0-120 mg/d of morphine equivalent dose, MED) and  
3. high-dose opioids (MED > 120 mg/d).  
Chi-2 tests were used for the analysis of differences between the groups.  
**Results:** 265 patients were took part in the study, out of which 205 questionnaires were eligible for the analysis. The frequency of constipation in the group 1., 2. and 3. was 44%, 62% and 83% and the differences between the groups were statistically significant.  
Laxatives were used in 19% of patients without constipation and in 54% of patients taking opioids (p < 0.001).  
**Conclusions:** There is strong evidence that the frequency of constipation depends on the opioid daily dose, in spite of use of laxatives. This implicates more aggressive anti-constipation prophylactic strategy in the group of patients taking high doses of opioids.

**Abstract number:** P2-038  
**Abstract type:** Poster

## Effects of Normobaric Hypoxia on Human Motor and Visual Brain Activation - A Functional Magnetic Resonance Imaging (fMRI) Study

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**Aims:** Palliative care patients with impaired lung function due to tumors, or chronic pulmonary diseases may develop decreased oxygen saturation and loss of daily activity of life. The aim of our study was to investigate the cerebral mechanisms of adaptation to normobaric hypoxia.  
**Methods:** A total of 16 healthy male subjects were studied with fMRI. During the baseline condition subjects were breathing room air containing 21% oxygen, whereas during short-term (7 min) and long-term hypoxia (8.5 hours) subjects were breathing air containing 13% oxygen. In each condition two different tasks were performed. In the visual paradigm, participants had to fixate a contrast-reversing (8 Hz) black and white checkerboard. In the motor paradigm participants had to execute intermittent finger tapping with all five fingers of their right hand. Arterial oxygen saturation was measured continuously.  
**Results:** Oxygen baseline values (97.9% ± 1.2) significantly differed from both hypoxia values (short term hypoxia 84.1% ± 3.8; long term hypoxia 82.8% ± 4.4; p < 0.001). Brain activation with regards to visual stimulation was found in primary visual areas as well as association cortex and decreased during both hypoxic conditions (p < 0.05 corrected for whole brain analysis). Brain activation due to self-initiated finger tapping was found in typical motor areas at baseline and decreased during short- and long-term hypoxia (p < 0.05 corrected for whole brain analysis). We did not find any changes of activation in the visual or motor cortex, comparing both hypoxic conditions. However, signal intensity changes

were lower after visual stimulation (p < 0.05).  
**Conclusion:** Hypoxia leads to decreased brain activation in fMRI during motor and visual stimulation despite a preserved function. The ability of the brain to adapt to chronic hypoxic conditions might differ between the primary motor and the visual system.  
This work was funded by the German Society of Mountain and Expedition Medicine.

**Abstract number:** P2-039  
**Abstract type:** Poster

## Cancer Anorexia and Cachexia Syndrome (CACS): Associations with Quality of Life, Inflammatory Markers, and Survival of Advanced Cancer Patients

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**Objectives:** To evaluate the prevalence of Cancer Anorexia and Cachexia Syndrome (CACS) in outpatients with advanced cancers in their first visit to the Outpatient Palliative Care Clinic (OPCC) and its association with quality of life (QoL), inflammatory markers and overall survival (OS).  
**Materials and methods:** One hundred and forty two advanced cancer patients had their weight, height, skinfold thickness, and arm circumference prospectively measured, from March/2011 up to May/2012. CACS was defined according to Fearon et al. in precachexia [PCx], cachexia [Cx], refractory cachexia [RCx], and "without cachexia" (WC). Those WC were further subdivided into malnourished or not malnourished. EORTC QLQ-C30 was used in order to access QoL. Hemoglobin, white blood count (WBC), C-reactive protein (CRP), and albumin were also measured. Mann-Whitney and Kruskal-Wallis tests were performed. Survival curves were estimated by the Kaplan-Meier method and differences assessed by the log-rank test.  
**Results:** Considering CACS criteria, there were 18 (13%) PCx, 33 (23%) Cx, 11 (8%) RCx, and 80 (56%) WC. From those, 20 (25%) were malnourished only. Occurrence of CACS (PCx, Cx, or RCx) had a negative impact on QoL, mainly in functional and symptom domains. CACS was also associated with lower levels of hemoglobin (p=0.018) and albumin (p=0.001) and higher levels of CRP (p=0.039), but not with WBC levels (p=0.176). The OS was significantly different between groups of CACS (p = 0.001). The worst and best median OSs were observed in RCx and WC groups, (130 d, 390 d, respectively). PCx and Cx patients had similar median OS. In addition, the diagnosis of malnourished among WC group was not relevant in terms of impact on QoL, inflammatory markers and OS.  
**Conclusion:** The identification of the CACS is relevant in clinical practice, since it is associated with poorer QoL and OS in patients with advanced cancer. The PCx proved as important as Cx, but in patients without Cx, malnutrition alone was not significant.

**Abstract number:** P2-040  
**Abstract type:** Poster

## Analysis of the Control of Symptoms and Emotional Distress in Patients with Cancer Attended Outside the Conventional Hospital: Following of 167 Cases

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**Aims:** Assess the physical problems and emotional discomfort of patients, with advanced cancer disease, who die at home attended by a Hospice Home Care Team (HCT) or in a hospice, and of their principal carer.  
**Material and method:** Observational study of a longitudinal cohort, with a cross-section design, 3-months prospective following, with patients consecutively referred during six months from the medical oncology service to their home or to a hospice for palliative treatment. An audit was conducted by an expert from outside the team care: the functional status by Barthel scale, the cognitive impairment by Pfeiffer scale, the load symptomatic by Edmonton Symptom Assessment System (ESAS) and the patient's emotional distress with the Hospital Anxiety and Depression (HAD) scale; HAD was also used for the principal carer.  
**Results:** A total number of 167 patients were studied, with a mean average age of 71.5 years old (sd 11.5), 100 men and 67 women. A 31% (51 cases) suffered from cancer in the digestive area, 29% (49) pulmonary cancer and 14% (24) urological cancer. A 60.5% (101 cases) had a Barthel index lower than 55 and a 21.8% (44 cases) a Pfeiffer greater than 4. The mean average intensity of the symptoms assessed during following were: pain 3.6, asthenia 5.4, nausea 1.3,

depression 3.5, anxiety, 2.7, drowsiness 2.4, anorexia 4.8, discomfort 3.2, dyspnea 2.9, insomnia 2.9, constipation 2.9 and dry mouth 3.3. HAD mean average of the 109 cases that have been followed: anxiety 6.43 (CI 5.5 - 7.3) and depression 8.9 (CI 7.9 - 8.9). For the 135 principal carers, who could be identified, the mean average results for anxiety and depression were 7.2 and 8.5, respectively.  
**Conclusions:** A good control of symptoms and emotional distress of patients have been observed (VAS of symptoms lower than 4, except for asthenia and anorexia, and depression and anxiety subscales < 9), as well as the levels of anxiety-depression (< 9) of the principal carers.  
Funded by Valencia Health Agency

**Abstract number:** P2-041  
**Abstract type:** Poster

## Dyspnea in Hospitalized Advanced Cancer Patients: Subjective and Physiologic Correlates

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**Aims:** Dyspnea is one of the most distressing symptoms in cancer patients. It is unclear if physiologic measures such as vital signs and the Respiratory Distress Observation Scale (RDOS) are useful for assessing dyspnea. We examined the association among the subjective rating of dyspnea according to advanced cancer patients, caregivers and nurses, and various physiologic measures.  
**Methods:** We enrolled consecutive hospitalized patients seen by respiratory therapy or referred for dyspnea. We asked patients, caregivers and nurses to assess the patients' dyspnea at the time of study enrollment independently using a numeric rating scale (0=none, 10=worst). The Edmonton Symptom Assessment Scale (ESAS), causes of dyspnea, vitals and RDOS were collected.  
**Results:** 299 patients were enrolled: average age 62 (range 20-98), female 47%, lung cancer 37% and oxygen use 57%. The median RDOS was 2/16 (Q1-Q3 1-3) and the number of potential causes was 3 (Q1-Q3 2-4), with pleural effusion (N=166, 56%), pneumonia (N=144, 48%) and lung metastasis (N=125, 42%) being the most common. The median intensity of patients' dyspnea (Q1-Q3) at the time of assessment was 3 (Q1-Q3 0-6) for patients, 4 (Q1-Q3 1-6) for caregivers (Kappa=0.23, P < 0.001) and 2 (Q1-Q3 0-3) for bedside nurses (Kappa=0.09, P < 0.001). Patients' expression of dyspnea correlated moderately with caregivers' (r=0.68, P < 0.001) and nurses' (r=0.50, P < 0.001) assessments, and weakly with the RDOS (r=0.35, P < 0.001), oxygen level (r=0.32, P < 0.001) and the number of potential causes (r=0.19, P=0.001). In multivariate analysis, patients' dyspnea was only independently associated with ESAS dyspnea (P=0.002) and dyspnea as assessed by caregivers (P < 0.001).  
**Conclusion:** Patient's level of dyspnea was weakly associated with physiologic measures. Caregivers' perception may be a useful surrogate for dyspnea assessment.

**Abstract number:** P2-042  
**Abstract type:** Poster

## The Effects of Cell-free and Concentrated Ascites Reinfusion Therapy (CART) on Ascites-relating Symptoms Evaluated by MDASI-J

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**Research aims:** CART: Cell-free and Concentrated Ascites Reinfusion therapy with use of membrane separation techniques is now attracting rising attention in Japan as a strategic symptom-relieving method replacing paracentesis against malignant ascites. The ascites were filtered using the first filter which removes cancer cells and microbes. Then, the filtered ascites was concentrated by the second filter. Finally, useful proteins including albumin and globulin obtained from the ascites are reinfused intravenously to the patients. However, there is no report evaluating its effects on ascites-related symptoms in objective way.  
**Study design and methods:** From April 2011 to September 2012, CART processes were performed on 38 patients (gastric cancer 24, ovarian cancer 6, pancreatic cancer 3, cancers of other origins 3, liver cirrhosis 1, chronic heart failure 1) at our hospital. In first session of each patient, severities of their symptoms were evaluated before and after each CART procedure, with numerical rating scale for abdominal tense and MDASI-J (Japanese version of M. D. Anderson Symptom Inventory) for various symptoms.

**Results:** Abdominal tense and both symptom scores and interference scores of MDASI-J were improved significantly after CART; abdominal tense scores decreased from  $7.3 \pm 2.39$  to  $3.8 \pm 1.79$  ( $p < 0.0001$ ), MDASI-J scores decreased from  $4.7 \pm 2.47$  to  $2.7 \pm 2.06$  ( $p = 0.0004$ ) in symptom scores and from  $7.2 \pm 2.8$  to  $5.1 \pm 2.8$  ( $p = 0.0007$ ) in interference scores. Detailed investigation revealed that many of the symptoms including fatigue and gastric symptoms, which is usually the target symptoms of paracentesis, as well as general symptom scores. Patients experienced no serious adverse event during procedures.

**Conclusion:** We conclude that various symptoms related to malignant ascites were improved with CART safely. Factors or causes that ameliorate symptoms during the procedures yet remain elucidated.

**Abstract number:** P2-043

**Abstract type:** Poster

### Restless for Sleep - What Do Palliative Care Professionals Assess in Patients with Insomnia?

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**Background:** Insomnia is an oft-neglected symptom affecting up to 70% of patients with palliative care needs. It is frequently multifactorial in nature and effective management requires identification of potential causes as well as the use of diverse interventions beyond the use of hypnotic drugs.

**Aims:** To identify the preferences and actions of doctors and clinical nurse specialists in managing insomnia compared with previously published regional standards and guidelines.

**Methods:** Two simultaneous surveys were done evaluating clinical practice and a case-note review of new assessments to specialist palliative care teams. These were disseminated across integrated palliative care clinical networks in the North West of England.

**Results:** 97 evaluations of clinical practice and 158 case note reviews were completed. 50% of clinicians stated they "always" assessed patients for insomnia - case note review suggested that this was higher at 74%. Pain (22%) and anxiety (20%) were the most prevalent factors identified on case note review. Some potentially common causes of insomnia, such as breathlessness and drug withdrawal, were less likely to be routinely assessed.

**Conclusions:** Insomnia and its symptoms are frequently reviewed in palliative care populations; however some potential causes may not be fully evaluated. Causes beyond direct effects of the individual's life-limiting disease, such as obstructive sleep apnoea and restless legs syndrome, should be considered. New guidance from sleep specialists emphasise the use of psychological therapies for management of chronic insomnia. These should be considered in patients with a prognosis that is long enough to go through short psychological interventions. We have updated and developed palliative care specific guidelines collating best practice in managing insomnia in palliative care populations, presented here.

**Abstract number:** P2-044

**Abstract type:** Poster

### Renal Function and Symptoms/Adverse Effects in Patients with Cancer in Opioid Treatment

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**Aim:** To analyze if symptoms/adverse effects were associated with renal function in patients with cancer in opioid treatment.

**Methods:** This investigation derives from a cross-sectional multicenter study (European Pharmacogenetic Opioid Study), conducted during 2005-2008. Inclusion criteria: malignant disease, age  $\geq 18$  years and regular scheduled treatment for at least three days exclusively with only one of the 3 most reported opioids (morphine, oxycodone and fentanyl) for moderate or severe cancer pain. 1154 patients had available data regarding creatinine and opioid plasma concentrations. Fatigue, nausea and vomiting, pain, loss of appetite, constipation and cognitive dysfunction were assessed through EORTC QLQ - C30 (cut-off=66.7). Renal function was analysed using the Cockcroft-Gault formula and cut-offs applied were:  $< 60$ ml/min impaired renal function and  $< 30$  ml/min severe renal impairment. Multiple logistic regressions were adjusted for age, sex, opioid serum concentrations and other medications.

**Results:** The patients in the three opioid groups had similar mean age (60y) and equivalent proportions between sexes. Renal impairment was observed in 48.0% of morphine, 50.0% oxycodone and 57.6% fentanyl groups. Logistic regressions showed that patients with mild impaired renal function in morphine treatment had higher odds of having severe constipation (OR: 2.03, 95% CI: 1.36-3.16,  $P < 0.01$ ). A tendency to loss of appetite in patients with moderate/severe renal impairment in morphine treatment was also noted (OR: 2.00, 95% CI: 1.14-3.49,  $P = 0.05$ ). No other significant associations were observed.

**Conclusion:** Severe constipation was the only symptom/adverse effect associated with renal impairment in patients in morphine treatment. The use of oxycodone and fentanyl, in relation to the six symptoms studied, seems to be safe in patients with renal impairment. However, further studies are necessary.

Study supported by EU Palliative Care Research Collaborative 6th Programme.

**Abstract number:** P2-045

**Abstract type:** Poster

### Ketamine and Midazolam for the Treatment of Refractory Seizures in Palliative Care Patients: A Case Series

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**Background:** In palliative care patients, refractory and nonconvulsant status epilepticus (RSE/NCSE) are a diagnostic and therapeutic challenge. Evidence to guide both the optimal choice of therapy and to define treatment goals is lacking. Ketamine is a NMDA receptor antagonist which has successfully been used as a reserve agent in cases of RSE/NCSE. Here, preliminary data on a combination regimen of ketamine and midazolam, a GABA receptor agonist, for the treatment of RSE/NCSE in patients with advanced brain lesions are presented.

**Methods:** Patients in a university palliative care unit with otherwise intractable RSE/NCSE caused by malignant brain lesions were assigned to receive intravenous ketamine at a dose of 1.5mg/kg body weight/24hrs in addition to the institutions' standard midazolam regimen (starting dose 5mg/24hrs, up-titration guided by clinical response). Diagnosis of RSE/NCSE was made by EEG and/or clinical signs.

**Results:** From June to October 2012, 3 patients with RSE/NCSE caused by Glioblastoma multiforme ( $n=2$ ) and metastatic brain lesions ( $n=1$ ) were treated with ketamine and midazolam after futile anticonvulsant drug therapy. Patient 1 (female, 46y) had received 1<sup>st</sup> line chemoradiation for Glioblastoma and presented with changing levels of awareness suspect of NCSE while on levetiracetam. Upon administration of ketamine 100mg/24hrs and midazolam 5mg/24hrs she promptly regained consciousness, was able to give short but adequate answers, and was discharged to hospice on that regimen after 14 days. Patient 2 had a similar response to treatment while patient 3 remained comatose and died within two days. Information on patient outcomes will be presented in detail.

**Conclusion:** Ketamine and midazolam may be a novel and effective regimen in the treatment of RSE/NCSE caused by malignant brain lesions. Mode of action, dose response and toxicity profile of ketamine have to be elicited.

**Abstract number:** P2-046

**Abstract type:** Poster

### Qualitative Results of a Mixed Methods RCT to Assess the Effectiveness of a Nurse-led Palliative Care Intervention in Psychosocial Terms for HIV Positive Patients on Antiretroviral Therapy

(ART)

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**Background/aims:** UNAIDS and WHO recommend palliative care (PC) alongside HIV treatment as part of a comprehensive care package. We conducted a mixed methods RCT, evaluating for the first time a nurse led palliative care intervention in HIV. The qualitative component of the study reported here explores the process, potential mechanisms of action and patients experience of the intervention and participation in the trial.

**Methods:** A purposive sample of 20 intervention and 10 control (usual care) patients were recruited. In-depth semi-structured interviews with patients were conducted by a local researcher up to 9 months after patients exited the trial. Transcripts were translated into English and analysed using thematic content analysis.

**Results:** Major themes include: physical, psychological spiritual and social wellbeing, participating in research and experiences of the intervention. Intervention patients reported benefit from the increased time spent with staff, e.g. being listened to, having their needs assessed and met. This fostered trust and ability to disclose problems. Patients reported taking medical advice more seriously, improving self-care, communication, and feeling "respected" and "loved" within the PC setting. Control patients reported benefit including feeling more able to express their needs in their interactions with the clinic staff and improved self-care.

**Conclusions:** The qualitative data presented here elucidates the psychosocial benefits experienced by HIV patients on ART receiving PC, complementing and explaining the quantitative findings. In particular, advice giving and therapeutic listening appear to be important mechanisms of action of this nurse-led PC intervention. In addition, the finding that eliciting self-reported outcome data had beneficial effects in the control group has important implications for intervention evaluation research in this population.

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**Abstract number:** P2-047

**Abstract type:** Poster

### Psychosocial Outcomes of a Phase III Randomised Controlled Trial to Assess the Effectiveness of a Nurse-led Palliative Care Intervention for HIV Positive Patients on Antiretroviral Therapy (ART)

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**Background:** UNAIDS and WHO recommend palliative care (PC) alongside HIV treatment as part of a comprehensive care package. However, the psychosocial effectiveness of PC in this population has not been evaluated.

**Aims:** To evaluate the effect of a nurse-led PC intervention on psychosocial outcomes for patients on ART and to examine the differences in health services receipt between study arms.

**Methods:** A randomly selected sample of outpatients attending an urban clinic in Mombasa, Kenya, were invited to participate in a RCT with 4-month follow-up and 60 patients per arm. Data was collected monthly at 5 time points using the MOS-HIV, General Health Questionnaire (GHQ), African Palliative Care Association African Palliative Outcome Scale (APCA African POS) and the Client Services Receipt Inventory (CSRI).

**Results:** Intervention patients reported more discussion about spiritual worries, emotional support, time to discuss worries, emotional support for the family, discussion about the future and opportunity to plan ahead ( $p < 0.01$ ). APCA African POS worry, ability to share feelings, help and advice to plan for the future and interpersonal problem, MOS-HIV mental health summary score and GHQ score were significantly better in the intervention group than the control group after 1 month. This initial difference attenuated for all outcomes apart from the APCA African POS interpersonal factor and item 'help and advice to plan for the future', which were significantly better in the intervention group at all time points.

**Conclusions:** This is the first study to demonstrate that simple nurse-led palliative care with specialist supervision can improve psychosocial wellbeing among HIV patients on ART. The receipt of palliative care appears to be particularly

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effective for psychosocial symptoms in the 1<sup>st</sup> month of care, and is of subsequent benefit in giving patients sufficient help and advice to plan for the future.

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**Abstract type:** Poster

### Is Neuromuscular Electrical Stimulation (NMES) an Acceptable and Feasible Exercise Intervention for Patients with Non-small Cell Lung Cancer (NSCLC) Receiving Palliative Chemotherapy?

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**Background:** Reduced exercise capacity is common in patients with advanced non-small cell lung cancer (NSCLC) and is associated with increased morbidity and mortality. Physical inactivity due to the cancer or its treatment contributes, and exercise may be beneficial, with NMES a pragmatic option. The primary aim of this phase II study was to determine if NMES is acceptable (assessed by adherence) to patients with NSCLC receiving chemotherapy.

**Method:** Patients with stage IV NSCLC scheduled to receive first-line palliative chemotherapy were randomised into a NMES or control group. The NMES group were asked to ideally attempt daily thigh stimulation for 30min and no less than three times weekly; the minimum criterion against which adherence was assessed using self-report diaries. The sample size was based on a Fleming's design in the NMES group to determine between unacceptable and acceptable rates of adherence (50% versus 80%,  $\alpha=0.05$ ,  $\beta=0.9$ ). Semi-structured interviews were conducted in a subgroup of patients to explore factors influencing adherence.

**Results:** 49 patients (28 male, mean (SD) age 67 (10) years) were recruited with 30 randomised to NMES. Of these, two did not commence chemotherapy, eight did not complete chemotherapy, and five withdrew (three because of NMES-related muscle discomfort). Overall, including those who withdrew secondary to a NMES related side effect, 8 of 18 (44%) met the minimum adherence criterion. Adherence was enhanced by incorporating sessions into a daily routine and hindered by side-effects of treatment and, for those for whom maintaining normality was a priority, the perceived disruption to everyday life.

**Conclusion:** Use of NMES in this setting is challenging with rates of adherence less than anticipated and muscle soreness limiting its use in some patients. Patient reports can be used to optimise rates of adherence in future studies.

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**Abstract type:** Poster

### The Management of Pruritus Associated with Cholestasis: A Systematic Review and Guideline

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**Introduction:** The pathophysiology of cholestatic pruritus is poorly understood with bile acids, opioids and serotonin all potential mediators. A number of drugs have been used, but consensus on a treatment strategy is lacking.

**Aim:** To identify and appraise the evidence for the effectiveness of naltrexone, rifampicin, ondansetron, cholestyramine and sertraline in the management of cholestatic pruritus, and to develop a guideline for use in palliative care.

**Methods:** Electronic databases (MEDLINE, EMBASE, PsycINFO, Cochrane trials register) and journals were systematically searched to identify randomised controlled trials comparing the above drugs with placebo or alternative treatments in patients with cholestatic pruritus secondary to malignant or non-malignant disease. The primary outcome was symptom relief/ patient-reported pruritus. The SIGN tool was used to grade evidence and recommendations.

**Results:** 12 studies met inclusion criteria. Naltrexone significantly reduced pruritus in two studies. Transient side effects consistent with opioid withdrawal-like phenomena were seen. Rifampicin was effective and well tolerated in three studies, with one conflicting report of no benefit. Two studies showed cholestyramine to be effective, but the quality of evidence was low and gastrointestinal upset reported. Ondansetron was well tolerated, but evidence inconsistent with high quality studies showing both a significant reduction in pruritus and no benefit. In one study

sertraline improved pruritus with minimal side effects.

**Conclusion:** The evidence reviewed is largely from chronic liver disease patients so guideline recommendations are based on extrapolation, reflected in the grading. Naltrexone and rifampicin are suggested as first line drug treatments for cholestatic pruritus. Cholestyramine is not recommended with intolerable gastrointestinal side effects limiting its use. Ondansetron and sertraline may be considered where other drugs have failed or are contraindicated.

**Abstract number:** P2-050

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### A Systematic Review of Hypogonadism and Opioid Use in Patients with Cancer

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**Context:** Hypogonadism has been found to be more prevalent in patients with cancer. The aetiology is multifactorial but may be associated with opioid use, previously linked to hypogonadism in patients without cancer. Development of hypogonadism in patients with cancer is likely to be clinically significant as it may amplify symptoms of malignancy experienced by the patient.

**Aims:** To assess the evidence for an association between opioid use and hypogonadism in patients with cancer related pain.

**Methods:** Medline and Embase databases were searched from 2000 to 16<sup>th</sup> May 2012. Search terms used included 'neoplas\$'; 'cancer\$'; 'opioid\$'; 'endocrin\$'; 'hormon\$' and 'hypogonad\$'. Studies were selected for review on the following criteria: original articles, English language, active cancer, patient taking any opioid by any route for any duration, defined endocrine parameters measured, article examined relationship between opioid consumption and endocrine parameters. Review articles and case studies were excluded.

**Results:** 4 articles met the criteria. It was not possible to amalgamate the findings due to heterogeneity of study methods. 3 articles suggested a dose-dependent link between opioids and hypogonadism. 1 study examined symptoms and found hypogonadism to be associated with reduced sexual desire score and negative mood. A 4th study showed no link between opioids and hypogonadism and furthermore no increased incidence of hypogonadism in cancer patients versus controls.

**Conclusion:** There is some evidence to suggest an association between opioids and hypogonadism in patients with cancer. It is difficult to draw definitive conclusions due to heterogeneity of study groups, definitions of hypogonadism and lack of evidence of symptom burden. Further research is required to quantify the scale of the problem in patients with cancer pain, impact on symptom burden, length of time on opioids required to have an effect and whether different opioids have varying endocrine profiles.

**Abstract number:** P2-051

**Abstract type:** Poster

### Locus of Control and Symptom Severity in Assessing Depressive Symptoms of Advanced Cancer Patients 65 Years Age

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**Research aims:** The relationship between depression, locus of control and distressing symptoms in advanced cancer patients receiving palliative care, and investigate the predictive power of locus of control and clinical symptom assessment in patients' depressive mood disorders.

**Study design and methods:** 70 consecutive Greek patients with advanced cancer referred to a Palliative Care Unit were included in the study. Demographics and clinical characteristics were recorded. Participants completed the Beck Depression Inventory, the Greek Cancer Locus of Control Scale, the Linear Analogue System Assessment (for quality of life) and the Greek M.D Anderson Symptom Inventory. For pain therapy, the World Health Organization (WHO) pain ladder (scales 1-3) was used.

**Results:** The total BDI questionnaire score was suggestive of depression. Significant correlations were found between the presence of depression and poor quality of life, ECOG, performance status and 'sense of control over the course of cancer' (higher external locus of control) ( $p < 0.0005$ ). Depression was significantly correlated with pain, distress and poor general activity, overall enjoyment of life and relationships with people ( $p=0.004$ ), anxiety, fatigue, anorexia, dyspnea, sleep disturbances ( $p=0.001$ ) (correlation

coefficient ranging from -0.569 to 0.435). Poor quality of life and 'sense of control over the course of cancer', as well as anxiety, fatigue, anorexia, dyspnea and sleep disturbances provided the strongest prediction of depression (statistical significance in the total model  $p < 0.0005$ ).

**Conclusions:** Patients with advanced cancer, younger than 65 years old, are prone to clinical depression. The model concluded that independent predictors of depressive thought content in such a patient cohort are poor 'control' over the course of cancer, quality of life and the presence of distressing symptoms (shortness of breath, sleep disturbances, loss of appetite, fatigue and sleepiness).

**Abstract number:** P2-052

**Abstract type:** Poster

### Cancer. Effect of Low-dose Morphine on Dyspnea in Advanced Cancer Patients

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**Objective:** To assess the therapeutic effect and side effects of low-dose morphine in patients with advanced cancer and dyspnea in Vietnam.

**Method:** Fifty-six mentally alert inpatients with stage III or IV cancers, ECOG performance status 3 or 4, moderate or severe dyspnea, and estimated survival time of at least 6 days were enrolled. All were opioid-naïve. Starting doses of morphine were 5mg by mouth or 2mg by injection. Data on dyspnea and typical opioid side effects such as nausea/vomiting and constipation were collected using a 0 to 10 scale at baseline and on days 1, 2, 4, and 6. Sedation was measured with the Ramsay Sedation Scale.

**Results:** Forty-seven male and nine female patients aged 21 to 70 year completed the study. At baseline, 31 patients reported severe dyspnea ( $\geq 7/10$ ) and 25 reported moderate dyspnea (4-6/10). On day six, daily morphine doses ranged from 30 - 160 mg by mouth in six divided doses or 12 - 20 mg by injection in six divided doses. By day six, 86% reported a reduction in dyspnea of at least 3 points. Side effects including nausea, vomiting, constipation, dysuria, and sedation were either mild or moderate when present. **Conclusion:** Morphine is safe and effective for relief of dyspnea in Vietnamese cancer patients.

**Abstract number:** P2-053

**Abstract type:** Poster

### How to Managing Living with Dry Mouth Can Physiotherapy Help the Palliative Patients who Struggle with Mouth Dryness?

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**Background:** Experiences from working 18 years with palliative patients has teased my curiosity for a physiotherapeutic aspect helping managing dry mouth. Most of the patients, both in daycare and bedcare units, seems to struggle with this symptom. I often instruct them to use their own tongue to produce some saliva.

**Aim:** Can physiotherapy help the patients to manage better:

- Producing more saliva using the tongue?

- Fokus on using the patients own muscles.

- Fokus on something the patients can do themselves.

**Methods:** The project will be added to other stimulants the patients may be using ( gum, salvie tea, gel...) And the stimulants will be registered. The project will be conducted as a project to develop a clinical practice. I will include at least, 30 daycarepatients and 30 bedcarepatients in the project with ESAS score 4-10.

The daycarepatients will give a subjectiv report on activ use of the tongue, at least 6 times a day for at least 30 seconds each time, over 4 weeks. The patients will note down in a diary every time they do the exercises. They will bring the diary once a week when they visit the daycare unit, and get a reminder and instruction about the exercises.

The bedcarepatients will give a subjectiv report on active use of the tongue at least 6 times a day for at least 30 seconds each time, over 2 weeks. The patients will be reminded and instructed nearly every time they exercises the tongue every day. They can be given some help with noticing in the diary.

ESAS will be an objective measure for the project together with the subjectiv feedback from the patients.

**Results:** In the end of april I will have some results ready for the poster. The main question may be: Are the patients willing and able to use their tongue?

Abstract number: P2-054  
Abstract type: Poster

### The Experiences of Patients Undergoing Blood Transfusion in a Day Hospice

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**Aims:** To explore patients' views on living with anaemia and their experience of undergoing blood transfusion in a day hospice.

**Methods:** 10 patients under the care of the local cancer centre haematology team who had received between them 90 blood transfusions (including at least 1 in our day hospice) were purposively recruited. Digitally recorded interviews were conducted using a semi-structured interview guide. Interviews were transcribed anonymously and analysed using a phenomenological analysis framework making links and connections between data in order to generate categories. Data sets from all participants were compared and contrasted in order to identify unique and common experiences. A composite summary of categories and then themes completed the analysis process.

**Results:** Participants had all had multiple transfusions (range 4-13) and were receiving regular transfusions every 2 to 4 weeks. Patients experienced tiredness as the most common symptom of anaemia and the symptomatic response to transfusion varied. Participants liked the day hospice for their transfusions due to differences in transport, parking, waiting time and space to ask questions. Few had concerns about attending the hospice but were reassured once they had been there. The majority had no concerns about hospice transfusion and would be happy to return for further treatment.

**Conclusion:** This is the first time in-depth qualitative interviews have been conducted where the focus has been blood transfusions in a day hospice. Haematology patients can have good experiences when undergoing blood transfusions in this setting and perhaps hospices should offer this procedure more frequently to a wider population.

**Funding:** The study was funded by a Cancer Research Network Charitable Fund. They had no influence on any part of the project or results.

Abstract number: P2-055  
Abstract type: Poster

### The Burden of Symptoms of Patients with Haematological Malignancy

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Patients with haematological malignancy access palliative care less frequently, and, for those who do, later in their disease trajectory compared to those with solid tumours. There are likely to be multiple reasons for this, including the unpredictable nature of haematological malignancy treatment responses, the lack of clear goals of care, and the potential for fatal treatment toxicity. In addition the burden of symptoms for patients with haematological cancer is not well understood, and may be a factor in low levels of engagement with palliative care.

**Aims and methods:** We sought to document the symptoms and levels of distress in consecutive patients with haematological malignancy using the Memorial Symptom Assessment Scale-Short Form (MSAS-SF).

**Results:** 180/190 (RR 95%) inpatients and outpatients presenting to a haematological centre completed the MSAS-SF including 37% with a diagnosis of lymphoma, 16% myeloma, 15% chronic and 11% acute leukaemia, 13% bone marrow failure and 9% with myeloproliferative disease. Most (72%) had performance status of ECOG 0 or 1, and 76% were deemed to have 'active' disease, with the remainder in remission. The most common symptoms, reported by 40-50% of patients, were lack of energy, feeling worried, difficulty sleeping, drowsiness, dry mouth and feeling sad. Psychological symptoms were present at least 'occasionally' or 'frequently' in more than 75% of patients. All symptoms were greater for inpatients, ECOG≥2, and those with newly diagnosed, relapsed or refractory disease.

**Conclusions:** Patients with haematological malignancy have a very significant symptom burden, particularly those with poorer performance status, with new diagnosis, relapsed or refractory disease. These symptom levels are comparable to populations with metastatic cancer who are traditionally

referred to palliative care services. Screening of 'at risk' populations of haematological malignancy patients may highlight opportunities for palliative care input.

Abstract number: P2-056  
Abstract type: Poster

### A Case in which Octreotide was Effective against Diarrhea due to Metastasis to the Mesentery

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We herein report a case we experienced in which octreotide was effective against refractory diarrhea due to metastasis of lung cancer to the mesentery.

[Case] A 54-year-old male with lung cancer. With a diagnosis of pulmonary adenocarcinoma, excision of the left superior lobe together with the thoracic wall was performed. One year four months after the surgery, an 8 cm intraperitoneal tumor was found through CT imaging, and although extirpation was attempted, the tumor was found to be wrapped around the small intestine and sigmoid colon, and extirpation was thus halted. By a core needle biopsy, a diagnosis of metastasis of lung cancer to the intestinal membrane was made. Chemotherapy was planned, but one month later, the patient was hospitalized due to diarrhea. There was no nausea or vomiting, but an increase in abdominal bloating and bowel peristalsis was observed. Rehydration, administration of antibiotics, and oral administration of loperamide were performed. Even one week after hospitalization, there was no improvement in the diarrhea, and watery stools were repeatedly observed at least ten times daily. In a CT, an intraperitoneal tumor, as well as gas patterns and nodule formation in the intestinal tract were observed. When the continuous subcutaneous infusion of octreotide at 300µg/day was started, two days later, the frequency of diarrhea decreased. Octreotide was clearly effective, so its administration was continued. One month later, the abdominal tumor had invaded the abdominal wall, and a fistula formed between the intestinal tract and the skin. Intestinal fluids flowed out from the fistula, so management was carried out using a stoma pouch. At the same time, diarrhea from the anus ceased, so octreotide administration was stopped.

Abstract number: P2-057  
Abstract type: Poster

### Cachexia: A Dutch Leaflet

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In the South of the Netherlands the Comprehensive Cancer Centre initiated a group of experts to implement the EAPC guidelines about cachexia.

Dietary advisors, physiotherapists, nurses and a general practitioner developed a leaflet for patients in imitation of the EAPCgroup. Finally we asked representatives of non professionals to give their comment. We organised meetings for professionals to introduce the leaflet

We'd like to present the Dutch leaflet and also a translated version.

Abstract number: P2-058  
Abstract type: Poster

### Clinical Decision-making in Palliative Care

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**Background:** Symptom burden influences perceived health status and quality of life in palliative patients. Hospice nurses play an important role in the treatment of the highest scoring symptoms fatigue, dry mouth and appetite loss. Getting insight into the process of clinical decision-making of nurses in palliative care is important to improve the quality of symptom management.

**Aim:** To explore how Dutch hospice nurses make clinical decisions in choosing interventions related to the symptoms fatigue, dry mouth or appetite loss, and to determine which factors influence the decision-making.

**Methods:** In this qualitative descriptive study, 9 nurses from an academic hospice in the Netherlands participated. Data were collected through a focus group, semi-structured interviews and by attending a multidisciplinary consultation. The interviews were transcribed verbatim. QUAGOL (Qualitative Analysis Guide of Leuven) was used to

analyze the data.

**Results:** Nurses described their decision-making as influenced by personal factors of their patients and themselves, care-related factors and environment factors. Four main themes emerged concerning the interventions nurses choose: diagnosis, medication, non-pharmacological interventions and evaluation. The themes diagnosis, medication and non-pharmacological interventions show a great amount of similarities with the national guidelines of palliative care. The theme evaluation shows less similarity. **Conclusion:** Clinical decision-making in palliative care is a complex process, because many factors influence the selection of a nurse for interventions. It is recommended to give nurses better insight into their own decision-making, because of the influence this may have on the quality of symptom management and the quality of care. Additional training on decision-making can contribute to these qualities.

Abstract number: P2-059  
Abstract type: Poster

### Doctors' Attitudes towards Prescribing Opioids for Refractory Dyspnoea

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**Aims:** Dyspnoea is a distressing and common symptom in palliative care. There is evidence that opioids can improve the experience of dyspnoea. Limited data suggests that doctors' attitudes may be a barrier to prescribing opioids for the relief of refractory dyspnoea. This study explores UK hospital doctors' experience of, and attitudes towards, prescribing opioids for refractory dyspnoea in advanced disease.

**Methods:** Anonymised semi-structured questionnaires were distributed to a convenience sample of doctors within the medical directorate of a UK district general hospital. Data was collated and simple descriptive analysis performed. The study was approved by the hospital research and development department.

**Results:** Sixty-five questionnaires were analysed from doctors of varying grades. Most doctors (94%) reported a willingness to prescribe opioids for refractory dyspnoea though 71% felt less confident than when prescribing opioids for pain. Three-quarters of doctors had initiated, or under supervision, prescribed opioids for refractory dyspnoea. This was most often for a patient in the last hours/days of life [90%], followed by patients with cancer [69%], heart failure [53%] and COPD [43%]. Confidence in prescribing was highest in relation to the dying [94% confident], falling to 45% in COPD. A significant proportion [63%] of respondents expressed concerns when prescribing. The majority of these related to side effects, particularly respiratory depression, or the practical details of prescribing. **Conclusion:** This group of doctors were aware of the use of opioids for refractory dyspnoea and willing to prescribe opioids for this symptom. However confidence varied considerably with patient disease. Fears about side effects were prevalent and need to be specifically addressed in the context of opioid use for dyspnoea. Doctors would also benefit from clearer guidance on prescribing regimes, especially in contexts other than the dying patient. No funding received.

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Abstract type: Poster

### The Mystery of Livedo Reticularis: What Does it Tell Us about our Patients?

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**Introduction:** Livedo Reticularis (LR): derived from the two Latin words; lividus (pale blue), and reticulum (net). LR is pinkish or reddish-blue mottled net like discoloration of skin. It is due to increased viscosity, deoxygenated hemoglobin and/or decreased blood flow in cutaneous vasculature (arterioles, capillaries, venules).

**Methods:** A state of art clinical review Medline search (1966-2012) of the human English literature was done. The key words were "Cancer"; "Livedo"; "Reticularis"; "Sneddon's Syndrome"; and "Vasculitis".

**Results:** Among 800 citations: 141 papers with common clinical diseases and cancers. LR reported in breast cancer, lymphoma, multiple myeloma, renal cell carcinoma. It may be a sign of previously unsuspected breast neoplasm or first sign of metastatic disease. 7% of those with cutaneous vasculitis have associated malignancy (most often myelo- or lymphoproliferative disease). Atrial myxoma may present

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with LR and non specific skin lesions.

### Conclusions:

1. LR can be a presenting sign of recurrent or newly diagnosed cancer
2. Sub-clinical disseminated intravascular coagulation (DIC), vasculitis and paraneoplastic disorders may contribute
3. Abnormal tissue factor expression is a major mechanism of DIC
4. LR associated with anti-neoplastic drugs a. Gefitinib (an epidermal growth factor receptor inhibitor) b. Interferon-2b (anti-angiogenic agent) c. Gemcitabine (nucleoside analogue)
5. LR clinical significance in cancer undetermined

Abstract number: P2-061

Abstract type: Poster

### Breath Work in Palliative Care Patients - A Pilot Study

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**Aim of the study:** Breath work is an increasingly popular experiential approach to psychotherapy in palliative care, especially in German spoken countries. It is based on specific breathing techniques and comprises three core components, namely the conscious connected breathing, mindfulness and relaxation. Some studies have already demonstrated its positive effects on patients with psychosomatic and anxiety disorders, but no data exist in the field of palliative care. Therefore, it was the aim of this pilot study to gain some insights on possible effects of breath work in palliative care patients. The presented data are part of a doctoral thesis.

**Methods:** Palliative care patients receiving breath work therapy were asked to complete questionnaires before and 24 h after breath work, including the subscales anxiety and depression of the Brief Symptom Inventory to assess the mental health and 18 numeric rating scales asking for their self-perceived quality of life, and their mental and physical state. In addition, breath work therapists reported their perceptions during therapy and patients were asked for self-perceived changes due to breath work.

**Results:** 27 out of 87 palliative care patients participated in the study (32%). 85% of the participants were female, the average has been 65 years. After breath work, the BSI scales showed a statistically significant reduction in depression and anxiety ( $p \leq 0.05$ ). Furthermore, there has been an improvement of mental well-being as well as quality of life and a reduction of physical symptoms ( $p \leq 0.05$ ). The participants were highly satisfied with breath work. They described relaxation effects and the feeling of inner peace and balance which lasts one day at least.

**Conclusions:** Breath work might have impact on symptom control in palliative care patients and enhances the quality of life. Further research is needed to find out in more detail what the active factors of breath work are and which patients can benefit most from it.

Abstract number: P2-062

Abstract type: Poster

### Palliative Interventions for Obstructive Uropathies in Advanced Cancer Patients

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**Aim:** Palliative care includes the approaches which improve the quality of life of patients by relieving the symptoms. Advanced cancer patients frequently encounter with urological problems through progression of their disease. Here we aimed to evaluate our patients with obstructive uropathies and managed through interventional methods. **Materials and methods:** Between December 2007-August 2012 the patients with obstructive uropathies due to advanced cancers requiring interventions were evaluated. The demographic data, and clinical analysis were retrieved from patient charts retrospectively. Obtained data were analyzed statistically with frequency, mean, standart deviation etc. were performed.

**Results:** A total of 1405 advanced cancer patients were treated during the period. Thirty-two patients (2.27%) who required interventions were included in the study. The mean age of patients was 68.35 +/- 7.8 (mean +/-SD) and 84.3% (n=27) was male. The distribution of tumor was as follows: 46.8 % (n:15) prostate cancer, 25 % (n: 8) metastatic bladder cancer, 18.7 % (n: 6), colon cancer, and 9.3% (n: 3) gynecologic cancer. While 68.7% of patients underwent percutaneous nephrostomy with the mean number of 2.9 +/-

2.34 times due to hydroureteronephrosis, 31 % underwent TUR-P due to lower urinary system obstruction caused by prostate cancer. The mean survival after percutaneous nephrostomy was 10.95 months +/- 17.6, whereas 10.48 months +/- 14.92 after TUR-P.

**Conclusions:** The interventional approach to obstructive uropathies due to advanced cancer is an important component of palliative care management. The relief of obstruction helps symptomatic control of patients even if multiple interventions required.

## Assessment & measurement tools

Abstract number: P2-063

Abstract type: Poster

### Fall Prevention in a Palliative Ward (Regional Quality Development Project for Helse-Vest, Norway)

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**Background:** As part of Helse-Vest's focus on quality in 2011, a regional project has been started at three hospitals where the aim was to reduce the number of falls in the hospital.

The project was conducted in four wards of the three hospitals. Orthopedic and Neurological wards were chosen at Haukeland Hospital and an Orthopedic ward at Haugesund Hospital.

The Sunniva Palliative ward has recorded many falls and so was chosen as a project ward from Haralds plass Diaconal Hospital. Studies show that more falls are registered in Palliative wards than in Geriatric wards.

**Method:** All patients in the Sunniva Palliative ward were screened for risk for falls in the four months, August to November 2011. In the first month the screening program "Stratify" was used. The following three months the "Downton Fall Risk Index" was used in addition to the "Stratify" program. When patients scored high fall risk, a detailed report was made and fall prevention action was started in the ward and extended to the primary health care.

**Results:** 56 patients were screened in the project period. In August when the "Stratify" program was used, 4 out of 11 patients scored high fall risk.

In September, October and November the "Downton" program was used in addition to the "Stratify". 11 of 36 patients scored high fall risk with "Stratify", while "Downton" gave high fall risk for 22 of 36 patients.

A total of 27 patients out of 56 scored high fall risk during the project period.

**Conclusion:** To be in a palliative phase implies that often the patient will have many risk factors which can create high fall risk. What creates fall risk varies from patient to patient. Focus on prevention for falls should be included in the treatment of patients in a palliative ward.

Abstract number: P2-064

Abstract type: Poster

### Measurement of Lymph Edema in the Head and Neck Region by Bioimpedance Analysis - Results of a Pilot Study

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**Objective:** Is it possible to use bioimpedance analysis (BIA) to evaluate the grade of interstitial lymph edema of the head and neck?

**Methods:** We have performed mono-frequent (50Hz) BIA in 17 head neck cancer patients (16 male, 1 female, mean age 58.9 +/- 9.8 years) after finishing radiotherapy. The distance between both electrodes (medioclavicular, preparotid) was 15 cm. We measured resistance (Rz) and reactance (Xc) as markers of total body water and the capacity of cellular parts within the electrical field. The results were analyzed in relation to the clinical grade (0 - none, 1 - mild, 2 - severe) of lymph edema of the neck region as a classical toxicity of irradiation.

**Results:** We included 33 measurements in 17 individuals. We have seen an inverse relation between the grade of lymph edema and the measured resistance ( $p < 0.05$ ): neck edema °0 (n=17) - median Rz/Xc 46.7 Ohm/m; neck edema °1 (n=10) - median Rz/Xc 36.5/7 Ohm/m; neck edema °2 (n=6) - median Rz/Xc 24.4/5 Ohm/m.

**Conclusion:** BIA may be a useful procedure to objectify the interstitial lymph edema of the neck region after finishing radiotherapy of head and neck cancer.

Abstract number: P2-065

Abstract type: Poster

### Muscle Mass and Muscle Strength in Cachectic Patients with Advanced Pancreatic Cancer

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**Objectives:** Expert surveys have identified muscle mass and muscle strength as important domains for inclusion in assessment of cancer cachexia. Study aim was to explore the association between muscle strength and cachexia in patients with advanced inoperable pancreatic cancer (PC) and investigate if decline in muscle mass was associated with decline in muscle strength.

**Methods:** 59 newly diagnosed patients (M 36) were consecutively recruited and followed every 4<sup>th</sup> week until death. At inclusion, the patients reported pre-illness stable body weight and duration of weight loss. At each assessment, the following anthropometric variables were measured; height, weight, arm circumference, triceps skinfold and handgrip strength (HGS). HGS is a rapid and valid method for measuring muscle strength, and was measured bilaterally in a sitting position with an adjustable analogue dynamometer. The highest value (kg) was used for analysis. Recent consensus criteria for diagnosis of cancer cachexia were used to classify patients as cachectic or non-cachectic.

**Results:** Median age was 62 (48-88) years. Median survival was 30 (3-151) weeks. Upon inclusion 36 (61%) patients were classified as cachectic. Cachectic patients had lower mid upper-arm muscle area (AMA) (cm<sup>2</sup>) (38.2 vs. 44.8,  $p < 0.05$ ) but not lower HGS (28.6 vs. 32.2, ns) than the non-cachectic patients. AMA was correlated to HGS in both men ( $r = 0.44$ ,  $p < 0.05$ ) and women ( $r = 0.54$ ,  $p < 0.05$ ) and explained more than 50% of the HGS variation (adjusted for sex and age). Patients with AMA consistent with sarcopenia (values  $< 32$  cm<sup>2</sup> for men and  $< 18$  cm<sup>2</sup> for women) did not have lower HGS than other patients. During the three first months of follow-up AMA declined, 9% in women and 6% in men (ns). The correlation between AMA decline and HGS decline was weak ( $r = 0.26$ , ns).

**Conclusion:** Cachectic patients with advanced PC did not have lower muscle strength than non-cachectic and change in AMA was a poor determinant for change in muscle strength.

Abstract number: P2-066

Abstract type: Poster

### Will it Be Tonight (Doctor)? Or: Can Tachypnoea and/or Tachycardia Predict Rapidly Approaching Death in Dying Patients?

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**Aim:** To assess whether respiratory rate and/or pulse rate are useful screens for patients on the LCP dying within 1 day.

**Background:** 'How much longer?' is a common question asked of palliative care professionals (Kirk & Kristjanson, 2004). Morita et al (1998) identified 4 signs that precede imminent death, but Hallenbeck (2003) found these are not infallible and further research was called for. The author has noted previously that higher respiratory rates predicted death within 24 hours.

**Methods:** A sample of 100 patients on the LCP was used and basic observations (pulse rate and respiratory rate) were noted as per usual care, along with basic demographic information and diagnosis. The interval between a single observation and a patients' death was then calculated. Correlation coefficients were calculated for RR and PR with time to death. Receiver Operating Curves were constructed to establish optimum cut-offs for RR and PR. The Chi-squared test was used to determine statistical significance. Prognostic test characteristics were calculated for these cut-offs using a test calculator.

**Results:** The sample was judged to be representative of a typical hospice population. 41% of patients died within 24 hours. RR and PR were weakly correlated with time to death. A RR of 28 breaths per minute and PR of 120bpm were pragmatic cut-offs. Tachypnoea was a statistically significantly correlate of death within 24 hours ( $p < 0.001$ ); tachycardia did not meet statistical significance on the chi-squared test. Tachypnoea was 87% specific for death within 24 hours, with a positive LR of 3.31 (1.77, 6.19) and post-test probability (and PPV) of 0.7 (0.55, 0.81); a negative test LR was 0.53 (0.37, 0.76), with post-test probability of 0.27 (0.2,

0.35) and an NPV of 0.79.

**Conclusion:** Measuring the respiratory rate of dying patients is a specific screen to identify patients who will die in the next 24 hours. This is a discrete and non-invasive test that can easily be used if appropriate.

**Abstract number:** P2-067

**Abstract type:** Poster

### Cheap Negative Pressure Wound Therapy

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**Aims:** Negative pressure wound therapy is an effective method of chronic wounds treating. However commercially available systems are relatively expensive. The main point of this project was to design and construct effective, simple and cheap negative pressure therapy system.

**Design and methods:** The main design problem was insulation of non-certified equipment from certified medical devices (vacuum regulator). To avoid this issue, image detection was used.

The system was developed with LabVIEW visual environment, web camera, medical vacuum regulator and various electronics components (microcontrollers, RF modules).

**Results:** The system was created with small amount of expenses. It allows to set up and monitor pressure value in negative pressure dressing. In case of dressing problems or critical pressure value, the system remotely calls medical staff.

**Conclusion:** Designed system creates similar therapeutical effects to commercial systems. The main advantage of this project is lower cost and greater availability.

**Abstract number:** P2-068

**Abstract type:** Poster

### Hospice Excess Opioid Protocol

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**Aim:** Development of a protocol for standardized monitoring of palliative patients who have received, or are exhibiting signs of, an excess of opioids, and for decision making regarding the appropriate use of naloxone and transfer to Acute Care.

**Method:** Based on a literature review, we developed an algorithm, with a practical guide ("Practice Points") and a specific monitoring flow sheet, for use when a patient has a known or suspected excess of opioid, whether from the wrong dose, wrong opioid, wrong patient, drug interactions or impaired elimination. An education plan forms part of the protocol.

**Results:** We will highlight the educational material designed to facilitate implementation in Hospice and will discuss successful uptake in cases where patients were monitored without the need for administration of naloxone or transfer to acute care. Use of the protocol in long term and acute care settings will be included in the presentation.

**Conclusion:** This protocol enables Hospice staff to monitor patient in place and make informed decisions regarding indications for naloxone use and transfer to acute care. Although it was initially designed for use in the Hospice setting, the protocol can be applied successfully in other areas where opioids are used for symptom control.

**Abstract number:** P2-069

**Abstract type:** Poster

### Feasibility of Collecting Phase of Illness in an Inpatient Palliative Population in the UK

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**Background:** Phase of illness is a system of classifying all palliative care patients to help inform their current and future care needs. Based on their clinical state, patients are allocated to one of four defined categories - *stable, unstable, deteriorating or terminal*. The method has been validated in Australia as a good predictor of resource use and outcome, but this is not yet tested in the UK.

**Aim:** To assess the feasibility of collecting phase of illness data in a UK inpatient palliative population.

**Methods:** Phase of illness data was collected using a paper based tool during the initial assessment of inpatient referrals to the palliative care team over an 8 week period. The distribution of phase of illness in our population was compared with data from the Palliative Care Outcomes Collaboration Report on Palliative Care in Australia (2010). **Results:** 87 patients (60% male, mean age 67[SD 19], 62% cancer, 38% non-cancer) were assessed. Outcomes were: 24% died, 71% discharged and 5% ongoing admissions. Median time to outcome was 7 days. In comparison, Australian inpatient data showed 85% had a malignancy and median length of stay was 7 days (13193 patients). Phase of illness was successfully recorded by the attending clinician in 98% of our patients. The distribution of phases was: 21% *stable* in UK (cf. 30.4% Australia), 35% *unstable* (cf. 26.6%), 32% *deteriorating* (cf. 29.1%), and 12% *terminal* (cf. 13.9%). In the UK, no patients classified *stable* died during admission whilst 90% of patients classified as *terminal* died (compared to 4.8% and 55% respectively in the Australian data).

**Conclusions:** These results demonstrate the feasibility of collecting phase of illness data in a palliative population in the UK. Despite differences in population size, the distribution of phases between the UK and Australia are similar. Further testing of the validity and reliability of this classification system as a potential casemix criterion is needed.

**Abstract number:** P2-070

**Abstract type:** Poster

### Consciousness Level Assessed with the Consciousness Scale for Palliative Care as a Prognostic Factor

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**Introduction:** A consciousness scale for palliative care was recently validated. We tried to find out if the scale levels have a prognostic value.

**Methods:** Retrospective study. Data were collected from the clinical files when the consciousness level according to the scale are recorded at least once a week. Only bedridden patients were included as other patients have a high probability of a normal consciousness level. For statistical analysis the Kaplan-Meier method was used to determine the survival curves and the Log-rank (Mantel-Cox) to compare the length of survival.

Consciousness level scale:

1. Awake
2. Awakens when called by his/her name and keeps awake during conversation
3. Awakens when called by his/her name but falls asleep during conversation
4. Reacts with movement or brief eye opening, but without eye contact, when called by his/her name
5. Reacts to trapezius muscle pinching
6. Does not react.

**Results:** 1001 assessments were made in 391 patients. All patients had oncological diseases. Patients with feeding tubes were excluded, as survival could be influenced independently of the consciousness scale; the observations after an occasional use of a sedative were also excluded. The median patients' age was 68 years (28 to 94). 222 (57%) were males. The survival differences between levels 1 and 2 and among levels 4, 5 and 6 were not statistically significant. Therefore a new scale for prognostic purpose was constructed: level 1 - previous levels 1 and 2; level 2 - previous level 3; level 3 - previous levels 4, 5 and 6. The survival medians of the new scale were: 1- 16,00 (CI 95%: 13,72-18,28); 2- 12,00 (CI 95%: 8,22-15,78); 3- 3,00 (CI 95%: 2,44-3,57). The survival differences were significant: between 1 e 2 -  $p = 0,001$ ; between 2 e 3 -  $p < 0,001$ .

**Conclusion:** The modified Consciousness Scale for Palliative Care has prognostic value.

**Abstract number:** P2-071

**Abstract type:** Poster

### Using Cognitive Pre-testing to Validate the Use of "Care of the Dying Evaluation" (CODE) for those who Die at Home: An Instrument to Assess the Views of Bereaved Relatives

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**Background:** In order to improve care for the dying we must

first be able to measure the quality of current care. One method of doing this includes conducting a post-bereavement survey with the next of kin.

**Aims:** To pre-test the CODE questionnaire to assess its validity as an appropriate and effective tool to evaluate care for those who die at home.

**Method:** Cognitive interviews were conducted with fifteen bereaved relatives, exploring both concurrent and retrospective thought processes involved in completing the questionnaire. A content analysis framework explored emergent themes specifically: ability to recall events, difficulties or ambiguities in comprehension, appropriateness of formatting and sensitivity of language.

**Results:** The instrument appeared sensitive and easy to understand although minor amendments may provide further opportunity to explore specific issues relating to care at home. These included the provision of care from external agencies, timeliness of care provided and supply of supportive equipment. Communication with the Healthcare team was cited as essential in both the preparedness for the common symptoms of dying and in carer assessment that the patient was treated with "dignity and respect". Analysis revealed strong motivation of participants to ensure others receive similar levels of support or highlight gaps in service provision.

**Conclusion:** The pre-testing of the CODE questionnaire indicates its appropriateness as a tool to evaluate the care of those who die at home. However, some modifications and additions may enhance its efficacy and appropriateness in capturing the specific issues of care in this context.

**Abstract number:** P2-072

**Abstract type:** Poster

### Validation of the Utrecht Symptom Diary for Healthcare Professionals

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The Utrecht Symptom Diary (USD) is the validated Dutch adaptation of the Edmonton Symptom Assessment Scale. The results of the USD are used (1) to support systematic assessment and monitoring of symptoms, (2) to make symptoms a subject of dialogue and (3) to plan and evaluate the effect of interventions. When patients are unable or not willing to self-report symptoms the USD is not applicable. Therefore, the USD-professional (USD-P) was developed, using clinical observations to assess symptoms.

**Aims:** To develop and validate the USD-P as a clinical tool to measure symptom burden systematically when patients are not able to self-assess their symptoms.

**Method:** This clinimetric study has a quantitative, prospective design. All patients admitted to a hospice from January to October 2012 were enrolled. Symptoms were measured using the USD concurrent to the USD-P. Feasibility was measured using the criteria of clinical feasibility, filled out by nurses after using the USD-P during the first month. Data analysis was performed using descriptive statistics. The validity and reliability focused on face-, content-, criterion validity and internal consistency. Statistical analyses are conducted according to the Cosmin criteria procedures. **Results:** The USD-P took 5 minutes or less to fill out, was positively evaluated in daily practice and used to systematically discuss the symptoms of all patients within the hospice setting. The Cosmin criteria are evaluated at this moment. The results will be presented during the EAPC of 2013.

**Conclusion:** The use of the USD-P ameliorates early recognition and monitoring of symptoms when self-assessment is not feasible. USD-P is proven feasible in daily hospice care and supports caregivers in a systematic approach of symptom management in the most vulnerable patients.

**Abstract number:** P2-073

**Abstract type:** Poster

### Identifying Patients with Advanced Conditions for Supportive and Palliative Care Using a Clinical Indicators Tool: SPICIT<sup>TM</sup>

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**Aims:** Systematic identification of people at risk of dying within 12 months is a prerequisite for effective end-of-life care in the UK and internationally. We developed and evaluated an evidence-based, clinical tool for identification of patients with any life limiting condition by multi-disciplinary teams in community and hospital settings. **Study design and methods:** We used a novel, participatory

research approach to develop the SPICIT<sup>™</sup> and evaluate its use in routine clinical practice: literature review, peer review via a website hosting regular project updates and through ongoing collaboration with professionals using the tool in primary and secondary care, and thirdly a case finding study in two acute hospitals in SE Scotland.

**Results:** The SPICIT<sup>™</sup> successfully identified 187 patients with advanced conditions after an unplanned hospital admission to cancer, renal, liver, cardiac, respiratory or acute medicine units. Many had multiple acute admissions due to complications of their illnesses or progressive multimorbidity. They experienced poorly controlled symptoms despite optimal disease focused treatment. A deteriorating performance status and increasing care needs were common. By 6 months, 85 (45%) had died, mostly in hospital. Clinicians from across the UK and internationally have contributed to refining the descriptors included in the SPICIT<sup>™</sup> which is available online ([www.spicit.org.uk](http://www.spicit.org.uk)) The SPICIT<sup>™</sup> provides clear guidance in accessible language that can be used to initiate care planning discussions with patient and families, as well as between professionals and teams.

**Conclusions:** The SPICIT<sup>™</sup> contains readily identifiable general indicators for any advanced illness and disease specific indicators for common life-limiting conditions. The SPICIT<sup>™</sup> can support clinical judgment and prompt identification of patients at risk of dying within 12 months who will benefit from supportive and palliative care.

**Abstract number:** P2-074  
**Abstract type:** Poster

## 49 Shades of Grey!: Impact of Hospice Ultrasound Use on Patient Care

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**Background:** Patients with advanced disease require transportation to hospital for ultrasound identification of abnormal fluid and location marking. This is not only exhausting, but introduces service delays, increases work for an already overburdened hospital radiology service and reproducing the exact position of original scan is difficult. **Aim:** Does the introduction of portable ultrasound improve patient, carer & health professional experience and co-ordination of care?

**Method:** Two hospice doctors underwent the necessary ultrasound scanning training for non radiologists. Following a selection process, an appropriate portable ultrasound machine was purchased, and support agreed with one of the local radiologists.

**Results:** A retrospective review of two years ultrasound use was undertaken. Sixty two patients have had ninety eight separate scanning episodes resulting in forty eight procedures. Used to identify presence & location of abdominal ascites prior to paracentesis, confirmation of location of pleural fluid prior to aspiration, confirmation of full bladder prior to catheterisation (urethral or suprapubic), monitoring the growth of large intra-abdominal malignant cyst, confirmation of hydronephrosis, biliary stent placement & locating nerve in real time neural blockade. The poster includes detailed analysis of use.

**Conclusion:** On each occasion a definitive clinical question was answered. Patients report greater satisfaction from a speedier service, families feel that patients are less fatigued by the interventions and staff feel able to give a better, more responsive, safer service, adhering to current best practice guidance. Being able to ultrasound patients in the home or in outpatients has prevented unnecessary admissions where the cause of abdominal distension had previously been in doubt.

**Abstract number:** P2-075  
**Abstract type:** Poster

## Experience of Barriers to Pain Management in Patients Receiving Outpatient Palliative Care

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**Context:** Patient-reported barriers are important obstacles in cancer pain management. For effective pain management and education, exploring patient-reported barriers and related factors are important.

**Objectives:** To determine factors associated with high patient-reported barriers to cancer pain management.

**Method:** We conducted a secondary analysis of data from a prospective observational study examining opioid

adherence in palliative care outpatients. We evaluated the association between high score on patient-reported barriers to cancer pain management (Barriers Questionnaire II, BQ-II; high BQ-II score=high barriers) and patients' race, sex, smoking history, pain intensity, opioid dose, and depression.

**Results:** Of 196 patients evaluated (median age, 55 years), 147 (75%) were white, 41 (21%) had gastrointestinal cancer, and 121 (62%) were receiving anti-cancer treatment when data were collected. The median pain score was 4 (Interquartile range [IQR] 3-7), 98% were receiving strong opioids, and 63% were satisfied with their pain medication. The median ESAS depression score was 1 (IQR 0-3). Mean (SD) BQ-II scores were 1.8 (0.9) for physiologic effects, 1.6 (0.9) for fatalism, 0.9 (0.9) for communication, 2.3 (1.1), for harmful effects, and 1.7 (0.8) in total. Only racial differences were associated with high total BQ-II score in multivariable analysis (R<sup>2</sup>=0.05, overall F test significance=0.02). Pain related factors including opioids dose, pain intensity, and satisfaction were not associated with high BQ-II score.

**Conclusion:** Patients receiving palliative care expressed low barriers to pain control. There were minimal association with demographics and no associations with clinical factors.

**Abstract number:** P2-076  
**Abstract type:** Poster

## Assessing Quality of Palliative Care Using a Quality Indicators Set: Results of a First Measurement in Belgium

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**Aim:** In Belgium, a quality indicator (QI) set for palliative care (PC) was developed using the RAND-method. We aimed at assessing quality of PC across different PC services using the set.

**Method:** The QI set was used in 9 specialist PC services in different health care settings in Belgium. Within each service, living patients under care and deceased patients (6 weeks to 6 months ago) were cross sectional selected. Questionnaires surveying outcome and process of care in 3 main modules (physical and psychosocial care, communication and organization of care) were sent to all living patients and their most involved palliative caregiver, and to a close family member and treating physician of the deceased patients.

**Result:** For patients under care we received questionnaires of 68 patients (response 53%) and 117 caregivers (response: 91%). For deceased patients we received 107 from bereaved family (response: 55%) and 125 from treating physicians (response: 65%).

Several process indicators could be measured, eg general symptom burden was assessed in 95% of patients, pain in 84%, delirium in 40%, anxiety in 82%; in 92% a care planning meeting with the family took place.

Several outcome measures could also be measured, eg 78% of patients with pain, 89% with anxiety, and 67% with delirium experienced improvement after treatment.

Symptom burden was adequately controlled during the last week of life in 98%. Expressed wishes by the patient were followed in 90% of cases. Family received bereavement support in 51% of cases.

**Conclusion:** It is feasible to gather a comprehensive set of quality indicators of palliative care involving palliative and regular care providers, patients, and bereaved family. Quality seemed good for some indicators whereas others had room for improvement. Further assessment of significant case mix adjusters and the discriminative power of the indicators is needed before they can be used for public comparison between the different services (benchmarking).

**Abstract number:** P2-077  
**Abstract type:** Poster

## Mapping Specialization in Palliative Medicine across Europe: Report from a 2012 EAPC Survey

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**Background:** Palliative medicine (PM) has been a specialization in the UK since 1987 and in Ireland since 1995. In 2007, the EAPC Task Force on the Development of Palliative Care in Europe reported that in five countries PM was considered a sub-specialty for which secondary certification was required.

**Aim:** To review the specialization of palliative medicine across Europe.

**Method:** A questionnaire was designed to explore the situation in each country including official certification name or title, year of approval, process of certification, number of physicians certified to date, etc. Qualitative analysis of answers was undertaken with categorization in three groups. The questionnaire was part of the EAPC Facts Questionnaire (FQ) which was completed by a 'key person' in 47/53 European countries; the information from the FQ is incorporated within the Second Edition of the EAPC Atlas of Palliative Care in Europe.

**Results:** There are 10-13 countries where PM is officially certified: there is specialization in UK and Ireland, and sub-specialization in Poland, Romania, Germany, Malta, Slovakia, Latvia, Czech Republic and Norway. France has the certification "Diplôme d'études spécialisées complémentaires de la Douleur et Médecine Palliative"; in Finland there is an award entitled "Specialist Competency in PM"; in Italy there is national official certification ("Master Universitario di Alta Formazione e Qualificazione in Cure Palliative per medici specialisti") that is legally regulated and possesses curricular importance but not professional recognition. Eight countries with certification 'in process' were identified: Austria ("Diploma in Special PM"), Denmark ("Field of competence"), Spain ("Specific Capacitation Area"), and Hungary, Iceland, Slovenia, Sweden and Switzerland (sub-specialization).

**Conclusion:** Further comparative analysis is required to examine the process of PM accreditation and the meaning attributed to such 'specialization' within professional practice.

**Abstract number:** P2-078  
**Abstract type:** Poster

## An Evaluation of Three ATOME Improving Access to Opioid Medication National Conferences

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**Background:** The Access to Opioid Medication in Europe (ATOME) project held one-day Improving Access to Opioid Medication National Conferences in Slovenia (March 2012), Turkey and Cyprus (both May 2012). The conferences (the first of twelve scheduled) were organized by Help the Hospices in collaboration with each country team and were attended by government representatives, health-care professionals, regulatory and law enforcement authorities, and experts from the field of palliative care, harm reduction and pain management.

**Aim:** To evaluate the impact of the conferences on the experiences, beliefs, and potential concerns of participants in relation to controlled medicines for pain and symptom management.

**Method:** A pre- and a post-conference questionnaire were distributed to participants at the beginning and at the end of the conference. Questions focused on (a) barriers and opportunities in gaining access to controlled medicines in their respective country, (b) knowledge and attitudes regarding access to controlled medicines as a fundamental human right, and (c) participants' evaluation of the conference.

**Results:** Over the course of the three conferences, a total of 167 participants completed both pre- and post-conference questionnaires (answers ranged from 'considerably' to 'not at all'): 156/167 reported that their knowledge about accessibility of controlled medicines 'had been enhanced' by attending the conference; 142/167 reported that their attitudes in relation to the accessibility of controlled medicines 'had been changed' by attending the conference; and 162/167 reported that their personal expectations of the conference 'had been realised'.

**Conclusion:** The results of the conference evaluation suggest that the ATOME one-day Improving Access to Opioid Medication National Conferences in Slovenia, Turkey and Cyprus were successful in enhancing participants' knowledge and in changing their attitudes in relation to the accessibility of controlled medicines.

**Abstract number:** P2-079  
**Abstract type:** Poster

## Validation Process of a Complexity Classifying Tool in Palliative Care. (In Spanish: Instrumento de Clasificación de la Complejidad en Cuidados Paliativos: ICC-Pal)

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**Aim:** Create and validate a tool assessing complexity levels (CL) according to presence of complexity elements (CE) in terminal situations to optimize resource utilization, based on Andalusian Palliative Care Integrated Strategy's Complexity Classification (PAI CP).

**Design:**

1. Covert PAI CP into Complexity Classifying Tool in Palliative Care, Version 0 (ICC-Pal V.0) by expert consensus panel.
2. Advance ICC-Pal V.0 tool's content validity:
  - a) Piloting tool through doctor's consultations of terminal patients, identifying CEs present, establishing a CL for each case.
  - b) Determination of inter-rater reliability, through filmed simulated terminal patient/caregiver cases.
  - c) Analysis of usability, format and content of ICC-Pal V.0.
3. Construction ICC-Pal, Version 1.
4. Progress ICC-Pal V.1's validation by on line study determining professionals' agreement with established CL for each CE. 5. Construction ICC-Pal Version 2.

**Results:**

1. ICC-Pal V.0 was developed from PAI CP with 55 CE each one assigned a CL (minimum, medium and maximum), classified in nine dimensions.
2. Initial pilot of ICC-Pal V.0 released a new version: ICC-Pal V.1, with 40 CE, each with their CL, in five dimensions including glossary for each CE. Participants agreed with CL assigned for each CE in 80% of ICC-Pal V.1's CE. No CE was considered of minimum complexity, so this level was eliminated.
3. New version: ICC-Pal V.2 was established containing 36 CE with their CL, in three dimensions, and a reviewed glossary.

**Conclusion:** ICC-Pal V.0 and ICC-Pal V.1 were well accepted by professionals. The tool was simplified in its format and a glossary for each CE was incorporated. The latest version of ICC-Pal is currently being evaluated by professionals. The final tool aims to be useful to diagnose if the situation of the patient and their families is complex or not and to what degree, in order to select the most appropriate resource to provide the care and to optimize service delivery.

**Abstract number:** P2-080

**Abstract type:** Poster

**Spanish Version of Patient Dignity Inventory (PDI): Translation Process and Preliminary Psychometric**

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**Introduction:** The Patient Dignity Inventory (PDI) was designed to measure different sources of distress related to dignity at the end of life patients.

**Aim:** Obtain a Spanish version of the PDI and measure the psychometric aspects in patients with advanced cancer.

**Method:** A translation-reverse translation method was used by bilingual following the guide of the European Organisation for Research and Treatment of Cancer (EORTC). The Ethics Committee on Clinical Research approved the study. Advanced cancer both inpatients and outpatients from the Oncology and Palliative Care department were included, with full cognitive abilities according to clinical criteria, Spanish native speakers and with informed consent. In addition to PDI, patients completed ESAS, HADS and FACIT-sp-12 surveys in Spanish validated version. The psychometric aspects evaluated were: internal consistency (Cronbach's Alpha); concurrent validity with the PDI-ESAS, PDI-HADS and PDI-FACIT-sp-12; discriminant validity between inpatients and outpatients, and between different performance status. The utility was obtained by the time of completion and patients perception.

**Results:** 37 patients were recruited and 35 completed the study. The Cronbach's Alpha coefficient was of 0.89. The PDI correlated well with the ESAS ( $r=0.61$ ,  $p<0.001$ ) and HADS ( $r=0.75$ ,  $p<0.001$ ), however the correlation with the FACIT was lower ( $r=-0.41$ ,  $p=0.014$ ). The survey distinguish between outpatient and inpatients and among patients with different performance status obtained by the KPS ( $r=0.48$ ,  $p=0.004$ ). The Patients took an average of 5.33 minutes to complete the PDI and considered that the instrument was clear and easy to complete.

**Conclusion:** The preliminary data of the validation shows that the Spanish version of the instrument has good psychometric properties. A larger study will be done to measure other psychometric properties as test-retest and factor analysis.

**Abstract number:** P2-081

**Abstract type:** Poster

**Can Mini Mental State Examination Represent Specific Neuropsychological Tests in Cancer Patients?**

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**Objective:** To verify the correlation between MMSE total score and Digit Span Test (DST), Trail Making Test A e B (TMT), Finger Tapping Test (FTT) e Continuous Reaction Time (CRT) scores.

**Methods:** Study composed by 181 cancer outpatients receiving palliative chemotherapy with no central nervous system cancer or brain metastasis. Data were collected between 2010 and 2012. Five neuropsychological tests were used to assess cognitive function: MMSE, DST, TMT A and B, FTT and CRT. Statistical analysis was performed by R v. 2.15.1 and correlations between MMSE and cognitive tests were verified by Pearson's test.

**Results:** Most patients were female (57%). Education mean was 11.6 y (SD=3.3), monthly income mean was US\$ 1927,87 (SD=1664,00) and median performance status (Karnofsky) was 90% (40%-100%). As expected, MMSE had negative correlation with TMT-A and B ( $r=-0.42$ ,  $r=-0.45$ , respectively,  $p<0.001$ ). As expected, positive correlation was observed between MMSE, DST ( $r=0.35$ ,  $p<0.001$ ) and FTT ( $r=0.23$ ,  $p<0.001$ ). A negative correlation between CRT and MMSE was expected, but it did not occur ( $r=0.09$ ,  $p=0.05$ ).

**Conclusion:** Cognitive functions are connected and deterioration in one domain may affect others. It was hypothesized that MMSE, given its ability to assess different domains of cognition, would have good correlation with more specific cognitive tests, which was partially observed. MMSE had weak correlation, though in the expected direction, with TMT A and B, FTT and DST, but was not correlated with CRT. Weak correlations suggest that these tests evaluate different domains of cognition and that MEEM cannot substitute more specific assessment. Although MEEM is comprehensive, its application is time consuming and apparently doesn't detect subtle alterations. Given this, researchers should analyze the pertinence of applying a general test or a battery of specific cognitive tests to monitor patients at risk for cognitive alterations or who already presents cognitive dysfunction.

**Abstract number:** P2-082

**Abstract type:** Poster

**Does the Palliative Care Outcome Scale Capture the Same Dimensions for Cancer as for Non-cancer Patients? A Factor-analytic Comparison**

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**Context:** The Palliative care Outcome Scale (POS) is widely used to assess needs and outcomes in palliative care. The POS has good concurrent validity as well being acceptable to both patients and health care professionals. The internal factor structure of the POS, using self-reported assessment data of cancer patients, has been investigated and showed that the POS captured two factors: 'psychological status' and 'quality of care'. The aim of the present study was to explore and compare factor structures in cancer and non-cancer samples. In this way the validity of the POS across patient groups can be examined.

**Methods:** Exploratory factor analyses were used for secondary analysis of data from 4 existing POS datasets. The non-cancer dataset included 216 patients (60 COPD, 82 Parkinson, 74 chronic kidney disease stage 5 patients) and the cancer dataset included 94 patients. For the factor analyses we used principal component analyses with Varimax rotation.

**Results:** Cronbach's Alpha was 0.70 for both cancer and non-cancer datasets. The number of factors extracted was based on the number of eigenvalues > 1.0. However the solution was not interpretable so we extracted and rotated a reduced number of factors until an interpretable solution with simple structure was observed. A factor reflecting 'psychological well-being' and one reflecting 'family issues' were identified in both samples. Within the cancer dataset the POS-item on 'practical problems' and in the non-cancer dataset the POS-items on 'practical problems' and 'wasted time' did not load high on either of these two factors. However strong ceiling effects were evident in both samples for these items.

**Conclusion:** The POS is a brief, reliable measure that captures two important dimensions in both cancer and non-cancer samples. Further work on the three items relating to practical aspects of care, in settings where ceiling effects due to high standards of care are not present, is required. EU FP7 funding.

**Abstract number:** P2-083

**Abstract type:** Poster

**Challenges of Conducting Research on Cancer Pain Classification: How Do We Make Sense of the Outcomes?**

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**Aims:** The complexity of the pain experience in advanced cancer presents unique challenges for pain classification. Currently, there is no universally accepted pain classification system that provides a prognosis of the complexity anticipated, as well as a standard to compare clinical and research outcomes. The Edmonton Classification System for Cancer Pain (ECS-CP) was developed to provide a standardized, comprehensive approach for the classification of advanced cancer pain. The purpose of this paper is to describe the unique challenges associated with conducting research on cancer pain classification, using the ECS-CP as a case example.

**Methods:** The findings from a recent ECS-CP multi-centre study of 1100 patients were compared with two other recent publications on pain classification, using the following parameters: study design, sampling frame, definition of stable pain control and study outcomes.

**Results:** The three studies varied in terms of study design (prospective vs. retrospective; patient vs. clinician assessments), sampling frames (consecutive sampling vs cognitively intact inpatients with specific exclusion criteria), stable pain control definitions and outcome measures (patient reported pain intensity, time to stable pain control, number of adjuvants, final opioid dose). Variability in patient-reported pain intensity time frames (current vs. over last week) further impeded cross time comparisons.

**Conclusion:** There has been a recent interest in developing minimum datasets for reporting research findings, to enhance the transparency of the research process and facilitate cross study comparisons. The lack of consistency in reporting pain features across studies reinforces the need to develop a standardized pain classification system for describing pain characteristics. Further research is needed to better understand the complexities of a pain classification system for cancer pain using prospective study designs that integrate patient and clinician reports.

**Abstract number:** P2-084

**Abstract type:** Poster

**Off-label Prescriptions in Palliative Care Patients at our Home Care Unit**

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**Aims:** The use of off-label drugs is considered to be frequent. This pilot study aimed to describe and to quantify the off-label use of drugs that have been prescribed to palliative-care patients just before admission in a Home Care Unit and explore the motives of off-label use. The secondary aim was studying if the off-label prescriptions were according with the most used guides in our environment (we tried four of them).

**Methods:** A cross-sectional study was carried out. Informed consent was obtained from patients admitted to 20 beds at our Home Care Unit during six months. Demographic and anthropometric characteristics, clinical background, current disease, and prescriptions just before admission were registered.

Medications were analysed to determine whether they had been used according to the term of the summary of product characteristics (SmPc).

**Results:** 31 patients (19 women) were included; mean age 61.2; IC95% 60.7-69.7. They received 217 prescriptions (117 different pharmaceutical products). Patients received from 2 to 14 (mean 8.0) medications for treating 244 health problems (52 different diagnoses).

Opioid analgesics were the most commonly used drugs according to the pain which was suffered by 93.5% of the patients.

39 prescriptions (18.1%) involving 26 (83.9%) patients were

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off-label due to their use in disagreement with the indications authorised in SmPc. 8 medications affecting 7 patients were off-label due to the lack of SmPC. The prophylaxis of ulcer by proton pump inhibitors and the palliative care in patients with terminal cancer by corticosteroids were the most frequently used off-label drugs. According with the four guides included in this study, just three of the off-label prescriptions weren't suggested by the authors of them.

**Conclusion:** Off-label use is a common practice in palliative care patients and is clearly shown by the gold-standard guides used in our environment  
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**Abstract number:** P2-085

**Abstract type:** Poster

### **Nursing Diagnosis in Palliative Care: The Use of the ICNP® Catalogue "Palliative Care for a Dignified Dying" to Compare Nursing Diagnosis between Specialized Palliative Care Hospital Support and Home Care Teams**

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Nurses are key players in palliative care teams. They identify nursing diagnosis and fulfill intervention to promote patients' well-being and family support.

**Aim:** To compare nursing diagnosis identified in patients cared by two different palliative care teams, specialized hospital support and home care teams.

**Methods:** A longitudinal comparative study was conducted both in a hospital support team and in a specialized home care team during one month in Portugal. Data were collected using a nursing diagnosis' identification instrument: The International Classification for Nursing Practice Catalogue, ICNP® Catalogue, "Palliative care for a dignified dying". The study included 22 patients.

**Results:** The most common nursing diagnosis identified by the hospital support team were: suffering (validated 30 times); spiritual distress (24 times); impaired ability to bathe (26 times), clean the house (22 times), get dressed/undressed (20 times); discomfort and anxiety (15 times each); feelings of powerlessness; caregiver's stress and social isolation (each one validated 14 times); fatigue (9 times) and pain (8 times). The home care team found: fatigue (validated 37 times); compromised skin integrity (26 times); lack of knowledge about the medication regimen (25 times); compromised family process, compromised family coping (both validated 21 times); caregiver's stress (14 times); pain and hopelessness (both validated 11 times); lack of knowledge about the treatment regimen (9 times), and suffering (8 times). Other nursing diagnosis were identified but with lower frequency.

**Conclusions:** The study indicates that similar nursing diagnoses were identified in both types of teams (fatigue, pain, suffering and caregiver's stress), although with different frequencies. Also, it concludes that specificities about nursing diagnosis were identified by considering the typology of palliative care teams. Further studies are needed to better understand nursing diagnosis in palliative care.

**Abstract number:** P2-086

**Abstract type:** Poster

### **Validation of the Ottawa Palliative Attitudes Scale (OPA) and the Ottawa Palliative Comfort Scale (OPC): Assessing Palliative and End-of-Life Attitudes in Medical Undergraduate (UG) and Postgraduate (PG) Learners**

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Assessing and evaluating how medical learners acquire palliative care competencies is a growing concern across medical schools and clinical practice sites. While evaluation

studies in palliative care education studies are plentiful, many draw on either newly constructed and non-validated instruments, or utilize tools validated within populations outside of medicine. This study aims to validate UG and PG versions of two instruments designed to measure

- 1) Attitudes - OPA; and
- 2) Comfort - OPC.

These instruments are part of a suite of 3 newly validated tools measuring attitudes and comfort/efficacy in palliative care, and also knowledge.

Medical students and residents in family or internal medicine, and oncology, who completed rotations in our palliative care program, were recruited to voluntarily complete all tools pre-and post-rotation. Attitudes and Comfort were measured with the OPA and the OPC, as well as three additional tools: Frommelt Attitudes Towards Caring for the Dying Scale-Form B (FATCOD-B); Thanatophobia Scale (TS); Self-Efficacy in Palliative Care (SEPC). 71 residents and 71 medical students participated. The OPA and OPC instruments showed high internal consistency (Cronbach alpha); ranging from 0.84 to 0.93. For the FATCOD-B, TS and SEPC coefficients were 0.82 to 0.97. The effect size and canonical correlation analysis indicate that there is considerable redundancy between the OAS and OPC on the one hand, and the FATCOD-B, TS and SEPC, on the other. The SEPC is strongly correlated with the OPC ( $R^2$  0.67 for PG and 0.74 UG). The OPA is largely uncorrelated with the other measures, suggesting that it provides distinct information about the learners.

Ensuring that we draw on tested and validated instruments in our UG and PG curricula for palliative care education and evaluation, furthers our accountability in ensuring that our palliative care education programs meet the best standards possible.

**Abstract number:** P2-087

**Abstract type:** Poster

### **Objective Clinical Symptoms Can Predict Imminent Death in Palliative Care Patients**

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**Introduction:** Being prepared for the death requires that impeding death can be predicted. Physicians' views are mostly too optimistic and many caregivers don't recognize that the patient starts to die, so the patient dies "unexpectedly" while the relatives want to be present at the ultimate moments. Therefore we searched for an objective everywhere easy to use tool to predict death, if possible applicable in every care setting.

**Material and methods:** A pilot-study with 100 patients suggested that 8 objective symptoms had some predictive value for imminent death in < 7 days. These symptoms are: cold/white nose, cyanotic lips, livores, cold extremities, death rattle, apnea for >15 sec /min, oliguria (< 300 ml urine/24h) and somnolence (>15h sleep/24h). We did a multicenter prospective observational study to evaluate the pivotal result on his validity. In 8 palliative care units is the presence of these 8 symptoms registered during routine nursing.

**Results:** The symptoms were registered in 657 patients. Fourteen days before death none of the symptoms is present but they increase up to 74% at 1 day before death. Somnolence and white nose are the earliest but less specific symptoms, while the other symptoms are observed between 2-4 days before death. One symptom can be present between 4 and 13 days before death, while 2 symptoms are present between 2.5 and 1 day before death. If 3 symptoms are present, the patient will die within 1.5 day and ≥4 symptoms predict that the patient dies within 24 hours. At 3 days before death about 30% of the patients have symptoms and this number increases exponentially up to 74% at the evening before the final day. The symptom profiles were similar in the 8 palliative care units although they had different patient profiles (different cancers and different non-oncological diseases).

**Conclusion:** The search for 8 objective symptoms during daily routine nursing can predict death within days in 75% of the patients in palliative care units.

**Abstract number:** P2-088

**Abstract type:** Poster

### **A Prospective Audit on Medication Adherence among Portuguese Palliative Care Outpatients**

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Adherence to medications (MA) is directly associated with improved clinical outcomes, higher quality of life, and lower healthcare costs across many chronic conditions. Little attention has been paid to non-adherence (MNA) issues among palliative care (PC) populations.

**Aims:** To evaluate MA and investigate predictors of MNA in a Portuguese cohort of hospital based-PC outpatients.

**Methods:** Prospective observational study, covering all visits, during a 4-month period; variables collected at baseline: age; gender; year/month of diagnosis; diagnosis; Charlson index and at each visit: Palliative Performance Scale status; current disease modifying treatment; PC phase; drug classes prescribed and responsibility for supply (patient self-administration or caregiver). MA was considered inadequate when < 100% of the dose prescribed. A physician perceived MA 5-point score (0=totally non-adherent to 4=totally adherent) was filled out following each encounter. Comparisons among drug classes and a logistic regression model assessing factors associated with the likelihood of MNA (perceived MA score < 3) are presented.

**Results:** 213 visits (114 patients, 33% first encounters) are analyzed. 2% of patients/caregivers didn't know current medication. The median number of drugs prescribed per patient was 7 (range 1-15). In 27% of visits patients were perceived as non-adherents. Breakthrough pain (BP) rescues (77%), proton pump inhibitors (60%), hypnotics (57%), antidepressants (46%), and strong opioids (42%) were the 5 most prescribed groups. PRN laxatives, PRN BP rescues and acetaminophen had the higher MNA rates (respectively, 69%, 58% and 41%). Patient self-administration (OR 2.7 95CI 1.4-5.1) and the number of prescriptions (OR 0.81 95CI 0.72-0.92) were stronger predictors of MNA.

**Conclusion:** The poor adherence to PRN medications and finding that MA in our cohort was supplier and drug class-dependent are relevant issues to treating clinicians. There was no funding for this study.

**Abstract number:** P2-089

**Abstract type:** Poster

### **NECPAL Tool in Argentina: The Pilot Phase Identifying Chronic Patients in Need of Palliative Care (PC) in a Geriatric Hospital in Buenos Aires**

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Argentina is a large South American country with a high prevalence of chronic disease-related mortality and needs for development of PC. There are many tools to identify these patients combining levels of severity, progression, and advanced frailty. In Catalonia, the NECPAL CCOMS-ICO tool has been adapted and validated from the Gold Standards Framework and currently introduced. It combines the perceptions of different healthcare professionals ('the surprise question'), with wishes and preferences of patients in relation to the limitations of curative therapies and the insertion of palliative measures ('the choice question'). Clinical parameters, the presence of co morbidities, geriatric conditions and the use of resources, can be included to identify advanced status of specific conditions. It is especially useful because of their simplicity, feasibility, availability in all settings and it is the first step to design and implement a Programme to improve PC in the health-care system.

The aim of this presentation is to show the pilot phase of NECPAL prevalence study in a Geriatric Hospital in Buenos Aires. Patient recruitment (n:69, aged 73) was based on interviews with health-care professionals using all conventional clinical information available. The process encouraged sensitivity in recruiting all patients with chronic conditions (1st level). To determine the prevalence of these patients in need of PC measures, we defined the "negative" response (i.e. "I would not be surprised if this patient were to die in the next 12 month") to the Surprise Question (or "SQ + patients") as the 2nd level and having at least 1 more positive parameter (or "NECPAL + patients") as the 3rd level. **We conclude:** According to the NECPAL tool, 73.4% of in-patients with advanced chronic conditions in need of PC measures could die in the next 12-14 month. PC must be an essential component of Chronic Care Programmes with a Community oriented and Public Health vision.

**Abstract number:** P2-090

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P2-091

**Abstract type:** Poster

**When a Symptom Becomes Refractory**

**Vayne-Bossert P.**

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Palliative Sedation (PS) is the treatment option in case of refractory symptoms at the end of life. A refractory symptom is an intolerable symptom as defined by the patient that remains uncontrolled after aggressive palliative treatments. Despite recently developed guidelines all over the world it still remains difficult to determine the exact moment, when a symptom becomes refractory. The aim of this study is to better define a refractory symptom by analyzing the evolution of medication used before the beginning of PS.

**Method:** This retrospective analysis included all patients (n=29) having received a continuous PS and who died within the 1<sup>st</sup> July 2010 and 30<sup>th</sup> June 2012. Besides demographic information, the equivalent doses of opioids, neuroleptics and benzodiazepines used 7 days before the beginning of PS and at the moment of PS were collected. Statistical analysis used the paired Student t test and the Wilcoxon test.

**Results:** 25 of the 29 patients suffered from cancer and almost half of them (12) were of pulmonary origin. The most frequent refractory symptoms were dyspnea (37%), agitated delirium (27%) and acute massive bleeding (15%). These patients received on average 48mg/24h of morphine 7 days before the beginning of SP and 99.7mg/24h at the moment of SP (p< 0.0001). Concerning benzodiazepines, the difference was not statistically significant. However, neuroleptic dosages have significantly risen in the last seven days of life (from 0.5 mg/24h of haloperidol to 2.9mg/24h, p = 0.03).

**Conclusion:** As expected, morphine consumption has significantly risen, as well as the use of neuroleptics, which are the main treatments for refractory dyspnea respectively agitation. The little use of benzodiazepines signifies that lowering the level of consciousness was not an aim until the beginning of SP. This study is just the first step into the direction of a better definition of a refractory symptom in the attempt to harmonize the indications of PS.

Abstract number: P2-092

Abstract type: Poster

### Comprehensive Cancer Symptom Assessment: "Orphans" and "Champions"

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**Background:** Cancer patients experience multiple symptoms which can adversely affect outcomes (survival, quality of life). Comprehensive assessment of symptoms is essential. Many validated symptom assessment tools are used. They have limitations; varied content, clinical utility, completion rates, and acceptability.

#### Aims:

1. Compare common cancer multisymptom assessment instruments to a comprehensive checklist
2. Identify commonly assessed ("champions") and frequently neglected ("orphans") symptoms

3. Examine the clinical importance of "orphan" symptoms

**Methods:** A 48-symptom checklist was developed from available evidence. This was compared against the content of 6 common multisymptom instruments. Those with ≤ 2 symptoms, cancer site-specific, and tumor response instruments were excluded.

**Results:** Symptom numbers varied in the 6 instruments; median (range) 19 (3-32). Of the 48 checklist symptoms, only 27 were present in at least 1 instrument.

**"Orphans":** 21 of the 48 were not evaluated in any of the 6 instruments (e.g., confusion, agitation, early satiety, indigestion, tremors). 12 of this 21 had prevalence rates >10%. These symptoms are often rated moderate/severe and distressful.

**"Champions":** Only four symptoms (pain, fatigue, dyspnea, anorexia) were present in all 6 instruments.

#### Conclusions:

1. Only four "Champion" symptoms were present in all validated tools.
2. Twenty-one "Orphan" symptoms (severe/distressing) were not captured by any tool.
3. Validated cancer symptom assessment tools are inconsistent and do not capture accurate, reliable comprehensive data on the cancer symptom experience.
4. Misdiagnosed and unreported symptoms can bias our view of the cancer symptom experience and challenge the validity and reliability of current symptom assessment tools in clinical research.

Abstract number: P2-093

Abstract type: Poster

### Developing a Framework for Palliative Cancer and Dementia Care: Quality Indicators to Guide Clinical Practice

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**Introduction:** Large numbers of vulnerable patients are in need of palliative care. However, a wide gap exists between the knowledge of best practice in palliative care and its use in every day clinical practice. To bridge this gap this study aimed to compose a generic set of quality indicators (QIs) that can help to assess and improve the organisation of palliative care.

**Methods:** A multidisciplinary, international panel of experts participated in a modified RAND Delphi procedure to compose a set of palliative care QIs. Consequently, panellists participated in two rounds without interaction, and one with interaction. The panel's median votes were used to identify the final set of QIs.

**Results:** The expert panel considered 37 QIs face valid after three Delphi rounds. These QIs represent key elements of good clinical practice. QIs on the structure of palliative care, such as the availability of palliative care teams, the availability of special facilities to provide palliative care for both patients and their relatives, and the presence of educational interventions for professionals. The included QIs are also related to the process of palliative care, such as the documentation of pain, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

**Conclusion:** This set of QIs is the first that has combined existing sets of QIs particularly on the organisation of palliative care. Applying these QIs in a large variety of settings addressing not only cancer but also dementia care in different European countries is unique.

Abstract number: P2-094

Abstract type: Poster

### Palliative Care Consultation in the Intensive Care Unit

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Although specific trials have demonstrated the favorable impact of palliative care consultation on high morbidity/severity intensive care unit (ICU) patients, there have not been national, multi hospital demonstrations of the effectiveness of palliative care screening in the ICU. We have conducted a quality improvement study utilizing a network of hospitals. A standardized screening tool was applied to all ICU admissions by day 1 of admission. Positive screen patients were prompted by nursing staff to have a formal palliative care consult ordered by the ICU physician. During palliative care consult days 1-5, a standardized bundle of care and communication interventions were conducted. Outcomes included number of patients screened positive and the association of palliative care consults with average length of stay, ICU mortality rates, and hospice referrals. Data will be presented from over twenty hospitals in 6 metropolitan areas. Initial pilot data from one hospital revealed a moderate rate of compliance (65% of admissions screened), 35% screened positive for consult, and an increase in the palliative care consultation rate. Results of over 2000 patients will be presented, with outcomes.

### Audit & quality control

Abstract number: P2-095

Abstract type: Poster

### Formal Relationship between Primary and Palliative Care Providers Improved Quality of Pain Management for Patients

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**Background:** In 2004, Cancer Prevention Center (CPC) introduced Palliative Care (PC) in Georgia. Since then, CPC has championed quality pain management for terminally ill patients with chronic pain, yet thousands of them suffer from lack of adequate quality pain management, due to shortage of PC and challenging government regulation on who and how to distribute opioids. Cumbersome regulations, General Practitioners' (GP) lack of knowledge of opioids, government's payment procedure to GPs for administration of opioids are a few of Georgia's current problems of quality pain management. Goals: In 2010, CPC and the "Institute for Cancer Prevention and Palliative Medicine" launched an investigation to assess GPs knowledge of opioids and its usage in relation to patients' pain management and quality of life. CPC developed a survey about chronic pain management for GPs. CPC used the survey and interviewed 51 physicians with authority to order opioids. CPC was alarmed with the survey's outcomes that showed indiscriminate patients' suffering, the followings are some of the alarming data: How GPs ordered morphine: 62% every 4 hour, 28% only severe pain, 4% before sleep and 8% never ordered morphine. How GPs managed morphine use and strength: 58% considered high doses dangerous, 24% of administration never allowed higher dose and 19% family refused morphine. 70% aware of proper dose for pain management without abuse, 30% find morphine dangerous, lastly, 8% use morphine only in last days of cancer patients.

**Outcome:** To address the problem CPC developed a chapter that included regulations and clinical reasons to utilize opioids for GPs to manage chronic pain. CPC distributed materials to GPs for comments. After incorporation of the comments, was created protocol for chronic pain management and introduced it to the Ministry of Health (MoH). MoH approved the protocol and CPC in collaboration with the MoH conducted trainings in different regions of Georgia.

Abstract number: P2-096

Abstract type: Poster

### Tools for Risk Management and Increased Patient Safety in Palliative Home Care

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**Aims:** Offering advanced health care in a patient's home is associated with special requirements in achieving high patient safety. In order to successfully manage risks, there is a need for a structured approach. At our unit we have developed a strategy with several components. The aim of this study was to analyze and evaluate the results and experiences.

**Design:** We have analyzed and evaluated each component in our risk management strategy, using consecutively collected data from our database of reported risks or events. The components include daily Safety briefings, "Risk awareness week" and internal risk audits with patient safety walkarounds twice a year.

**Results:** Being a large unit with high throughput of patients we have been able to retrieve large sets of data, of which more details will be presented at the congress. The main finding is a clear peak in risk reporting adjacent to the "Risk awareness week" and the internal risk audits. Over time this peak has been less steep and is accompanied by a steady increase in the risk reporting emanating from the routine work between the "Risk awareness weeks".

**Conclusion:** Having a structured approach to risk management and patient safety is crucial in specialized palliative home care. Our approach has lead to an improved patient safety culture captured with this study.

Abstract number: P2-097

Abstract type: Poster

### A Multi-centre Survey of Paracetamol Prescribing Habits for Specialist Palliative Care Inpatients

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**Background:** Paracetamol is commonly prescribed in conjunction with strong opioids for patients with cancer pain, a practice supported by the WHO. There is no convincing evidence for efficacy of paracetamol in these patients and concerns have been raised regarding full-dose paracetamol in cachectic and malnourished patients.

**Aims:** To establish how commonly regular paracetamol is prescribed in conjunction with strong opioids for patients with cancer in 4 Specialist Palliative Care Units (SPCU). To investigate whether paracetamol prescribing is associated with morphine equivalent daily dose (MEDD), low body weight, concomitant use of enzyme inducers or presence of liver disease.

**Methods:** A case-note review of all inpatients in 4 SPCU was conducted. Inclusion criteria: age >18 years, cancer diagnosis, inpatient > 24 hours, able to take enteral medications.

**Results:** 65 patients met the criteria, of whom 43 (66%) were prescribed regular paracetamol. The MEDD was 158(0-1800)mg for those prescribed paracetamol vs 79(0-400)mg for those who were not. 26% patients on paracetamol were measured/estimated to weigh < 50kg. 4 patients were prescribed a reduced dose of paracetamol, 1 of whom was < 50kg. 84% patients on paracetamol were co-prescribed enzyme inducers and >1/3 of patients in both groups had documented liver disease. Patients on paracetamol took an average 21 tablets/day, compared to 9 tablets/day for those not on paracetamol.

**Conclusions:** Palliative care inpatients with cancer taking strong opioids are commonly prescribed regular paracetamol, seemingly irrespective of known risk factors for potential toxicity. Paracetamol contributes significantly to tablet burden.

**Recommendations:** Given the lack of evidence for efficacy in this population, we question whether current paracetamol prescribing habits are judicious. In the absence of robust evidence, we should appraise efficacy on an individual basis and take into account known risk factors for paracetamol to do harm.

**Abstract number:** P2-098

**Abstract type:** Poster

## Are Two Pairs of Eyes Better than One? Exploring Agreement around Clinical Uncertainty between Nursing and Medical Professionals - A Case Note Review

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**Background:** Case note review is often used amongst hospital palliative care teams for audit and service quality control.

**Aims:** To examine levels of agreement between senior physicians and nurses in the identification of possible clinical instability with limited reversibility at the end of life and explore barriers to reaching consensus.

**Methods:** Case notes were reviewed for all patients (n=154) on five wards in a UK NHS hospital (from Nov. 2011 to Apr. 2012) who died in hospital or < 100 days post discharge. Case notes were reviewed independently by a senior palliative care nurse and a physician, for evidence of clinical uncertainty, defined as: deterioration, clinical instability, limited reversibility, and being at risk of dying within 1-2 months.

**Results:** There was agreement on the status of 71% of patients (109/154). Where there was disagreement (45/154), it was more common for the nurse (28/45-62%) than doctor (17/45-38%) to identify clinical uncertainty. Following a consensus discussion, the final decision aligned as often with the nurse's original decision (48%), as the doctor's (52%). Prevalence of clinical uncertainty was 25% (agreed by both professions for 38/154 cases). However individually this varied, with 36% (55/154) identified by the physician, and 43% (66/154) by the nurse.

Difficulties were reported in predicting deterioration when baseline functional status was low and with expected levels of uncertain recovery (e.g. after stroke). Differences were noted, in the decision making process, between the doctor and nurse when there were advance care planning needs, but limited clinical uncertainty. Agreement was reached for all patients post consensus discussion.

**Conclusions:** This review highlights the contrasting views of professionals in identifying uncertainty. Effective multidisciplinary team working has the potential to increase consensus and to optimise care for patients approaching the end of life.

**Funding:** GSTT Charity.

**Abstract number:** P2-099

**Abstract type:** Poster

## Basic Quality Indicators for Palliative Care Services in Portugal: Cultural Aspects of Care

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Cultural Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study.
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.
- The criteria to determine the agreement and consensus were:
  - o Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
  - o High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
  - o Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
  - o Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- To define the standard we use the median rating on the 10-point scale (10-100%)
  - Only the indicators that obtained the classification of very-High or High were chosen.

**Results:**

- A total of 2 from 3 quality indicators were defined.
- These indicators 1 are of structure and 1 of process (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 2 basic quality indicators which belong to the domain of "Cultural Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-100

**Abstract type:** Poster

## Basic Quality Indicators for Palliative Care Services in Portugal: Physical Aspects of Care

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Physical Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively
- The criteria to determine the agreement and consensus were:
  - o Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
  - o High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
  - o Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
  - o Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- To define the standard we use the median rating on the 10-point scale (10-100%)
  - Only the indicators that obtained the classification of very-High or High were chosen.

**Results:**

- A total of 16 from 20 quality indicators were defined.
- These indicators 2 are of structure, 11 of process and 3 of outcomes (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 16 basic quality indicators which belong to the domain of "physical aspects of care". So

they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-101

**Abstract type:** Poster

## Basic Quality Indicators for Palliative Care Services in Portugal: Care of the Imminently Dying Patient

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Care of the Imminently Dying Patient, for palliative care services using Delphi technique with palliative care experts.

**Methods:** First, we conducted a Systematic Review, to identify the indicators to use in the study.

- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.
- The criteria to determine the agreement and consensus were:
  - o Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
  - o High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
  - o Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
  - o Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- To define the standard we use the median rating on the 10-point scale (10-100%)
  - Only the indicators that obtained the classification of very-High or High were chosen.

**Results:**

- A total of 13 from 15 quality indicators were defined.
- These indicators 7 are of process and 6 of outcomes (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 13 basic quality indicators which belong to the domain of "Care of the Imminently Dying Patient". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-102

**Abstract type:** Poster

## Basic Quality Indicators for Palliative Care Services in Portugal: Spiritual, Religious and Existential Aspects of Care

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Spiritual, Religious and Existential Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
- 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively
- The criteria to determine the agreement and consensus were:
  - o Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
  - o High: ≥80% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
  - o Moderate: Median rating £ 4 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
  - o Low: Median rating < 4 on the 5-point agreement + < 60% of agreement + IQR > 1
- To define the standard we use the median rating on the 10-point scale (10-100%)

-Only the indicators that obtained the classification of very-High or High were chosen

**Result:**

- A total of 3 from 3 quality indicators were defined.
  - These indicators 1 are of structure and 2 of process (their description and standard will be done in the presentation).
- Conclusions:** We found a total of 3 basic quality indicators which belong to the domain of "Spiritual, Religious and Existential Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-103

**Abstract type:** Poster

**Basic Quality Indicators for Palliative Care Services in Portugal: Structure and Process of Care**

*Capelas M.L.<sup>1</sup>, Nabal M.<sup>2</sup>, Rosa F.C.<sup>1</sup>*

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Structure and Process of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
  - 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively
  - The criteria to determine the agreement and consensus were:
    - o Very high:  $\geq 80\%$  of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
    - o High:  $\geq 80\%$  of agreement + Median rating  $\geq 4$  on the 5-point agreement scale + IQR = 1
    - o Moderate: Median rating  $\geq 4$  on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
    - o Low: Median rating  $< 4$  on the 5-point agreement +  $< 60\%$  of agreement + IQR  $> 1$
  - To define the standard we use the median rating on the 10-point scale (10-100%)
    - Only the indicators that obtained the classification of very-High or High were chosen.

**Results:**

- A total of 33 from 43 quality indicators were defined.
- These indicators 13 are of structure, 17 of process and 3 of outcomes (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 33 basic quality indicators which belong to the domain of "structure and process of care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-104

**Abstract type:** Poster

**Basic Quality Indicators for Palliative Care Services in Portugal: Psychological and Psychiatric Aspects of Care**

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**Introduction:** The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of care at the end-of-life.

**Aim:** To define basic quality indicators of the domain of Psychological and Psychiatric Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

**Methods:**

- First, we conducted a Systematic Review, to identify the indicators to use in the study
- 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study.
  - 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively
  - The criteria to determine the agreement and consensus were:
    - o Very high:  $\geq 80\%$  of agreement + Median rating of 5 on

the 5-point agreement scale + IQR = 0

- o High:  $\geq 80\%$  of agreement + Median rating  $\geq 4$  on the 5-point agreement scale + IQR = 1
- o Moderate: Median rating  $\geq 4$  on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1
- o Low: Median rating  $< 4$  on the 5-point agreement +  $< 60\%$  of agreement + IQR  $> 1$

- To define the standard we use the median rating on the 10-point scale (10-100%)

-Only the indicators that obtained the classification of very-High or High were chosen.

**Results:**

- A total of 14 from 14 quality indicators were defined.
- These indicators 1 are of structure, 10 of process and 3 of outcomes (their description and standard will be done in the presentation).

**Conclusions:** We found a total of 14 basic quality indicators which belong to the domain of "Psychological and Psychiatric Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

**Abstract number:** P2-105

**Abstract type:** Poster

**A Retrospective Audit of the Use of Subcutaneous Rantidine in a Palliative Care Unit**

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**Aims:** Clinical practise guidelines recommend the use of either H2 blockers or PPIs as part of the medication regime to best manage inoperable bowel obstructions. Based on this recommendation, a metanalysis was undertaken that confirmed that rantidine is more effective to reduce the volume of gastric secretions than PPI's as a class of medications and placebo. As a result, subcutaneous infusions of rantidine has become accepted as routine practise in Australia with little data to support the tolerability of this practise to patient. This retrospective audit is being undertaken with the aim of documenting the experiences of a palliative care service when subcutaneous rantidine was prescribed.

**Methods:** Using a proforma developed for the purpose of this work, the inpatient notes of people prescribed rantidine where reviewed. Items of interest included: demographic details, reason for prescription, documented adverse effects, change in daily symptom scores.

**Results:** The charts of 50 people prescribed rantidine were reviewed. The results of the audit will be presented.

**Conclusion:** Based on metanalysis level evidence, rantidine offers a potentially useful addition to the medications available to palliative care clinicians. However, such changes to prescribing practise must be accompanied by audit and pharmacovigilance data to ensure new practises are safe and tolerable.

**Abstract number:** P2-106

**Abstract type:** Poster

**Carrying out Qualitative Research with Palliative Oncology Patients in the Acute Hospital Setting: A Feasibility Study**

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**Background:** More people are dying in acute hospitals, despite this rarely being the place people choose to die. Yet the psychology of death and dying in an acute hospital is an area we know very little about. The sensitivity and complexity associated with conducting research with terminally ill patients in an acute hospital is a hindrance. However, in order to provide optimal care for increasing numbers of people dying in acute hospitals, facing the challenges of conducting sensitive research with terminally ill patients in the acute environment is necessary. The logical place to begin is with the patient. However, a realistic forecast of patient participation rates is currently lacking.

**Objective:** The aim of the present study was to audit the number of palliative patients who could take part in sensitive, interview-based research at a large university teaching hospital. Further, we identified reasons why palliative patients in this setting may often be considered unsuitable for research participation.

**Method:** The MDT reviewed 175 patients as potential participants over seven months in respect to the study's inclusion criteria, and a formal log was recorded.

**Results:** 86% were immediately identified as unsuitable due to reasons such as not being under the care of two oncologists or having a diagnosis other than cancer. Of the remaining 14% invited to participate, only 6% agreed and were interviewed while the other 8% did not participate for reasons such as personal decision to decline participation,

death, discharge, and being unsuitable upon review.

**Conclusions:** Conducting research with palliative patients in an acute hospital is challenging. Many factors contribute to this, most significantly restricting inclusion to named treating consultants. This may be a common stumbling block for future researchers, given that patients are oftentimes under the care of numerous different physicians, but seldom under direct care of the palliative team.

**Abstract number:** P2-107

**Abstract type:** Poster

**The Challenge of Blood/Urine Glucose Monitoring and Management in a Hospice Inpatient Unit: An Audit Cycle over 2 Years**

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Monitoring and management of blood/urine glucose measurements remains uncertain in the palliative care population. The priorities for this group of patients are avoidance of symptomatic hypo/ hyperglycaemia and individualised blood/urine sugar monitoring regimens in both diabetics and non-diabetics taking corticosteroids.

**Aims:**

1. To assess against in-house written guidance the monitoring and management of blood/urine glucose measurements in a 48 bed in-patient unit.
2. To assess for improvements in practice against updated guidance.

**Methods:** Data was collected from the drug and blood/urine glucose monitoring charts of all current in-patients as a "snapshot survey" on 2 occasions: in 2011 and again in 2012, after revision and re-launching of the guidance. Glucose monitoring schedules were noted alongside prescription of "rescue" medication for management of hypo/hyperglycaemia.

**Results:** Of the patients eligible for blood/urine glucose monitoring (27/45=60% in 2011 and 31/43=72% in 2012: the majority were non-diabetics requiring monitoring on steroids), monitoring schedules were completed in 63% of cases on both occasions. For patients on steroids, the frequency of prescribed CBG measurements varied from 0 to 2/week on both occasions. The number of patients receiving 2/week CBG readings fell from 8 to 3 between 2011 and 2012 and 2 patients had urine glucose monitoring only in 2012, compared with none in 2011. Frequency of prescribed measurements of CBG in known diabetics varied from 1 to 3/day on both occasions. Although all diabetics had CBG recorded on admission, recording of baseline CBGs for patients on steroids worsened between 2011 and 2012. The number of diabetics prescribed no "rescue" medication improved from 4/7 in 2011 to 0/7 in 2012.

**Conclusion:** There is a suggestion that the updated guidance resulted in improved practice with regard to known diabetics. Further work is required to improve glucose monitoring in non-diabetic patients receiving steroids.

**Abstract number:** P2-108

**Abstract type:** Poster

**Quality Palliative Care across Europe for Cancer and Dementia: International Challenges**

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**Background and aims:** There is increasing interest in the quality of palliative care across Europe. There has been a policy-push for quality indicators and measures of palliative care to be universally accepted and used across different countries and care systems. However for this to be successful there needs to be a consensus about what the main problems in palliative care are. In the IMPACT study we are investigating common national European problems in providing high quality palliative care for people with cancer or with dementia.

**Methods:** One focus group and 54 interviews were conducted in five European countries (England, Germany, Italy, the Netherlands and Norway) with professionals within the specialities of cancer, dementia and palliative care, through the use of purposive sampling and snowballing methods. A sampling frame of macro- (policy), meso-

(management) and micro-(patient care) level responsibilities was used to capture different experiences. Transcribed interviews were subject to thematic analysis in the national language, and main themes summarised in English.

**Results:** Results revealed six main common themes;

- 1) communication failures between patients and professionals, between professionals, and between agencies;
- 2) the lack of structural/functional integration of services,
- 3) difficulties with funding streams and sources,
- 4) problems within processes of care,
- 5) time limitations, and
- 6) inclusion of non-cancer patients within the remit of palliative care services.

**Conclusion:** Despite having different models of healthcare, the five European countries in IMPACT have common problems which affect the quality of palliative care delivered to both people with cancer and to people with dementia. Although many problems appear at first sight simple and easy to rectify, many have deep rooted origins which make solutions far more complex.

**Funding:** 7th framework program European Commission

**Abstract number:** P2-109

**Abstract type:** Poster

### Piloting a Web-based Critical Incident Reporting System (CIRS) for Palliative Care: First Reports

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**Background:** Critical incident reporting systems (CIRS) that encourage professionals to anonymously report medical errors and near-misses, have proved to enhance patient safety in anaesthesiology, surgery, and critical care medicine. For palliative care there was no special CIRS so far, but such a system could serve to understand kinds, causes and consequences of errors in palliative care and help to prevent them.

**Methods:** We developed a pilot CIRS for palliative care in Germany that was launched in May 2011. Professionals can anonymously report critical incidents in a web-based platform. Each report is reviewed, anonymised and commented by an interdisciplinary team of experts prior to publication online. Published reports were analysed using quantitative content analysis.

**Results:** In the first 15 months there have been 12 reported cases. Three quarters were reported by physicians, one quarter by nurses. Most errors occurred in the area "diagnostic and therapy" (n=5, essentially in drug treatment) and in the area "organisation and system" (n=4, specifically in communication). Only one case described the death of a patient as result of an error; in six cases there was a light or temporary harm for the patient, and in the five remaining cases the patient was not harmed.

**Discussion:** The reported areas of errors are similar to what is known from other medical disciplines. The number of reports, however, is low and the CIRS should be better promoted to enhance its utilization. A larger database is necessary to conduct robust patient safety studies, assess the needs in palliative care and design specific interventions to increase patient safety.

**Abstract number:** P2-110

**Abstract type:** Poster

### How to Find out - An Ongoing Follow up

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**Background:** It is important that patients as well as loved ones, experience the nursing and medical care as good and safe. To improve and ensure the quality of the care, it must be evaluated.

**Aim:** Methods and loved ones must be able to give their views on the quality of the care, so the staff can identify areas for improvement.

**Method:** Since 2001 the Palliative Care Unit has been using questionnaires as a method for evaluation. A patient who is leaving the ward receives a questionnaire at the day of discharge and returns it when completed the same day.

Questionnaires are sent to loved ones to patients who died in the ward after about two months after the patients' death.

The questionnaires contain questions about information about the ward, disease and treatment, perceived participation, attitude and confidence in the ward. The loved ones are also asked about the follow-up call.

The questionnaires are submitted anonymously with possibility to own comments.

**Result:** Mean value for how patients feel that they have received information about the ward is 78% and for loved ones 58%.

90% of both patients and loved ones are satisfied with information about the disease and treatment.

Almost everyone reported satisfaction with the medical care as well as in attitude and confidence.

85 % of the loved ones were involved in some kind of planning meeting.

All survivors were pleased with being contacted after the patients' death.

**Conclusion:** Our conclusion after ten years of evaluation by questionnaires, is that patients as well as loved ones, in many ways are satisfied with the care but that there are improvement opportunities regarding information and participating.

It is important with follow-up to provide good and safe care. By continuously using questionnaires, an ongoing assessment of the quality of care can be done to identify areas that need improvement.

**Abstract number:** P2-111

**Abstract type:** Poster

### Is the Patient Satisfaction Questionnaire (PSQ) an Acceptable Tool for Use in a Hospice In-patient Setting?

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**Aim:** The PSQ is an assessment tool recommended to inform the continued professional development (CPD) of medical staff in the UK, aiming to evaluate patients' perspectives of their doctor's communication and interpersonal skills.

The aim of this study was to investigate the acceptability of administering the PSQ to hospice in-patients and relatives. **Method:** Over a two week period, all in-patients deemed well enough to complete a brief questionnaire by the multidisciplinary team, were asked to complete a PSQ (9 hospice in-patients and 1 relative acting as surrogate) equating to 45% of all hospice in-patients during that period.

All in-patients asked to complete a questionnaire were subsequently invited to take part in a brief interview study. Semi-structured patient interviews were used to explore patient experiences of the questionnaire process, their interest in completing a questionnaire about their doctor, and any feelings of coercion. A collaborative inductive content analysis involving three members of the study team was then used to identify major themes.

**Results:** All 10 approached (9 patients and 1 relative) agreed to take part in the interview process following completion of the PSQ.

The findings suggest that:

- Hospice in-patients believe that the PSQ is clear and easy to understand
- Hospice in-patients do not feel that the PSQ is burdensome in terms of time or effort
- Hospice in-patients feel they can be honest when responding to the PSQ
- Some hospice in-patients see themselves as a valuable resource for information and feedback
- Some hospice in-patients view completing the PSQ as an opportunity to be involved and empowered

**Conclusion:** The PSQ is an acceptable tool to use in a hospice in-patient setting in order to inform the CPD of medical staff. Many patients welcome the opportunity to be involved in the feedback processes.

**Abstract number:** P2-112

**Abstract type:** Poster

### Audit of Identification and Advance Care Planning Management of Patients with Heart Failure and Poor Prognostic Features

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**Background:** The prognosis of advanced heart failure is comparable to or worse than most cancers and as such

heart failure patients should be offered the same standard of integrated palliative care.

**Aims:** To assess the management of patients with heart failure and poor prognostic features across the North West of England.

**Methods:** A regional, retrospective audit of patients who had died from heart failure. Standards were agreed, with reference to best available evidence, by a multi professional group.

**Results:** 123 patients were included from 8 sites across hospital, hospice and community. 51% of patients were recognised to be in the last year of life, less than three months before death. The average number of admissions in the 12 months prior to death due to worsening symptoms of heart failure or decompensated heart failure was 1, range 0-4. 59% of patients were under the care of a heart failure specialist nurse. Within the last year of life, 46% of patients were given the opportunity to discuss the implications of their diagnosis, 12% were given the opportunity to discuss their preferred place of care and 11% were given the opportunity to discuss advance care planning. For patients with an implantable defibrillator, 33% had documented evidence of a conversation regarding its deactivation. 29% of patients were considered for referral to specialist palliative care services and 92% of these were referred.

**Conclusions:** The pharmacological management of heart failure with poor prognostic features is now well established; however there is a need to improve identification of patients in the last year of life to allow timely discussions about the implications of the diagnosis, preferred place of care and advance care planning. Greater collaboration between palliative care and cardiac services may help to facilitate this.

**Abstract number:** P2-113

**Abstract type:** Poster

### Opioid Prescribing in a Cancer Centre

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**Background:** Opioid medications are commonly prescribed for cancer pain. National studies have consistently shown high numbers of drug errors when prescribing opioids. The National Patient Safety Agency recently issued a report on the safe management and use of controlled drugs including written requirements in order to reduce dosing errors. Local and national guidelines have been produced in line with these requirements.

**Aim:** To assess safety and appropriateness of opioid prescribing in a cancer centre by investigating adherence to local and national guidelines.

**Methods:** Drug chart review of opioid prescriptions in an inpatient ward at a single point in time.

**Results:** There was a total of 45 opioid prescriptions in 19 patients (range 1-7/patient). The most common opioid prescribed was morphine, in 56% of prescriptions. 151 deviations from policy were identified (range 0-7/prescription). Deviations in prescriptions per patient ranged from 0 to 29. Deviations in morphine were the commonest (60%). Most deviations were minor; in formulation (23%), strength (17%) or generic name (8%). The number of clinically important deviations was 23 (15% of total). These included under dosing of regular and as required opioids and omission to prescribe as required opioids for patients on regular morphine. There were also errors in dose and frequency when prescribing diamorphine for a catastrophic bleed. Two prescriptions were unreadable. Pharmacy had endorsed 49% and corrected 12% of prescriptions with deviations. The palliative care team corrected 3%.

**Conclusion:** There were few clinically significant errors. Most deviations were minor including errors in specifying formulation, strength or generic name and this is consistent with national data. Morphine was the most common opioid prescribed and most common with deviation from policy. Pharmacists had endorsed and corrected fewer prescriptions than we expected. Recommendations to improve practice are offered.

**Abstract number:** P2-114

**Abstract type:** Poster

### Safe & Sound: Audit of Medical Handover in a Specialist Palliative Care Service

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**Background:** Although nursing handover is audited on the inpatient specialist palliative care unit, there had been no audit of verbal medical handover. The Royal College of

Physicians (RCP) has set standards for medical handover to ensure patient care and safety.

**Standards:** The RCP standards were adapted to include local & specialist priorities resulting in 23 items to be audited, including demographics, diagnostic, holistic assessment, drugs and allergies, communication, progress and plans.

**Method:** Data collection was undertaken by the auditor and delegated clinicians who completed an audit proforma of items expected to be mentioned, at each medical handover, morning and evening, including weekends, which resulted in 126 patient handovers in the first cycle (July/Aug 2011) and 86 in the re-audit (Sep/Oct 2011). These were collated and analysed using a Microsoft Excel spreadsheet.

**Results:** Results showed that demographic, diagnostic, treatment, admission, assessment/management and social situation details were already well handed over as were Gold Standards Framework registration and Preferred Place of Care. The second cycle showed improvement in the transfer of information about Advance Care Planning and comorbidities. However details about psychological and spiritual assessment, insight of patient and family and communication issues were less well transmitted than in the original audit.

**Conclusions:** It may be that at the end of a training year (ends July/August) the quality of medical handover is at its best and in the Autumn when new doctors have started in post it may take some time for them to familiarise themselves with what is expected of them. However to try and improve the quality further, recommendations for practice were made. These included the use of prompt cards, prompt structured handover, using the computer record to support the process and avoidance of interruptions. The results of the next audit in January 2012 will be reported.

**Abstract number:** P2-115

**Abstract type:** Poster

### Uncontrolled Background or Breakthrough Pain: Are We Differentiating? A Re-audit

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**Background:** Pain is common in patients with cancer, affecting up to 75% with advanced disease. Effective pain control requires accurate assessment in order to determine appropriate management. A previous audit identified weaknesses in assessment and documentation of various domains of pain including temporal patterns. The aim of this re-audit was to evaluate pain assessment documentation after introduction of a redesigned pain assessment tool.

**Methods:** The redesigned pain assessment tool was piloted in 15 patients admitted to the inpatient specialist palliative care unit. Data collected covered the ten recognised pain assessment standards in palliative patients, including recording of pain location, intensity, duration, temporal patterns, quality, exacerbating/relieving factors, and also effect on quality of life, pain significance, and previous pain experiences.

**Results:** Improvements in documentation were observed after the introduction of the redesigned assessment tool. There were marked improvements in documentation of temporal patterns 96% (76%\*), exacerbating/relieving factors 100% (60%\*), pain quality 76% (24%\*) and significance of pain 40% (9%\*). Previous pain experiences were documented in 21% (0%\*). In 93% of cases there was documentation distinguishing between constant or intermittent pain (55% constant and 40% intermittent). Further characterisation of intermittent pain was observed in around half of these patients, of these 55% had intermittent exacerbations on a background of uncontrolled pain.

**Conclusion:** Redesigning the pain assessment tool to incorporate the ten recognised standards in pain assessment has led to improvements in documentation, allowing a more comprehensive pain history to be detailed. Inclusion of an additional tool to better describe intermittent pain has produced some improvements in characterising temporal patterns of pain.

(\* Values in brackets relate to initial audit for comparison)

**Abstract number:** P2-116

**Abstract type:** Poster

### MRSA in Palliative Care - Quantifying the Issue

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**Aims:** This study follows two previous audits of MRSA in the specialist palliative care unit (SPCU). The aims were threefold. 1. To determine the prevalence and incidence of MRSA in the SPCU. 2. To describe the clinical characteristics of MRSA positive patients in the SPCU. 3. To determine the clinical impact of MRSA on palliative patients.

**Methods:** In this prospective study data was collected for all admissions to a 36-bed SPCU over an eighteen month period. A proforma was developed to collect demographic data, MRSA screening data, and clinical outcome data for each admission. All patients were screened for MRSA on admission and one week later. Prevalence and incidence of MRSA colonisation, length of stay, details of infection episodes, and mortality data were recorded.

**Results:** Data was collected for 609 admissions and readmissions. This included data for 467 individual patients. The mean age at admission was 69 years (71 for MRSA positive subgroup). There were no significant differences in gender, care setting prior to admission or diagnosis. 336 (55.2%) of those admitted were male, 227 (37.3%) were admitted from the hospital setting, and 557 (91.5%) of admissions had a malignant diagnosis. The prevalence and incidence of MRSA colonisation were 10.67% (65 of 609 admissions) and 1.84%, respectively. MRSA colonisation was significantly associated with having an infection during admission ( $p < 0.01$ ) and MRSA positive patients had more infection episodes (1.07 versus 0.68). Lower respiratory tract and urinary tract infections were the two most common infection types. MRSA colonisation was also associated with increased length of stay (33.7 versus 21.5 days,  $p < 0.01$ ), but was not significantly associated with survival.

**Conclusion:** MRSA remains prevalent in the SPCU. There were no significant demographic differences in the MRSA positive subgroup. MRSA colonisation conferred a greater risk of infection but did not impact significantly on overall survival.

**Abstract number:** P2-117

**Abstract type:** Poster

### Possible Improvement of Earlier Diagnosis and Control of Pain on a Palliative Care Unit by Standardized Protocols in the Context of a Certification Process

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**Aims:** About 50-80% of patients with advanced cancer suffer from pain. Therefore, pain is one of the leading symptoms in palliative care units. The main goal is to identify patients with pain as early as possible and to start an efficient management and treatment according to the up-to-date guidelines at once. It was demonstrated that implementation of standards of analgesia, according to recent guidelines and recommendations, for patients with postoperative and non cancer-related pain in the daily practice of general hospital wards in the context of certification programs is able to improve the success of pain control in a significant way. Hence, our hypothesis was that participation in such a certification program could have an impact in earlier detection of patients suffering from pain and consecutive earlier pain control in our palliative care unit (PCU).

**Methods:** Nurses, physicians, physical therapists and psychologists developed standard operating procedures (SOP's) according to the latest guidelines and recommendations for treatment and assessment of pain. A complex but easy to interpret documentation-system for the existing patient's charts was generated, as well. After a short training period this system and the SOP's were implemented in daily practice.

**Results:** It was possible to improve the process quality and structural quality regarding pain assessment, documentation and time to treatment leading to an earlier and better pain control for patients. This was confirmed in an external audit as a part of the certification process.

**Conclusion:** Participation in a certification program regarding implementation of standards in documentation, assessment and treatment of pain can lead to an improvement of pain control for patients in palliative care units, as well. We will try to confirm and complete these findings by doing a patient survey in our PCU using a standardized questionnaire as a next step.

**Abstract number:** P2-118

**Abstract type:** Poster

### Audit of Analgesia Prescribing in Cancer Patients - Are We Meeting the Current Standards?

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**Introduction:** Cancer pain is frequently inadequately managed, despite guidelines at regional, national and international levels. Current NHS Lanarkshire prescribing practices are guided by regional guidelines developed in 2009 by the NHS Lothian and NHS Lanarkshire palliative care teams using SIGN 106.

**Aims:** This audit aims to ensure that prescribing within Monklands Hospital adheres to current standards.

**Methods:** A cross-sectional study was performed over the medical, surgical, surgical specialities and care of the elderly wards in Monklands Hospital. The notes and drug charts were reviewed of those inpatients with documented cancer pain and assessed to ensure the prescribing was adhering to NHS Lanarkshire guidelines.

**Results:** 29 patients were included in the analysis, 6 (20.69%) patients were female and the average age of the study population was 67.7 years (62.2 - 73.1 years). 14 patients had proven metastatic disease.

Non-opioid analgesia (paracetamol, NSAIDs or adjuvants) was prescribed in 23 (79.31%) of 29 patients.

In this study population, 25 (86.21%) patients were prescribed regular opioid analgesia. Of the 25, there are 2 patients prescribed more than one type of regular opioid. Of the 25 patients prescribed regular opioids, 14 (56.00%) patients were prescribed breakthrough analgesia. 11 (44.00%) patients on regular opioid analgesia had no breakthrough analgesia prescribed. Of those prescribed breakthrough, 9 (64.29%) patients had a breakthrough dose too low and 5 (35.71%) patients had too high a breakthrough dose prescribed.

**Conclusions:** This audit has demonstrated that prescribing practices at Monklands Hospital are not meeting the current standards set out by the existing NHS Lanarkshire guideline for the management of cancer-related pain.

A significant deficit exists in prescribing of breakthrough analgesia for those on regular opioid analgesia.

A update session for medical and nursing staff is to be organised to improve prescribing practice.

**Abstract number:** P2-119

**Abstract type:** Poster

### Does the Liverpool Care Pathway Improve Patient's Access to Symptomatic Relief?

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Five years after its initial introduction in NHS Lanarkshire, this review provides an insight into the use of the LCP.

**Aim:** This audit compares access to symptom relief for patients who are cared for on the LCP with those who are known to be dying but are not cared for on the LCP.

**Methods:** A retrospective analysis of deaths in the three acute NHS Lanarkshire Hospitals - Hairmyres Hospital and Monklands Hospital during February 2012. Case records were reviewed for patients who had died in either the care of the elderly, general surgical, medical or surgical speciality directorate. Data retrieval was by completion of a standardised data extraction proforma.

**Results:** 36 patients died on the LCP, 80 patients not on the LCP. Of the 80 patients who died not cared for on the LCP 69% were expected to die. Comparing LCP with non-LCP for these patients the following results were obtained:

Non essential drugs discontinued:

- LCP - 64 %
- Non LCP - 25%

As required medication provided for symptomatic relief of:

- Pain:
- LCP - 89%
  - Non LCP - 64%

Agitation:

- LCP - 89%
- Non LCP - 49%

Dyspnoea:

- LCP - 78%
- Non LCP - 42%

Respiratory Tract Secretions:

- LCP - 81%
- Non LCP - 41%

Nausea and Vomiting

- LCP - 72%
- Non LCP - 37%

When the discontinuation of inappropriate interventions were reviewed, the results below show that again patients

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on the LCP have these issues addressed.

Discontinuation of blood tests:

- LCP - 86 %

- Non LCP - 39%

Discontinuation of antibiotics

- LCP - 83%

- Non LCP - 32%

Discontinuation of IV medications:

- LCP - 83%

- Non LCP - 32%

Discontinuation of artificial hydration:

- LCP - 75%

- Non LCP - 25%

**Conclusion:** From these results it can be clearly seen that dying patients cared for on the Liverpool Care Pathway have better access to medication to relieve the common distressing symptoms which occur in patients who are dying. They are also more likely to have unnecessary interventions discontinued such as regular blood tests and antibiotics.

**Abstract number:** P2-120

**Abstract type:** Poster

### Assessment of Quality in Palliative Home Care with FEHC

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**Aim:** To assess the quality of care offered by the home care team and identify the domains which need improvement.

**Method:** Telephone survey using the Family Evaluation of Hospice Care (FEHC) questionnaire with 61-items covering all domains of care, developed by National Hospice and Palliative Care Organization. Family members were approached six months after patient's death for patients who had minimum 3 interventions from the home care team and died in first 2 months of 2012.

**Results:** Out of the 95 patients who died in our care 34 were not complying with the inclusion criteria, 12 families were not answering the survey. The response rate was 80,64%. The average period of care was 45 days, mode 61 days. 96,85% of families declared they and the patient received as much support as they needed for symptom control and 78,48% for psychoemotional support. Discussion about end of life care - 16,88% wanted more discussion, 37,5% whom didn't had discussion declared that they would have liked to have this;

Support after the love one died 15,29% had less than they wanted; Discussion about spiritual/religious aspects - 36,66% of them wanted more support and 12,72% from those which didn't get support would like it.

**Conclusion:** Symptom management is one of our strengths but we need to foster more discussions on end of life care and improve spiritual care and support for emotional issues.

**Abstract number:** P2-121

**Abstract type:** Poster

### Order of Frequency of Complications for Each Type of Catheter (Metal/Biomaterial) Regarding Bolus vs. Continuous-infusion Operation Modes

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**Introduction:** The improvement of quality of life for patients with advanced disease is a key aim of Palliative Care. In this sense, the subcutaneous vascular access represents a suitable home-management device to best handle symptomatic control.

**Goal:** Categorize the order of frequency of the arising complications for different types of catheter operating as bolus vs. continuous-infusion modes.

**Material and methodology:** Two-staged multicentre descriptive observational method: piloting (4 months) and study (6 months), including permutation of type of catheter at half of each stage period and for each of the two teams involved (those of Badajoz and Llerena-Zafra Areas).

All patients who joined the program during the period under study and who needed subcutaneous vascular access for symptomatic control were asked to take part in the project (provided they met the inclusion criteria).

**Results:** 132 available vascular accesses, categorized as 50 metal and 82 vialon, out of which only 35 (metal) and 37 (vialon) were used for bolus administration. The observed complications as related to the type of vascular access for bolus administration were the following: Metal type: 26.10% diverse unusual causes.

Vialon-type: 20% accidental release.

**Conclusions:** No significant difference between the two manufacturing catheter materials regarding the incidence of complications was reported for the particular abovementioned use.

With regard to the nature of complications, a set of unusual ones (with no particular complication standing out from the rest) were reported for metal catheters. However, accidental release (for the two types of material as well as for each of the two possible uses) was seen to be the most frequent complication for vialon catheters.

**Abstract number:** P2-122

**Abstract type:** Poster

### Improving Documentation of Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) Decisions: A Cross Organisation Spot Audit

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**Aim:** The South East Coast (NHS, England) principles for Do Not Attempt CPR (DNACPR) decisions include using the Resuscitation Council of UK 'red bordered' form to document the decision and ensuring this form follows the patient to all settings. In an NHS Trust in the South East of England with 2 acute hospitals the form was already in use but needed reviewed to ensure best practice if utilised in other settings.

**Method:** A cross site spot audit was carried out by one of the authors with assistance from members of the resuscitation team. All acute medical and surgical beds were included in the audit and all identified forms were assessed using a pro-forma using the UK national guidance on DNACPR decisions as a standard. This was repeated after introduction of a new DNACPR policy and presentation of initial survey.

**Results:** 133 DNACPR forms were in place on the first survey (18% of all patients), 112 on the second survey (15%). Only 11.7% of all forms had all sections of the document completed to the standard in the first survey, 20% in the second. Main sections of the form that were incomplete were around communication with patient and family members. In the first survey only 26.7% had a countersignature by Consultant, which is expected, and this increased to 56% in the second survey.

**Conclusions:** The design of the audit provides a good overview of practice and has highlighted areas that need to improve. This audit is to be repeated on a regular basis and on-going initiatives to improve quality of documentation are underway including re-designed form folder and awareness initiatives.

**Abstract number:** P2-123

**Abstract type:** Poster

### An Audit of Respite Care Admissions in an Inpatient Specialist Palliative Unit

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**Aims:** To determine whether patients booked for respite in an inpatient specialist palliative care unit are admitted and discharged without changes to planned length of stay, medications or provision of home care.

**Methods:** Nine months of respite bookings were identified retrospectively using the unit booking diary. Respite care was available in one allocated bed for a 7-day stay. There were no formal criteria for respite referrals. Notes were analysed retrospectively to determine if patients had died prior to admission, were admitted elsewhere, died during admission, length of stay, medication changes and changes to home care provision. Audit standards were taken from a literature review.

**Results:** 45 bookings were made but only 21 (45%, audit standard 90%) were admitted. 18 patients (39%) died prior to the date of admission, 4 patients (19%) were admitted elsewhere and 2 patients (9.5%) declined admission on the day. Of the 21 admissions, 4 patients (19%, audit standard < 10%) died during admission. 3 patients (15%, audit standards < 10%) had a length of stay  $\leq 7$  days. 10 patients (47%, audit standard < 50%) had medication changes during admission. One patient (5%, audit standard 0%) had changes to home care.

**Conclusion:** Mean waiting time for respite admission was 80 days and 55% of patients booked for inpatient respite died before admission. This may reflect the frailty of patients referred and also the use of a respite offer as a holding measure during a crisis period. A large proportion (19%) of patients died during admission and this probably also reflects a changing clinical situation due to the comparatively long waiting time. Only 21 respite slots out of a possible 38 were filled which suggests that this method of booking and accepting referrals may not serve either our

patient population or be an appropriate use of resources. A shift towards booking a shorter number of weeks ahead may enable better access for patients and better use of resources.

**Abstract number:** P2-124

**Abstract type:** Poster

### Polypharmacy and Drug Omissions Across Hospices in Northern Ireland

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**Background:** Polypharmacy and drug omissions (DO) (i.e. drugs prescribed but not administered) may impact on quality of life of hospice inpatients.

**Aim:** To assess for polypharmacy and DO across hospice inpatient units in Northern Ireland (NI).

**Design:** A retrospective chart review of consecutive admissions to five adult hospices in NI in 2011-12 was performed. Only regularly prescribed oral and nebulised medications were analysed.

**Results:** 138 inpatient admissions were reviewed (58% male, median age 68, 91% had cancer). The average number of regularly prescribed medications was eight (range 0-17) on admission, 10 (1-21) at discharge and two (0-15) at time of death. A total of 35,575 regular drug doses were prescribed for the 138 inpatient admissions. 8.8% of all doses prescribed were omitted. The most frequent DO were laxatives (38%), mouth care (11%) and mineral supplements (9%). Analgesia and antiemetics were less likely to be omitted. Reasons for DO included patient refusal (46%), 'patient asleep or drowsy' (19%) and 'drug not available' (7%). 197 DO lasted 24 to 72 hours. No action was taken by medical staff for 79% of these. 85 DO lasted over 72 hours and no action was taken in 60% of these instances. There was no documented recognition by medical staff for 52% of prolonged drug omissions. While fewer drug doses were prescribed for patients who died during admission, the proportion of DO was higher (12.4%) than for those discharged (6.9%). DO increased in the last week of life (23%).

**Conclusions:** Polypharmacy is prevalent among hospice inpatients. 8.8% of drugs were omitted with the frequency of DO increasing in those who were dying. Documentation justifying DO was lacking. Daily focused drug chart review, pharmacy support and electronic prescribing may all potentially help to reduce and rationalise medication burden and aid prompt and effective management of DO.

**Abstract number:** P2-125

**Abstract type:** Poster

### Does it Affect the Type of Material of Catheters Subcutaneous Occurrence of Complications and Duration?

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**Introduction:** Two types of catheters, suitable for subcutaneous administration, are available in the market: metal and vialon.

**Goals:** The study aimed to categorize, describe and compare reported complications as a function of the type of subcutaneous catheter used.

**Methodology:** The method involved piloting (4 months) and study (6 months) stages, and including changing the type of catheter used half way through each stage. Exclusion criteria included: patients in distress and those with sensitivity to the catheter material.

The study sample included 132 available vascular accesses, of which 73 presented a complication.

**Results:** A descriptive analysis showed that the mean duration of vascular access which resulted in complications was 7.78 days (sd = 6.844) and the mean time until first complications was 7.29 days (sd = 6.513). Research hypotheses included Kolmogorov-Smirnov ( $p = 0.07$ ) and Levene ( $p = 0.05$ ) statistical tests. No significant statistical difference was found to reject the null hypothesis. Further analysis using independent samples based on the t-student test (ANOVA) yielded no significant difference to reject the null hypothesis of equal means between the two groups. It was therefore concluded that the two types of catheter showed the same performance in relation to the duration of the vascular access ( $p = 0.337$ ) and to the mean period until first complication ( $p = 0.797$ ).



Table 1

	N	Mean	Standard deviation (sd)	Standard error	Confidence interval of mean at 95%		Lower limit	Upper limit
					Minimum	Maximum		
DAYS_1_Metal	29	6,83	5,458	1,014	4,75	8,90	0	20
DURATION_2_Valon	44	8,41	7,617	1,148	6,09	10,72	0	33
Total	73	7,78	6,844	,801	6,18	9,38	0	33
DAYS_1_Metal	27	7,04	5,222	1,005	4,97	9,10	0	18
Number of days until complication	39	7,46	7,337	1,175	5,08	9,84	0	33
Total	66	7,29	6,513	,802	5,69	8,89	0	33

**Conclusions:** An apparent decline in the use of metal vascular accesses catheters as compared with vialon-type was observed, which might be linked to some reluctance by professionals to use the former, given that evidence regarding risk of complication and lower effective duration had been reported elsewhere. Although the results achieved in the present study do not confirm such conclusion, it should be noted that metal catheters show a series of drawbacks when used by the patient's relatives. This suggests that special care must be paid to specific requirements in their use.

**Abstract number:** P2-126  
**Abstract type:** Poster

**High Satisfaction with a Swedish Specialist Palliative Home-care Service**

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**Background:** Most of the Swedish specialist palliative care is provided by multiprofessional home-care teams that operate around the clock, 7 days a week. The teams provide psychosocial support and symptom control, treat infections and perform e.g. infusions, blood transfusions, laparocenteses or pleuracenteses in the patients' own homes.

**Aim:** The aim was to evaluate the satisfaction with the service, as perceived by severely ill and dying patients.  
**Methods:** During 2010, a County Council office sent a partially validated 26-item questionnaire in Likert-format to every new patient (mainly cancer patients) within 16 palliative specialist home care services in the region, three weeks after admission. In total, 922/1424 (78%) responded.  
**Results:** The proportions of positive and very positive responses with the service were as follows: Information about the service - 85%; around the clock availability - 96%; confidence with the staff - 93%; perceived respect and consideration (from the staff) - 95%; possibilities to supportive talks - 95%; influence and shared responsibility 87%.

As regards symptom control, the figures for total relief versus total+partial relief were as follows: Pain - 82% vs. 99%; anxiety 77% vs. 97%; other symptoms 79% vs. 98%. The overall satisfaction with the service was 99% and generally the responses were similar from male and female patients.

**Conclusion:** The current model of a multiprofessional, physician-led, around-the-clock service provides a high-quality palliative care in the patients' own homes and is highly appreciated. The high percentage of satisfied patients is not due to floor-ceiling effects of the questionnaire, as almost identical questionnaires within the same county council normally produces a lot more dissatisfaction within other health care services.

**Abstract number:** P2-127  
**Abstract type:** Poster

**Patient Safety Strategy in the Regional Palliative Care Program of Extremadura (RPCPEX): Methodology and Design of a Training Program on Safe Use of Drugs by Home Caregivers**

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**Introduction:** Patient safety (PS) is defined as the minimization of adverse events (AE) or damage to the patient during the health care process. Palliative Care interventions are regarded as fairly prone to yielding EA. This becomes more relevant when it is the main caregiver who manages strong opioids and is responsible for

administration by him/herself, given that doubts, fears, etc. might rise incident probability (errors regarding misunderstandings with drugs, wrong dosing...).

**Goal:** Design a project aimed at facing PS within the Regional Palliative Care Program of Extremadura (RPCPEX) to promote safe use of drugs and AE prevention in patients, from the multiperspective framework of all agents involved in end-of-life interventions (patients, caregivers, professionals).

**Methodology:** In line with the strategic plan for PS developed by Extremadura Health Service, and after a review of the scientific literature, the RPCPEX supported the creation of a team of experts (managers, technicians and other professionals) who have designed a Training Program to account for the actual field of application. The overall design process, together with the identification of appropriate quality indicators for the monitoring and further assessment of the projected actions, were delivered under the supervision of the Observatory for Palliative Care in Extremadura.

**Results:** Regional coordinated project involving active participation of all concerned agents (see attached figure).  
**Conclusions:** The perspective of PS has not become rooted in Palliative Care so far. It is therefore strongly advisable to plan training/establishing strategies for safe clinical interventions that might promote PS culture in professionals and prevent AE in patients. The contribution of users and caregivers, the local leadership of professional teams and the involvement of managers are key factors to appropriately promote an adequate management of PS in Palliative Care.

**Abstract number:** P2-128  
**Abstract type:** Poster

**Perception of Patient Safety Culture by the Support Teams of the Regional Palliative Care Program of Extremadura (RPCPEX)**

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**Introduction:** Patient safety (PS), regarded as the set of structures and procedures aimed at reducing the likelihood of adverse events (AE) or damage derived from health care to the patient, is a key dimension in quality of care. The knowledge of the perception of PS by RPCPEX professionals is a crucial task for the implementation of safe clinical actions intended to minimize risks associated to incidents and AE.

**Goal:** Assess the perception of PS culture by the support teams of the RPCPEX in order to identify problematical aspects to be overcome, to develop possible solutions and to monitor further evolution.

**Methodology:** Adaptation of the PS questionnaires validated by the Ministry of Health, Social Services and Equality to the reality of Palliative Care; Hospital Survey on Patient Safety Culture and Medical Office Survey on Patient Safety Culture.

Descriptive study on the environment regarding safety of professionals from RPCPEX and analysis of dimensions, considered as opportunities of improvement for safety of patients involved in the Program.

**Results:** Response rate: 70,73% (n=41) Survey dimensions (Tables 1a, 1b)

**Table 1\_Summary of results for each dimension (a)**

Dimension	Medicine Medicine Nursing Nursing Psychology Psychology Global						Global
	+	-	+	-	+	-	
1.Frequency of performed events	71,8	2,6	90	3,3	58,8	75,6	2,3
2.Perception of safety	44,23	26,92	55,26	15,79	50	25	49,12 22,81
3.Expectations and coordination actions by the Palliative Care Support Teams (PCST) to promote patient safety	82,69	2,85	67,5	15	75	12,5	75,86 9,48
4.Learning from continuous organization/improvement	23,08	48,72	50	30	55,56	16,67	39,08 35,63
5.Teamwork within PCST	71,43	5,77	51,28	23,08	83,33	4,17	65,22 11,3
6.Openness in communication	48,72	38,46	50	33,33	61,11	22,22	51,72 33,33

Table 1\_Summary of results for each dimension (b)

Dimension	Medicine Medicine Nursing Nursing Psychology Psychology Global Global							
	+	-	+	-	+	-	+	-
7.Feedback and communication about errors	58,97	23,08	42,86	25	55,56	22,22	52,94	23,53
8.Non-punitive response to errors	51,28	23,08	40	33,33	61,11	27,78	49,43	27,59
9.Staffing	32,69	50	37,5	45	41,67	45,83	34,48	48,28
10.Support on hospital management with regard to patient safety	20,51	51,28	33,33	46,67	27,78	22,22	26,44	43,68
11.Teamwork between units/departments	50	25	51,28	30,77	58,33	16,67	52,17	25,22
12.Troubles regarding shift changes and transitions between units/departments	23,08	48,08	35,9	56,41	33,33	29,17	29,57	46,96

**Conclusions:** There is an unreal overestimation of the environment of safety, as a result of the unawareness regarding PS by the involved professionals. The design of specific training sessions on PS and on AE risk analysis is strongly advisable in order to set an objective and real assessment of the environment of safety.

**Abstract number:** P2-129  
**Abstract type:** Poster

**Palliative Care Professionals' Awareness and Adherence of National Palliative Care Guidelines**

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**Aim:** The purpose of this study is to evaluate the awareness and adherence to national palliative care guidelines in the Netherlands.

**Methods:** We conducted a cross-sectional, retrospective, digital survey in August-September 2012. After a literature search we developed a questionnaire, to assess awareness of, adoption of, and barriers to national palliative care guidelines. About five thousand professionals from the relations system of our institute were informed on the study by mail and social media. Further distribution took place through newsletters of professional associations to their members and websites concerning (palliative) care. We asked all respondents questions regarding palliative care guidelines in general and specifically on the guideline that they most commonly used in the past year.

**Results:** Study population consist of 316 physicians, 108 GPs, 574 nurses and 297 others (i.e. physiotherapists, dieticians and chaplains), from different kind of settings. 1164/1295 respondents (90%) were aware of the national palliative care guidelines, 83% of them also have accessed a guideline. Pain and palliative sedation were most commonly used of the published 40 guidelines for palliative care. The guideline that was most frequently used was easily found (92%), understandable (92%) and the recommendations were often directly usable in their specific situation (69%). Main barriers to national guidelines are the use of local protocols (36%) and not feeling the need to use them (17%). Interesting differences in awareness of, adoption of, and barriers to national palliative care guidelines between disciplines, speciality and care settings will be presented.  
**Conclusion:** The palliative care guidelines are well known and adopted by professionals providing palliative care in the Netherlands. Further efforts should focus on the quality of local protocols (based on national palliative guidelines) and on unconscious incompetent professionals, who not feel the need to use them.

**Abstract number:** P2-130  
**Abstract type:** Poster

**Concordance between Expressed and Achieved Preferred Place of Care for Acute Hospital Inpatients**

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**Aims:** Achieving patients' preferences for end of life care (EoLC) is a priority, including their preferred place of care (PPC). Most people do not wish to die in hospital, yet 53% of people in the UK do. An audit was designed to examine: concordance between expressed and achieved PPC, reasons

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for variance, and whether diagnosis (cancer or non-cancer) influenced PPC achievement. This was essential to assess one aspect of the quality of EoLC and inform continued improvement.

**Methods:** A retrospective audit was conducted using data on all inpatients referred to the specialist palliative care team (SPCT) of a large UK teaching hospital over 1 year.

**Results:** PPC data was analysed for 1010 patients. Home was the expressed PPC for 45%, hospice for 18%, hospital for 8%, and care home for 11%. 18% of people did not express a PPC. 34% died in hospital. Of the 1010, 76% achieved their expressed PPC (excluding those discharged by the SPCT before hospital discharge). Reasons for variance included: 15% were actively dying at referral, 13% became too ill to move to hospice, 13% died during discharge planning to home or care home, and for 11% no hospice bed was available. Patients with a cancer diagnosis were 55% more likely to achieve their PPC than those with non cancer (68% versus 44%).

**Conclusion:** The hospital death rate compares favorably with the UK average. This audit only included patients referred to the SPCT. However, the large cohort and setting provide lessons for all referrers and acute SPCTs. Routine and continuous assessment of PPC achievement is essential for SPCTs. Collaboration across care boundaries is necessary to reduce deaths during discharge planning. The rates of those actively dying at referral and the lower rate of PPC achievement for those with a non-cancer diagnosis highlights the need to educate referrers on the value of early SPCT intervention and their own responsibility in providing EoLC, including Advanced Care Planning in the acute setting.

**Abstract number:** P2-131

**Abstract type:** Poster

### ISPC - A New System for Documentation and Benchmark in Outpatient Palliative Care

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In Germany the so called Spezielle ambulante Palliativversorgung - SAPV (special outpatient palliative care) has been made a patient's right by law in 2009. A core documentation is obligatory to participate in a network of SAPV. To guarantee continuity of care between all team members and all the different situations (e.g. emergency) ad hoc exchange of information is essential. A case management software for daily care, benchmark, and scientific use is presented.

**Methods:** The ISPC case management software provides the net members with a mobile record of all aspects of patient management in palliative care. The available functionality takes care of all aspects needed in communication of the different health providers (physicians, nurses, pharmacy, support team) and different locations of patients (home, hospice, hospital, residential home). The software is web based and therefore running on all systems (PC, Mac, Linux, iOS, Android) and hardware (tablet, computer, smartphone). A list of all own patients and all patients of the net enables realtime cooperation between home physicians and palliative care teams on duty. The symptom list is a longitudinal record enabling the estimation of treatment effects or the progression of the disease. This is underlined by graphic figures. A rota system, calendar for appointments and team meetings, templates for referrals are included. The knowledge and experience of the users is continuously integrated into the system and improving the workflow. Safety is guaranteed by the Entrust® IdentityGuard driven one time password (OTP).

**Conclusion:** Realtime information enables ad hoc integration of all care providers. The system has proven stability and flexibility over 2 years of use and 450 users and more than 20.000 patients. The high number of patients has enabled scientific work with the anonymized data of different palliative care teams. As an example the data demonstrated that in the end by far not all patients want to die at home.

## Basic & translational research

**Abstract number:** P2-132

**Abstract type:** Poster

### Acceptance and Effectiveness of a University Hospital Palliative Care Team

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**Aim:** In 2010 an inpatient palliative care hospital support team (HST) was established at a 1000-bed German University Hospital. Its implementation was accompanied by a study to gain data on the acceptance and effectiveness of the HST as judged by patients and staff.

**Methods:** A survey of medical and nursing staff members was conducted before the implementation using a self-designed questionnaire including Numeric Rating Scales and free text questions and asking about the staff expectations towards the HST. A post-implementation survey is currently ongoing. Outcome measures for patients included the *Palliative Outcome Scale (POS)*, the modified *ESAS*, the *MIDOS 2* and the *Satisfaction with Life Scale*.

**Results:** Staff questionnaire (return rate 60%, n=243): The staff expected the HST to be highly helpful (NRS 0-10) for pain therapy (median= 8.0; inter quartile range IQR=4.0), other symptom control(7.0; IQR=3.0), end of life decisions (7.5; IQR=5.0) and particularly for the psychosocial support of patients (9.0; IQR=2.75) and their families (9.0; IQR=2.0). Patient survey: Up to now we could include 38 patients pre and post HST intervention. Preliminary data analysis show a significant improvement of the patients' assessment of the intensity of pain (before HST: median 2 = moderate impairment by pain, IQR= 3; after HST: median 1 = mild impairment, IQR= 2; p < 0.001), as well as a significant drop in the POS, indicating improved symptom control and patient well being (before HST: mean 20.0; SD 6.78; after HST: mean 16.8; SD 6.17, p < 0.01).

**Conclusion:** The staff's expectations regarding the HST were particularly directed at the psychosocial support of the patients and their families. The preliminary results of the patient survey indicates that the HST contributes significantly towards an improved symptom control and overall patient well-being. Full data will be presented at the congress.

**Abstract number:** P2-133

**Abstract type:** Poster

### Participatory Research in Palliative Care: Opportunities and Challenges

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**Aim:** This presentation aims to introduce participatory research to the palliative care audience. There are several key characteristics of participatory research that shape how it is undertaken: its position in a critical paradigm; the focus on action and reflection; participation and empowerment as key processes for involvement. Although a number of studies have been undertaken by specialist palliative care in generalist settings, little action research is undertaken in specialist palliative care to date. There are considerable congruences between palliative care and participatory research. However, opportunities and challenges exist when undertaking participatory action research in the palliative context.

**Opportunities:** Participatory research in palliative care can impact upon the individual, the team/group, organisational and the wider system level which leads to a greater, sustainable outcome. As actions are taken within the research process the impact of the research in the setting occurs quickly. Such a process also not only contributes to social change but can also add to social science knowledge.

**Challenges:** Challenges arise due to the fact that the research is participatory (challenges in action research); other challenges originate in the field of palliative care (challenges of palliative care research). Most challenges are situated at the intersection of both: issues of relationship, initiation and sustainable participation, processes of change, issues of power, ethical considerations and engagement with sensitive topics.

**Conclusion:** Participatory action research is an appropriate methodology for research in palliative care as they both engage with the whole person in their whole context. Both put the patients and their families in the centre (participation); and, both seek solutions through inter- and transdisciplinary collaboration.

**Abstract number:** P2-134

**Abstract type:** Poster

### Improving Pain Management for Community Palliative Care Patients with Advanced Cancer: A Pilot Knowledge Translation Study

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**Aim:** To determine the effectiveness of the implementation of a multi component nursing intervention, in addressing the evidence - practice gap in pain management for community palliative care patients.

**Methods:** This pilot study has a pre and post implementation effectiveness design. The intervention included individual assessment of patient barriers to pain management and tailored education. Specific knowledge translation strategies including a theory based education workshop for community nurses and discussion forums supported the implementation process. Outcome measures included adherence to analgesia, level of distress caused by pain and functional status scores. The process evaluation included qualitative interviews with the community nurses to explore factors which influence effective implementation of the intervention. These data were analysed using the Theoretical Domains Framework. Implementation fidelity was monitored using intervention logs and questionnaires. **Results:** A total of 11 participants were recruited to the pre implementation cohort and 10 participants to the post implementation cohort. Descriptive analyses of scores for key outcome variables were similar for both groups, although scores for 12 of the 13 barriers items decreased following implementation of the intervention. All 14 of the theoretical domains emerged in the preliminary analysis of process data from 10 community nurse interviews. Environmental context and beliefs about consequences were judged to be of particular importance.

**Conclusion:** This study suggests larger scale research is needed to test the effectiveness of specific knowledge translation strategies in implementing evidence based pain management interventions in to routine practice in community nursing settings. Data from such a study could inform the development of knowledge translation policies for community palliative care services. This study was funded by the National Health and Medical Research Council, Australia.

**Abstract number:** P2-135

**Abstract type:** Poster

### Undertaking Evaluation Projects in Community Palliative Care: Issues for Research

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Regular evaluation is necessary in the management of health services, without which improvements in service models would be difficult to achieve and demonstrate. Evaluation is integral to policy, program development and clinical service provision, part of a quality improvement cycle. This is just as important in palliative care services, where there has been increased demand for evaluation to determine aspects like the worth, relevance, impact and effectiveness of particular programs or interventions. Information in this paper arises from involvement in a number of evaluation studies undertaken by the authors in a number of clinical sites.

**Aims:** This paper describes experiences and challenges in undertaking a number of independent evaluations of community palliative care services. Particular questions were: to address the experiences and challenges in undertaking independent evaluations; exploring the issues of process and systems in evaluation; and what strategies enable effective evaluation.

**Methods and results:** A number of methodologies are discussed, including questionnaires, consensus seeking and surveys. The paper highlights emergent issues about processes and systems of the evaluation itself, namely: challenges arising from project designs; achieving an ethical evaluation process, including balancing the risks of negative outcomes versus possible benefits; working with vulnerable populations and recruitment difficulties; the perceptions of staff to undertaking evaluation; and the expectations of funding bodies. From these experiences strategies are suggested for enabling effective evaluation.

**Conclusion:** As health services have increased in complexity, evaluation has become a necessary aspect of policy, program development and service provision, including palliative care services. Palliative care services need to grapple with the challenges described in this paper, in ensuring that their care remains as optimal as possible.

**Abstract number:** P2-136

**Abstract type:** Poster

**Abstract withdrawn**

## Bereavement

Abstract number: P2-137  
Abstract type: Poster

### Rehabilitation for the Bereaved Family Following the Death of a Child from Cancer

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**Aims:** Recognition of bereavement support for families of cancer patients as an essential element has taken root in the provision of comprehensive oncology care. However, reform of the current system of remuneration and administrative support is called for. In this report we will describe the progress of our program that bereavement support meeting for families following the death of a child from cancer.

**Methods:** A few months after separation, we sent invitation letters to the bereaved inviting them to the bereaved family meeting from the OTs who were caring for the patient. The theme and events at the meeting was planned not only for parents but also for sibling participation in mind. After each meeting we issued bulletins for the participants.

**Results:** 4 to 10 families with 6-month to 6-year bereavement period were available for participation for each meeting. Repeated participation was seen among families, participation once being 15 people from 6 families, twice being 5 people from 2 families, thrice being 15 people from 7 families. Families with repeated participation showed more father and sibling (infant to teenage) attendance as a trend. Comments showed a trend where female participants emphasized reception and sympathy, whereas male participants placed importance on problem-solution style approach. Some families distanced themselves from the meeting after realizing a change of thought through conversation.

**Conclusion:** Bereavement family meeting is a place having the during the lifetime to following the death continuity of the child for the families. The bereaved family meeting supports that they are restored a connection with oneself and the society. It is also benefits health professionals involved, preventing burnout syndrome, and improvement in quality of care. Considering the quality of palliative care provided by the University Hospital, we believe the bereaved family meeting has an important role.

Abstract number: P2-138  
Abstract type: Poster

### Systematic Review of Trajectories of Depressive Symptoms for Bereaved Family Caregivers of Chronically Ill Patients

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**Aims:** Family caregivers of chronically ill patients shoulder heavy caregiving burden and their suffering can extend into bereavement. Grieving is an individualized process. The few studies that treat grieving as heterogeneous used different criteria in identifying distinctive trajectories. The purposes of this systematic review were to synthesize distinctive trajectories and to estimate the prevalence of each trajectory for bereaved caregiver of chronically ill patients.

**Methods:** Relevant databases were searched using the following keywords: caregiver, depressive trajectory, bereavement. Inclusion criteria were: (1) prospective longitudinal study, including 1 pre-loss and at least 2 post-loss assessments, and (2) the studies identified depressive-symptom trajectories. 6 studies were identified. Depressive symptoms were predominately measured by the Center for Epidemiological Studies Depression Scale (CES-D). Scores of the CES-D were classified as low, moderate, and high using 10, 16, and 30 as the cutoffs.

**Results:** Five distinctive trajectories were synthesized, named as "endurance", "resilience", "recovery", "chronically distressed", and "chronically depression", and contained 43.08%, 4.74%, 16.38%, 23.74%, and 12.06% of samples, respectively. Caregivers in "Endurance" group have consistently low levels of depressive symptoms over time. "Resilience" is one with moderate to high depressive symptoms initially but rapidly returning to normal. "Recovery" group's distress lasts several months then gradually returns to pre-bereavement function. "Chronic distress" and "chronic depression" groups are with high depressive symptoms but "chronic distress" group's depressive symptoms decrease gradually during the bereavement.

**Conclusion:** Caregivers' depressive symptoms from pre-loss to bereavement are not homogenous. Clinicians should identify trajectories of caregiver depressive symptoms and provide suitable interventions to facilitate healthy psychological function.

Abstract number: P2-139  
Abstract type: Poster

### The Care about Bereaved in Czech Hospices

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**Introduction:** Hospices provide palliative care for terminally ill. Palliative care also includes care about bereaved. The papers deals with forms of support to family members, whose loved one died in the hospice. **Aims:** The purpose of the study was to describe the opinions of bereaved on the services provided by hospice for family member after the death of their loved one. Further are examined factors affecting contacts bereaved with members of the hospice team and their participation on the memorial programs for bereaved.

**Methods:** Data were collected using a questionnaire of our own construction. The research sample consisted of 412 bereaved whose loved one died in hospices at least one year ago. Data were analysed using quantitative methods.

**Results:** For selected socio-demographic factors were not found impact on meeting bereaved with members of hospice team. Participation of bereaved on memorial programs depends on the previous sharing hospice room by family members with loved one ( $p=0.001$ ) and also depends on faith of bereaved ( $p=0.000$ ). Length of stay in hospice or distance between hospice and bereaved residence do not affect participation of bereaved on memorial programs. All bereaved were satisfied with hospice support of bereaved.

**Conclusion:** Czech hospices offer support for bereaved shortly after death, prayer service for the death and memorial programs. Systematic support through individual counseling for bereaved is not currently by Czech hospice offered.

Abstract number: P2-140  
Abstract type: Poster

### Validity of the Spanish Adaptation of the Perceived Ability to Cope with Trauma Scale (PACT)

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**Aim:** Spanish adaptation of the "Perceived Ability to Cope with Trauma Scale" (PACT). The instrument evaluates the flexibility for coping with traumatic events. It's composed of 20 items, divided in two subscales: trauma focus, which includes items related to the active processing of the experience; and forward focus related to the possibility of moving beyond the trauma. The PACT has shown a negative relation between coping flexibility and complicated grief and positive relations with resilience.

**Methods:** The scale was translated into Spanish by two independent English speakers. Sample was composed by 82 university students (69% females, Mean age=21.27 years, SD=3.7). In addition to the PACT, the Life Optimism Test, the Posttraumatic Symptom Scale and the Adult Attachment Scale were given. Cronbach's alpha value was calculated to test the internal consistency of each subscale. A hierarchical cluster analysis was performed in order to group the items. Finally, bivariate correlations were carried out to assess discriminative validity.

**Results:** Cronbach's alpha value for Trauma Focus subscale was .72 and .90 for Forward Focus subscale. The item analysis showed an acceptable typical deviation (around 1), a variety of response for each item and a significant correlation with their own subscale. The hierarchical cluster analysis also supported the split of the items in two subscales. Finally, results on discriminative validity pointed out a positive relation between flexibility and emotional self-reliance ( $r=.38, p<.05$ ), between optimism and forward focus ( $r=.35, p<.01$ ) and self-esteem and forward focus ( $r=.33, p<.01$ ).

**Conclusion:** The Spanish adaptation of the PACT has an acceptable internal consistency. Further studies are needed with a larger sample to conduct a factor analysis. Also this version has to be tested on clinical sample like bereaved people or people who have experienced a trauma.

## Education

Abstract number: P2-141  
Abstract type: Poster

### Changed Knowledge, Attitudes and Practices of Health Providers towards Use of Opioids Analgesics for Pain Management in Ukraine. Experience of Ivano-Frankivsk Training Center

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**Situation:** Currently existing system for training of health providers does not offer enabling environment for study of pain management principles at the undergraduate and post-diploma levels. While no separate courses on pain management exist, questions on prescription of both non-opioid and opioid medication are poorly integrated in lectures and seminars on cancer care or care for terminally ill patients. While palliative care is only beginning its integration into general health care system, current knowledge, attitudes, and practices are mostly formed under influence of old-school books and manuals dated in 1970ies and 80ies, practice of older physicians who by large have never been exposed to evidence-based practice, with little knowledge of pharmacological principles of drugs' prescription.

**What we do for changing situation:**

- Shows patients' stories of pain denial and a positive stories of patients who had been able to access pain management
- Inform and disseminate international guidelines and standards of practice for pain management to urge the need of locally developed and approved Protocol/Clinical Guidelines
- During trainings for health care provides dismantling myths and wrongful believes:
  - ü that not all types of pain can be adequately managed by existing medications
  - ü that prescription of opioids equates to giving up on patient
  - ü that pain management with opioids leads to dependency problem
  - ü that pain management should not be prescribed to former or current drug users, children or other 'special' groups
  - ü that providing pain management with opioids automatically makes you a target for controlling officials, searches and prosecution
- Supporting professional seminars, conferences and meetings of health providers to discuss pain management with opioids by offering credible and comprehensive information

Abstract number: P2-142  
Abstract type: Poster

### 'Opening the Gate' to the Workforce: Rolling out a Local Spiritual Care Education Programme across a Critical Mass of the Workforce

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**Background:** Two large North West England cancer networks chose to roll out the established 'Opening the Spiritual Gate' education programme across their health & social care workforce to increase spiritual awareness & improve the confidence of staff in assessing & meeting spiritual & religious needs of patients & families.

**Method:** Individuals from each network, mainly health professionals, skilled in communication, education & group facilitation, were trained to deliver the face to face study day to their own local health professional workforce. Each network chose to undertake this in a slightly different way. Additionally, a 4 week online facilitated version of the same course was developed with a local university, & commissioned for staff (with other learning preferences) across three cancer networks. The facilitated course runs 10 times a year for small mixed groups. Evaluation of the impact on participants is measured by collation of face to face/e-learning evaluations, analysis of pre & post course questionnaires, analysis of postings to e-learning course & participants' assessment of ease of use of & navigation of the online course.

**Results:** More than 60 facilitators are now in place offering the study day in 30 health organisations within two cancer networks. 643 individual staff from Network 1 & 286 from

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Network 2 have since completed the face to face study day & 108 (Network 1=85, Network 2=14 & Network 3=9) people completed the online course. A formal evaluation of the programme is underway but early results demonstrate a significant shift in confidence amongst participants with regard to both assessing spiritual & religious needs and providing spiritual & religious care.

**Conclusions:** This presentation describes the training process for facilitators & the differences in roll out process between the two networks. It also compares the shift in confidence, participants end of course evaluations, & post course comments on the impact of the programme.

**Abstract number:** P2-143

**Abstract type:** Poster

### High Fidelity Simulation Training for Multi-disciplinary Healthcare Professionals Working in Hospital, Hospice and Community Settings

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**Aims:** To assess whether high fidelity simulation training can improve confidence in health care professionals providing end of life care in hospital, hospice and community settings.

**Method:** 7 courses took place between October 2011 and July 2012 for multi-professionals working in hospital, hospice and community settings. Courses were designed for specialist palliative care and non-specialist clinicians.

Participants took part in simulated clinical scenarios relevant to their clinical setting. These were videoed and constructive feedback was given in a safe learning environment. A high fidelity patient mannequin was used to simulate life-like signs and symptoms. Course facilitators undertook role play as relatives. 4 courses were provided for hospital teams; two for community specialist palliative care teams and one course was undertaken (using portable simulation equipment) in a hospice. All participants completed pre and post course questionnaires to rate their confidence in aspects of care using visual analogue scales.

**Results:** Of the 44 participants, there were 40 nurses and health care assistants; 2 occupational therapists; 1 pharmacist and 1 physiotherapist. Evaluation of the mean scores before and after each course demonstrated that the confidence of participants in all areas of end of life care improved following the course. Free text responses revealed that specialists and non-specialists felt that simulation training offered an effective method of training and that multi-disciplinary nature of the course enhanced the experience.

**Conclusion:** Simulation training offers an innovative education model. Participants learn by experience and via facilitated discussion with colleagues. Scenarios can be adapted for the participant's skill level, discipline and working environment. In order to explore the impact of the training in the work place, an additional questionnaire will be completed by community palliative care nurses 6 months after undertaking the course.

**Abstract number:** P2-144

**Abstract type:** Poster

### Competencies in Social Work Hospice Practice: An International Update

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**Aim:** The aim of this panel is to update on the development of social work competencies for social work in hospice care in Canada, the UK, Ireland, and Europe.

**Design:** In Canada, a Delphi process was undertaken for the development of social work competencies for hospice and end-of-life care.

**Results:** The Canadian competencies were completed in 2007 by a social work task group comprised of social work practitioners and educators. The competencies include knowledge, values, and skills for clinical and community practice, advocacy, education and research. During 2008-2009 social workers, schools of social work educators, and providers of continuing education were consulted to validate the competencies and develop practical strategies for the utilization of the competencies. In 2010-2012, workshops were held in various venues in Canada and internationally in order to communicate the competencies. Since then the competencies produced in Canada provided a crucial basis for discussion in Ireland and enabled the participation of Irish Palliative Care Social Workers in the development of the National Palliative Care Competence Framework, a work

currently coming to completion. In July 2012 the UK End of Life Care Programmes Board and the School of Social Work produced a guidance document for generalist social workers working with people at the end of their lives; the competency framework informed some of the document. Social workers in the UK and a range of European countries have contributed to the EAPC Taskforce on social work competencies, which is also based on the Canadian work. **Conclusion:** The articulation of social work competencies is important in order to advance the profession and the contribution it makes to patients and families in receipt of palliative care. The members of the panel have all been involved in the process in various countries and will report on the state of the development.

**Abstract number:** P2-145

**Abstract type:** Poster

### The Introduction of an On-line Spaced Education Program to Augment Palliative Medicine Teaching

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**Introduction:** Final year medical students at the University of Newcastle (NSW, Australia) undertake a week long placement in palliative care. This may involve placement in a tertiary referral palliative care unit or may be more general with allocation to rural nursing-led community teams. Whilst both experiences reflect the scope of palliative care practice, there is a need to ensure that holistic patient assessment, optimised symptom control and a high-degree of communication skill is emphasised to all students. These fundamental tenants of Palliative Medicine are increasingly recognised as core requirements of the practise of medicine in all settings.

**Primary aim:** To develop an integrated, on-line spaced education program in Palliative Medicine that is deliverable on a variety of mobile devices across a wide-range of geographical locations to final year medical students attending a university in NSW, Australia.

**Secondary aims:**

- 1) To compare the education experiences of students before and after the implementation of the program;
- 2) to compare the performances of students rotating through a specialist unit compared with those undertaking general placement.

**Methods:** Literature search and review of spaced education. Development of a 36 question online spaced-education program.

Review of pre and post test data from student rotations prior and subsequent to the implementation of the program. Comparison of spaced education results from students rotating through a specialist unit versus community placement.

**Results:** Student performance before and after the implementation of the spaced education program will be discussed. Any difference in the performance of the students undertaking different rotations will be explored. Spaced education may provide an optimised platform for the delivery of online Palliative Medicine teaching to large numbers of students regardless of location and has the potential to deliver inter-professional education effectively.

**Abstract number:** P2-146

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P2-147

**Abstract type:** Poster

### Developing a Workforce Development Programme on End of Life Care for Generalist Social Care Staff: An Education Initiative Led by Specialist Palliative Care Social Work

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Our hospice has been delivering workforce development programmes on end of life (EoL) care for generalist social care staff across 4 local boroughs since 2010.

Our approach is multi-pronged, aimed at staff at all levels, across disciplines and services, and with crucial buy-in at senior level. It is developed in partnership with local authorities, taking account of their priorities and responsive to needs as they become apparent. The 5 core elements of the programme include the development of EoL champions, strategic reviews with managers and broader consultancy. We aim to take local authorities beyond the

delivery of isolated training days on EoL to the more holistic approach essential for the culture shift required to improve generalist social care EoL provision in the UK.

Programmes are commissioned by local authorities and delivered by the hospice with specialist expertise being shared from the hub of the hospice but likewise hospice staff benefitting from newly established links with statutory services. Benefits are mutual.

Specialist palliative social workers are well placed to deliver the programmes, with their particular understanding of the social care background and ability to offer social care colleagues an opportunity to reconnect with core social work skills and values.

The project is on-going and open ended. For the next phase we aim to:

- consolidate current work with an emphasis on sustainability (i.e. continued commissioning),
- fine-tune approach to facilitate transferability to other locations (we are in dialogue with a number of other boroughs regarding this),
- work with research partners on economic modeling of the approach.

In conclusion, we believe that our multi-faceted and sustained approach to workforce development goes some considerable way towards meeting the objectives of the 2010 Framework for Social Care at the End of Life published by the UK National End of Life Care Programme.

**Abstract number:** P2-148

**Abstract type:** Poster

### Inspire a Generation! Growing End of Life Education with the Tree of Knowledge

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**Aim:** The End of Life Skillset Challenge (EoLSC), implemented locally across Community, Hospital & Hospice has inspired staff to undertake End Of Life (EoL) education, which all staff at any grade could access. A simple reward system has engendered healthy competition, whilst reaching a wide critical mass of the generic workforce.

**Design:** A tree of education was developed from a combination of 'e-elca' (National e-learning Programme U.K.) and locally available study days and sessions.

Each branch is delivered by existing EoL education and as such has promoted the use of e-elca online modules. It has also been an opportunity to involve all providers of EoL education across all care settings, e.g. mortuary & transplant services.

Staff collect evidence of completion of each topic at 3 levels to achieve bronze, silver and gold awards, 'Olympics' style. To achieve a gold level award, a reflective case study and an EoL related audit demonstrate the practical application of theoretical knowledge gained.

**Results:** Although only just begun, increasing numbers of nursing, allied health professionals, and clerical staff, from across all healthcare settings, are undertaking the challenge. The first bronze awards have been presented and already staff are working towards silver. The poster will show the first six months results.

**Conclusion:** The EoLSC has complemented the Route to Success work programme in the locality with limited expenditure using existing resources. The overwhelming incentive for the challenge was the consistency of education for all staff in all settings and the ability to recognise training already undertaken.

Staff have welcomed the active competition, the ease of access and the ability to study at their own pace to the level they choose.

Introduction of the EoLSC has re-invigorated EoL education, through recognition of hard work and achievement giving staff an appetite for more.

**Abstract number:** P2-149

**Abstract type:** Poster

### Liverpool Care Pathway: Evaluation of a Nationwide Implementation Program in the Netherlands

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**Introduction:** The Dutch version of the Liverpool Care Pathway for the dying patient (LCP), *Zorgpad Stervensfase*, is a quality instrument for the care of dying people in the

Netherlands. Since 2009 this pathway has been implemented nationwide in hospitals, nursing homes, hospices and homecare settings. Evaluation of this implementation program might show optimal strategies for implementing other quality instruments.

**Aim:** Describe the implementation of the Dutch LCP and the most important facilitators and barriers from different stakeholders' perspectives.

**Methods:** We used quantitative and qualitative methods to get insight in the perspectives of stakeholders who were involved in the implementation process. In total 27 stakeholders were interviewed: 7 employees of the regional Comprehensive Cancer Centres (CCC), 8 palliative care network coordinators and 12 project leaders of successful implementation projects. Subsequently, we organized a focus group with the interviewees to discuss facilitators and barriers of implementation of the Dutch LCP.

**Results:** Main reasons for institutions to implement Dutch LCP were to improve quality in end of life care, and to create a clear and uniform care plan at the end of life. Also extrinsic motivation was present, e.g. by financial incentives of insurance companies. Different successful strategies have been used for implementation of the LCP. Seven CCC's trained local project leaders and supported them in different ways. Network coordinators especially played a role in informing institutions within their regions about the advantages of the Dutch LCP.

**Conclusions:** In the dissemination process of the Dutch LCP a variety of strategies were used. Stakeholders identified shared facilitators and barriers, independent of chosen strategies. Knowing these facilitators and barriers can contribute to a successful implementation program, which is also of importance for other quality instruments in palliative care in the Netherlands.

**Abstract number:** P2-150

**Abstract type:** Poster

### Improving Perception of Pain in Graduate Pain School

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The purpose of this structured pain school is to enhance support group representatives as discussed EAPC 2011. It is advocated that both the patient and caregivers must understand pain in totality. The patients attending the support groups regularly are attentively selected to be enrolled into the "Graduate Pain School".

Copious amount of research revolves around the relationship between pain and the meaning of pain specifically in chronic pain. Many patients believe tissue injury remains the core of their problem and those who do not, does not verbalize their condition in terms of nervous system dysfunction. In support groups we discuss the physical, psychological, social, cultural and emotional intelligence or locus of control with both the patients and care givers. The latter being spiritual support for some patients.

The amount of patients attending the group sessions grew vastly. We needed more staff to assist with groups. Patients who understand what pain is and those that understand how to manage pain, wanted to share their experience. The patients call it a pain free zone.

Enrolled patients sign a contract where the punctuality, commitment and confidentiality are discussed. The course program differs weekly. The first day revolves around group introduction, team involvement and course content. We use pain diaries to document PQRST pain characteristics, understanding rating your pain and the holistic approach in pain management. Every class concludes with physiotherapy and relaxation.

Feedback from our pain school graduates affirmed our purpose. "Sharing my experiences, meeting patients with similar problems, learning to cope, reflecting in my journal releases my daily dose of build in morphine the endorphins. It's about my attitudes, beliefs and choices. I use this within the community, in waiting rooms, in the clinics and often with a staff shortage, to support people experiencing pain".

**Abstract number:** P2-151

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P2-152

**Abstract type:** Poster

### Clinical Supervision in the Reflective Learning Organisation

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**Purpose:** Children's Hospice Association Scotland (CHAS) has created a strategy to position them as an influential leading provider of children's and young people's palliative care in Scotland, the UK and beyond. To ensure that staff understand their role and the responsibilities in their work CHAS has identified key goals: practitioner development and reflective learning; enhancement of the reflective learning organisation to demonstrate a commitment to evidence based practice through structured approaches to learning, development and research; and, contribute to and enhance education of paediatric palliative care professionals.

**Process:** To realise the above, CHAS conducted staff surveys, held meetings to capture strategic developments from practitioner perspectives, and gathered feedback from annual development days to engage with and achieve the staff identified-need for an organisation approach to clinical supervision and reflective learning. Following this, CHAS established a short life working group to meet initially over a period of 10 months.

The aims of the group are to:

- Conduct an options appraisal of the multidisciplinary clinical supervision models and select the model appropriate for CHAS
- Identify and train facilitators of clinical supervision from within CHAS
- Promote reflective practice
- Monitor, audit and evaluate the model implemented
- Improve standards of care

**Outcome:** Staff interest and critical inquiry of the realisation of clinical supervision in their work environment has created professional excitement and enriched the multidisciplinary approach in CHAS. Some staff members have identified themselves as facilitators of supervision. A bespoke clinical supervision training programme has developed. Working partnerships and enhanced professional commitment to quality of care has been observed. It is also intended to use this project to design a future programme of reflective learning for all CHAS staff.

**Abstract number:** P2-153

**Abstract type:** Poster

### Simply Schooled! Impact of a Simple Model of Communication Skills on Generic Staff

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**Background:** Good communication skills in healthcare professionals are acknowledged as a core competency. The consequences of poor communication are well recognised with far reaching costs including; reduced treatment compliance, higher psychological morbidity, incorrect or delayed diagnoses, and increased complaints. The 'Simple Skills Secrets' is a visual, easily memorised, model of communication for healthcare staff to respond to the distress or unanswerable questions of patients, families and colleagues. This was taught to staff across healthcare settings in care homes, hospital, hospice and community.

**Method:** A qualitative evaluation of the impact of the course was undertaken, using semi-structured telephone interviews with participants 6-8 weeks post course. Using a purposive sampling approach, 14 participants out of the 153 staff trained, agreed to follow up qualitative interviews.

**Results:** Several themes were obtained from the qualitative data, including: a method of communicating differently, a structured approach, an easy to remember visual model, thinking differently, increased confidence, using small amounts of time effectively, gaining additional skills and helping the person come up with answers themselves. The value of the model in clinical practice was reported.

**Conclusion:** This model appears to be easily remembered, increase the confidence of staff, in dealing with difficult conversations and empower them to more willingly undertake these otherwise avoidable conversations, which could lead to earlier, shorter interventions & minimise distress.

**Abstract number:** P2-154

**Abstract type:** Poster

### Experience of Ukraine to Educate Medical Professionals Involved in Palliative Care

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According to research of experts of the Institute of Palliative and Hospice Medicine of MoH of Ukraine (IPHM) and the Department of Palliative and Hospice Medicine (Dep.PHM) of the National Medical Academy of Postgraduate Education (NMAPE) over the past 5 years nearly 2 mln incurable patients and their families require palliative care (PC) in Ukraine annually. Moreover, there is an insufficient number of specialized PC facilities and lack of Home PC service. It stipulates that every doctor and nurse must have the PC knowledge and skills to control chronic pain and treat of end-of-life patients. Besides the medical care, health professionals involved in PC should have the knowledge and skills on the psychological, social and spiritual support. According to the recommendations of experts IPHM and Dep.PHM, roughly, 2250 physicians, about 11500 nurses and 2000 social work specialists, psychologists and chaplains must be taught to provide PC in specialized PC facilities and at home.

The first Dep.PHM in Ukraine was established in NMAPE in December 2009. Seven curriculums for PC training of general practitioners/family doctors, oncologists, geriatrists, PC facilities doctors, health care managers and other health providers were developed. Since May 2010, more than 400 doctors and nurses improved their knowledge and skills at the training courses. The Palliative and Hospice Medicine Textbook for medical colleges students was developed together with teachers of Zhytomyr Nursing Institute in 2012.

**Conclusions:** The main tasks to improve medical professionals PC training are: to develop of PC standardized curriculums, textbooks, manuals, guidelines, etc. for health providers educating; to advocate of approving the Palliative Medicine Specialty for doctors and nurses by MoH of Ukraine; to advocate of optimizing by MoH of Ukraine of PC facilities staff regulations and working norms, according to international guidelines and standards.

**Abstract number:** P2-155

**Abstract type:** Poster

### Learning about Legal Aspects of Palliative Care

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**Aims:** Hospice staff recognise legal problems impact negatively on patients' daily living. Legal information & referrals for legal assistance may relieve worries and improve quality of life.

**Methods:** A group of palliative care & legal practitioners collaborated to develop a manual to address practitioners' legal problems. Legal issues put forward by hospices were tackled by 21 writers with legal & palliative care practitioners pairing up to co-write chapters. Legal problems troubling patients include: Who will care for children after parent's death, who will inherit the family home, how to access pain relief, falling into debt, grappling with discrimination, struggling to navigate application procedures for identity documents & financial grants.

**Results:** The collaboration resulted in 13 chapters and the 1st edition of Legal Aspects of Palliative Care published by HPCA in 2009. This is a practical resource for those working in palliative care & for legal practitioners assisting people facing life-threatening illness and requiring legal advice. A new layout in the 2nd edition of 2012 puts the text of international & national law alongside palliative care with new content, new case studies & colour photos throughout. Now with more resources & templates for leaflets (for example - how to draft your Will & writing a Living Will) & a sidebar for reader's notes. The book is now also a training resource with training exercises in each chapter. The updated edition was launched to a packed audience during the HPCA 25th anniversary conference in Cape Town. Three editors/authors presented case studies to demonstrate how the book assists staff to help patients and families with legal problems.

**Conclusion:** Training sessions using material from the book, will help hospice staff to identify legal problems & provide information or suggest referrals. The book will be used to orientate legal practitioners to enhance their understanding of palliative patient needs.

**Abstract number:** P2-156

**Abstract type:** Poster

### Grief and Loss in Children and Young Adults

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**Background:** In 2013 our Palliative Care Unit will celebrate its 10th anniversary. We would like to take this opportunity to contribute to reducing taboos that exist in public around illness, death and mourning. Also Children and adolescents frequently experience loss while growing up, adults often find it difficult to address sadness and grief with children. However, open communication can reduce anxiety and feelings of uncertainty, and help to emerge stronger from crises. When addressing these subjects with children, it is important to do so in a safe space. School can be one such space because it is not only the place where they spend the majority of their time, but it is also a key living environment. **Aims/method:** Teachers from different grades and types of schools are asked to creatively engage students regarding the topics of grief and loss. Student participation is on a voluntary basis, and the form of the discussion is determined by the supervising teachers. This approach enables an age appropriate handling of the subject area that can be tailored to the specific situation. The goal is to reduce taboos and to encourage of open communication, the acquisition of coping strategies, and the development of an awareness of students for their own needs and the needs of others. A visit to our ward is possible in the context of the project, but is not a requirement for participation. **Results:** A total of 9 classes from different school forms are participating in the project. A wide variety of approaches is being used to engage students in the subjects of grief and loss. A concert of the youth symphony orchestra will take place in March 2013. Participating classes will be invited and be given the opportunity to present their project outcomes. **Conclusion:** We hope the creative examination on topics as grief and loss with children and adolescents can offer an opportunity to remove taboos, enable to communication in an age appropriate way and develop coping strategies.

**Abstract number:** P2-157  
**Abstract type:** Poster

### 'The Missing Link' - Developing a Palliative Care Link Nurse Programme in a Tertiary Cancer Centre

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**Background:** A link nurse is defined as 'moving towards being an expert and resource person for an identified topic of speciality practice, in which they have an interest and passion'. This tertiary Cancer Centre in the UK has 88 beds with many complex patients with specialist palliative care needs. A job description was developed to help aid the roles and responsibilities of the link nurse. The two main purposes of this role were to share information and provide two-way communication between the specialist team and staff in the clinical area and to act as a resource and a role model for their colleagues. **Aim:** To develop a sustainable link nurse programme with clear aims, objectives and evaluation process. To outline a robust process whereby link nurses can be recognised professionally for their contribution to the programme. To provide education and training. **Method:** Two link nurses were identified by each ward manager. Each nurse was provided with a resource folder which included a job description and an outline of the full programme for the following 12 months. A Clinical Nurse Specialist was assigned to each ward to help mentor the link nurses and to act as a resource. The link nurses were expected to attend at least 3 study days per year and to feed the information back at ward level. The link nurses were also provided some basic teaching skills in which could be developed throughout the programme. A national conference was funded each year for the link nurses to attend. **Results:** All study days and events would be evaluated. There has been a huge element of enjoyment both from the link nurses and the team. Staff awareness about palliative care has increased throughout the Centre and important links have been built. There has been some difficulty releasing staff from ward areas which can have negative effects on the programme. **Conclusion:** All staff involved have benefited from increased awareness and education and a further 12 month will be planned.

**Abstract number:** P2-158  
**Abstract type:** Poster

### The Experience of Leadership Training - Palliative Care Physicians from India

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**Aim:** To explore the experiences of senior palliative care physicians in India participating in a unique international leadership development initiative (LDI). **Background:** In India leadership training has become key in business management but is not a part of a palliative care physician's armamentarium. 7 senior physicians underwent leadership training designed for palliative care leaders. **Methods:** Utilizing a thematic qualitative approach Interviewers used a semi-structured questionnaire derived from initial discussion. Interviews were recorded and emerging trends further analyzed. Relevance to palliative care - The practice of palliative care needs many leadership principles over and above clinical skills: to help liaise with government officials, negotiate, train and sensitize. This has special relevance in a branch which is still not established in our country. The concept of using leadership principles to help improve the coverage and scope of palliative care by clinicians already practicing in this field for more than 15 years was explored. This is the first time this kind of study has been conducted on Indian palliative care physicians. The Leadership Development Initiative at San Diego delivered a comprehensive, structured program over 2 years. This included Strategic Planning, Presentation Skills, Conflict Management, Negotiation Skills, Crucial Conversations, Change Management, Talking to power, Presentation skills, Learning styles, Team Building and sustaining. The curriculum was delivered through 3 residential courses and regular one on one mentorship and coaching. Result - The international networking, knowledge and skill training and opportunity of peer and expert mentoring offered a unique learning experience. Participants were selected based on their existing and potential leadership roles. **Conclusion:** The study revealed that the innovative LDI programme is a rich, demanding and rewarding experience that has changed practice.

**Abstract number:** P2-159  
**Abstract type:** Poster

### Training in End of Life Care for Paramedic Practitioners: Evaluation of a Pilot Study Day

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**Aims:** The potential role of paramedic practitioners (PP) in end of life care (EOLC) was highlighted through analysis of local incidents. This pilot learning event was set up to explore how best to engage and explore the learning needs of this group of clinicians. **Methods:** A basic agenda was established with a focus on multi-professional delivery from specialist palliative care, ambulance and district nursing staff; the morning sessions covered aspects of EOLC and the afternoon focused on medication used in symptom control utilising case based learning. A 'goldfish bowl' observed carer interview was included to demonstrate aspects of carer need and communication difficulties at end of life. Additional objectives were collated at the beginning and middle of the day. Feedback was obtained on a semi structured form. **Results:** 8 ambulance staff (including 6PPs) attended. There was an overwhelming positive response to the day with 100% of PP attendees stating they found the day relevant to their role and that teaching was at the right level. All attendees said they would recommend a similar teaching day to their colleagues. Particular feedback highlighted the fishbowl observed interview and multi-professional learning as highlights of the day. Key objectives identified were: Accessing the right information; Knowledge of local services; Developing confidence in: decision making, symptom control and the role of PP; Understanding patient and carer experience; Promoting EOLC to all ambulance staff; Informing other healthcare staff about EOLC role of PPs and building relationships. **Conclusion:** A multi-professional approach to engaging and developing EOLC skills is beneficial and in this group of paramedic practitioners was seen as very relevant to their roles, however as attendance was voluntary this group may be a self-selected interested group. In addition the use of patient stories, in this case through an observed carer interview, was very beneficial.

**Abstract number:** P2-160  
**Abstract type:** Poster

### Palliative Care for Multiple Diagnoses in Multiple Settings - Creating a Master's Program for Health Professionals

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In 2009, the National Board of Health and Welfare in Sweden started developing national guidelines for palliative care, involving different diagnoses. A secondary aim with the guidelines was to equalize recognized regional disparities in palliative care. Nationally, the development of palliative care aims to ensure that there is palliative care knowledge and expertise, in the different care settings where these patients are cared for.

**Objective:** To describe the development of a Masters' program in palliative care, suitable for health professionals from different care contexts, based on evidence and with high relevance for clinical practice. **Result:** The program consists of 7 separate courses, and is developed in cooperation between clinicians, researchers and lecturers. It is mainly internet based, allowing students nationwide to participate, while continuing their clinical work. The first course started in September 2012, with students from various settings e.g. ICU, elderly care, primary care and specialized palliative care. Since clinical relevance for individual students is paramount, student engagement is purposefully included in the program structure and design. Clinical application and relevance have also been central in designing the study assignments and examinations. Person-centered care, academic reasoning and research methodology are integrated themes throughout the program. Students' experiences from three courses will be presented and discussed. **Conclusion:** Development of higher education with strong relevance for clinical practice, poses challenges for lecturers as well as students. Combining students from different clinical settings, with different backgrounds and from different parts of Sweden vouches for dynamic discussions and contributes to spreading knowledge of palliative care. This is a focused step in increasing the competence levels within palliative care, irrespective of patients' diagnoses and care settings.

**Abstract number:** P2-161  
**Abstract type:** Poster

### Meeting the Needs of Emerging Leaders in Palliative Care: Results from a European Wide Online Survey

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**Background:** Effective leadership in palliative care (PC) is essential to position the specialty to meet future challenges. However, leadership skills and knowledge gaps exist in the PC workforce, particularly among some emerging member states in Europe. **Aim:** Under the auspices of the Robert Bosch Stiftung's newly founded 'European Palliative Care Academy' to survey key stakeholders and health/social care professionals across Europe to gain their views on the need for, and composition of an educational programme to develop emerging leaders in PC. **Methods:** Invitations to participate in an online survey were sent by each 'Academy' partner to stakeholders and PC professionals across European countries. The survey was advertised by the EAPC. **Results:** We obtained 194 views from respondents located in UK, Poland, Romania, Germany, Switzerland and Portugal. The main professions represented included physicians (40%) and nurses (32%) who were working in hospices, hospitals, or in home-based care. 75% of respondents possessed more than 6 years experience in PC. 91% stated a leadership course would enable them to develop local and national services. Respondents' motivations to participate in the programme included: (i) personal self-development;

(ii) career development;  
 (iii) sharing knowledge; and  
 (iv) being better positioned to develop services.  
 Suggestions for programme content included practical and theoretical skills in developing and evaluating palliative care across different settings, evidence-based practice, appraising evidence, change management, advocacy, and management skills.  
**Conclusion:** We have identified evidence of unmet leadership skills among PC professionals working across Europe. Moreover, we have identified demand for a new educational programme to develop emerging leaders. This programme has potential to effect positive change in countries where PC is emerging as a new speciality.

**Abstract number:** P2-162

**Abstract type:** Poster

### **Education for Volunteer Coordinators for Hospice-palliative Care. Action Research Conducted in Poland in 2007-2010**

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**Aims:** A chance to serve growing number of patients could be achieved with increase of volunteering. Hospice-palliative care units could contribute to social inclusion at the local level, be part of the promotion of pro-social attitudes and to fill the missing link in the formal care. However, only appropriate coordination of voluntary actions could assure that volunteering will served those purposes. Proper recruitment, training and ongoing formation of volunteer coordinators is needed. Nationwide program in 2007-2010 had as a main goal proper training for volunteer coordinators.

**Methods:** Research has been conducted among the volunteer coordinators in 100 hospice-palliative care centers according to the action research methodology. Data have been a source of information allowing to answer following questions:

What is the relationship between adequate volunteer coordination and recruitment, training and involvement of volunteers into hospice-palliative care?  
 How the training and textbook for coordinators have influence their work in the caring team and help to build the interdisciplinary team mentality among professionals?

**Results:** Achieved results showed the position of volunteer coordinators in preparing and implementing team work with volunteers. This research is a record of efforts made by coordinators, who had acceptor invitation for proper training in Poland. Data collected during three years program, as well as life stories, written by coordinators from across the country were published in 2012.

**Conclusion:** Volunteer coordinator is responsible for his team of volunteers, and builds public trust in volunteering in caring team and local society. Volunteers, with a good coordinator, feel prepared for their role in the caring team. Coordinator should prepare candidates, and be their advocate in the team of professionals. This research shows how important is coordination of volunteers within the caring team, and in the local community.

**Abstract number:** P2-163

**Abstract type:** Poster

### **Social Education in Hospice-palliative Care. Action Research Conducted in Poland in Years 2004-2010**

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**Aims:** This analysis of series of educational actions of Hospice Foundation in Poland during 2004-2010, shows how experiences from the Gdansk Hospice brought about a series of public events, which resulted in more than a hundred teams working together. Thanks to their efforts and cooperation it has become possible to integrate the hospice-palliative care community in Poland and create series of social education events and promotion of volunteering.

**Methods:** Qualitative and quantitative research has been conducted according to the action research methodology. Acquired and elaborated data have been a source of information allowing to answer following questions: What is the relationship between social initiatives designed to improve the quality of palliative and hospice care and the mission to educate the general public about end-of-life care?

Have these initiatives in any way affected individuals,

communities and society at large and, if so, how and to what extent?

Action research methodology has been used, and during the implementation of the projects presented, modifications were made to their original assumptions. These objectives were relevant in preparing and implementing further steps of team work with volunteers.

**Results:** This research is a unique record of efforts made by coordinators and voluntary workers in Poland - above all at a local level, to raise social awareness about hospice-palliative care. Life stories, written over the years by many people from across the country and published in the book in 2012 as conclusion of these projects, have been a source of inspiration for public education on end-of-life care.

**Conclusion:** Analysis of action research carried out from 2004-2010, published in 2012, presents recommendations as to how questions and problems relating to hospice-palliative care should be addressed and what further action - in terms of research and publications - should be taken.

**Abstract number:** P2-164

**Abstract type:** Poster

### **Can Different Cultures Lead to Different Medical Humanities in Palliative Care? A Comparison Between Two Countries in Europe**

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Italy and Hungary could, respectively, represent Western-Mediterranean culture and a Central-Eastern European one, but not like classical cultural models. We highlighted all the aspects about palliative care (PC) in our two European countries - history, cultural differences, structure, educational programs, awareness, and problems related to communication. As a consequence of this close analysis, it could be stated that the two countries are examples of a deep cultural, social, and historical specificity, but are particularly an example of the desirable level of European integration. This research could represent a way to select a special type of analysis in palliative care by a cultural point of view. In addition, establishing partnership and delving into a ongoing comparison could help to eliminate misperceptions and stereotypes and to improve the development of PC in Europe.

**Abstract number:** P2-165

**Abstract type:** Poster

### **Introducing an Evaluation Framework to Measure the Impact of Education on End of Life Care**

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**Introduction:** Clear evaluation strategies are necessary to demonstrate the impact of education and training beyond the classroom. Traditional approaches to evaluating the impact of education are many and varied, ranging from 'happy sheets' (that ascertain the participants' feelings at the end of a session), through academic assignments (establishing whether learning has taken place), to evidence of behavioural change in the workplace. The literature demonstrates a need to produce a coherent set of measures that show that learning has occurred and brought about change in working practices.

**Aim:** To introduce an evaluation framework that enables the impact of education to be measured.

**The framework:** Models of evaluation have been developed in business and clinical practice, predominately based on Kirkpatrick's model developed in the 1950s. Clinical models measure patient outcomes while business models measure return on investment. Hospices, as charitable institutions, do not fit neatly into either a business or a clinical model; both perspectives must be addressed when considering impact. The proposed framework enables the measurement of impact across core domains through the use of: staff questionnaires; academic assignments; clinical observation; staff interviews; and patient outcome measures. The efficacy of evaluation is dependent upon organisational culture. Challenges will include engaging clinicians in adopting the framework and supporting leaders when implementing the framework in practice.

**Conclusion:** The framework will potentially demonstrate a change in clinical working practices that is directly linked to education. The advantages of the framework are expected to be: individual and team, with an ability to demonstrate the application of learning in clinical practice; organisational, with evidence for commissioners when reviewing standards of end of life care; and the tangible integration of education into clinical practice.

**Abstract number:** P2-166

**Abstract type:** Poster

### **Anticipatory Care Planning (ACP) for Patients Suffering of Chronic Heart Failure (CHF)**

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**Research aims:** To investigate whether education on ACP for family practitioners and cardiologists would improve their communication with patients suffering of CHF.

**Study design and methods:** In-depth-interviews (recorded, transcribed and coded) and file-analyses identified how ten cardiologists and ten family practitioners practiced ACP for patients with CHF. The file-analyses were discussed with the doctors to know if ACP was done formally (written) or informally (only spoken).

One educational session was given to nine participants - non-participation was mostly due to practical difficulties. Evaluation papers were filled the same day. In-depth-interviews and file-analyses were done respectively 3 and 6 months after the educational session, to evaluate the effect of the intervention.

**Results:** The most frequently cited barriers to use ACP were prognostic uncertainty and fear to depress patients with bad news. There are diverse ACP practices. For instance, some cardiologists always discuss ACP when considering an ICD, some never do that. ACP often occurred informally. All participants received the educational session well.

The last in-depth interviews showed that all doctors knew better about ACP. The last file-analyses showed that more patients had received ACP, and more often formally. **Conclusion:** This small-scale-study investigated the attitude and self-reported performance of medical doctors concerning ACP. The results suggest that this kind of education can improve their ACP communication skills. It is recommended that more studies, rather on a larger scale, will be done to evaluate and improve post-graduate medical education on palliative care and ACP.

Patient opinion on ACP, clinical outcomes linked to ACP and ACP performance of (heart failure) nurses, geriatricians and palliative care doctors could be the subject of future investigations.

**Funding declaration:** No funding.

**Abstract number:** P2-167

**Abstract type:** Poster

### **Catalysts Identified to Make Continuity of Specialist Palliative Care Possible beyond Out of Hours Provision**

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Finding the right balance in patient and family care is at the heart of what constitutes Specialist Palliative Care (SPC) and how to provide continuity of care. Influencing feasibility remains a challenge for policy makers, managers and professionals. The debate is furiously alive; out of hours care provision yet to be solved. Some groups are specially affected: children, adults with non malignant disease in rural communities as continuity goes beyond out of hours provision.

**Aim:** To identify, appraise and clarify relevant factors to avoid families feeling disempowered; patients abandoned. To implement appropriate changes to make SPC accessible for all who need it, when they need it based on early identification of needs/ program inclusion, continuous domiciliary expert palliative care and central contact point for patients, carers and professionals.

**Method:** Prospective, longitudinal, descriptive design to analyze up to date data from electronic database collection (SPC) strategy in its 5th year.

**Results:** Data from 6.5 m population attended by 700 PC professionals, including 12 exclusively dedicated to providing 24h care show clinical activity, incoming and outgoing phone calls, round the clock generalist and expert visits and reason for them, from over 25000 contacts to central expert resource.

**Conclusions:** Continuity of SPC is possible when barriers are overcome using facilitators such as: language and concept clarity; target population identification; procedures and tools; professional ownership, key worker identification; truly interdisciplinary expert models of care; electronic records, pathways involving all resources; real PC philosophy societal awareness; research showcasing patient and professional experience and systems that facilitate Preferred Place of Care and Death, establishes the home as the ideal place of care

## Poster sessions

for those who so wish as long as continuity and coordination is facilitated by means of appropriate tools and activity monitoring.

**Abstract number:** P2-168  
**Abstract type:** Poster

### More Patients Were Informed about Transition to End-of-Life Care after an Educative Intervention

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**Background:** Results from the Swedish Register of Palliative Care shows that 45 % of dying patients in Sweden are informed by a doctor about transition to end-of-life care according to their medical records. Since information is an important prerequisite for high quality end-of-life care we wanted to examine if an educational intervention to doctors and nurses could increase the proportion of informed patients.

**Methods:** Two municipalities (in charge of nursing homes and basal home care) and two hospitals in Sweden were randomized to receive an intervention. Doctors and nurses at these places were invited to an interactive half-day education about how and why to inform patients and about transition to end-of-life care, led by palliative medicine and care specialists. The proportion of informed patients before and after the intervention was measured with register data. Register data is collected by a web-based questionnaire answered by health care staff after death of the patient.

**Results:** The proportion of patients who were informed by doctors about transition to end-of-life care increased from 29 % (during a six months period before the intervention) to 39 % (during a six months period after the intervention). In the hospitals the proportion of informed patients increased from 18 % to 33 %, and in the municipalities from 37% to 44%. Further statistical analyses with comparison with matched control hospitals and municipalities that did not receive the intervention will be performed.

**Conclusion:** More dying patients were informed by a doctor about transition to end-of-life care according to their medical records after an educative half-day intervention directed to doctors and nurses working outside the specialized palliative care.

**Funding:** This study was funded by the Swedish Register of Palliative Care, which receives financial support from the executive committee of the National Quality Registries in Sweden and from the Swedish government.

**Abstract number:** P2-169  
**Abstract type:** Poster

### Interpreters in Palliative Care: 'On Speaking Terms-matters of Life and Death'

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**Background:** This development project aims to develop resources to improve the quality of palliative care delivered to people with Limited English Proficiency (LEP). Many patients wish to know their diagnosis or prognosis although many patients do not want to know the full information, preferring to negotiate a gradual disclosure of information—this can be more difficult when a patient has LEP and when communication is via an interpreter. Symptom management, requiring accurate history taking, is also more challenging.

**Objectives:** To identify challenges for specialist palliative care staff in caring for LEP patients/families to improve access and provision of palliative care services.

**Methodology:** Focus group discussions with specialist palliative care staff across hospital/community/IPU services. Caring for patients and families with LEP challenges palliative care practice, for example a need to probe more deeply and get more information on first consultations. Difficult to provide emotional, psychological and social support—no opportunities for unplanned conversations, with patients/family members.

Insufficient information regarding the cultural appropriateness of discussions about death and dying. Variations in understanding, fluency and literacy (patients and family members) require a range of resources and strategies to appropriately address information needs. Distinguishing between informal and formal interactions and appropriate ways to facilitate interpretation, for example using family members/volunteers/ professional interpreters.

Current HSE resources do not meet all current needs. Resources, including technological applications available across a number of platforms, could be developed and impact positively on the high costs of providing interpreters. **Conclusion:** Information from this stage of the project will inform and assist the development of resources for specialist palliative care services and interpreters.

**Abstract number:** P2-170  
**Abstract type:** Poster

### Development of a Strategy for Palliative Care Training in the Republic of Serbia

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**Aims:** A national palliative care (pc) strategy was passed by the government of the Republic of Serbia in 2009 & set out a comprehensive government policy to develop pc in Serbia. In implementing a model of pc it is vital all health professionals are adequately trained. Therefore a comprehensive strategy for pc education was developed, including the provision of in-service education to the multi-disciplinary team.

**Design:** Standardisation & accreditation of education programs is a key part of the national strategy. A team of national & international pc experts met to develop an in-service training program. The development process included reviewing existing curricula, deciding on numbers & cadres to be trained, designing a program which was reviewed by the education & steering committees for the project, including the Ministry of Health, & the finalisation of the program.

**Results:** In-service training is based on courses delivered on 3 levels: Level 1 ensures health workers have foundation knowledge on the principles & philosophy of pc; level 2 training builds on this & level 3 training, provided for a smaller number, includes self-directed learning, clinical placements, clinical supervision & mentorship. Comprehensive Serbian training materials were developed & the courses accredited by the Health Council. To date, 682 doctors, nurses, social workers, physiotherapists & psychologists have been trained at level 1 & 338 at level 2. Level 3 training is due to start late 2012.

**Conclusion:** The development of an accredited national pc training program is challenging but possible. In developing pc in Serbia such programs must train professionals from different levels of care i.e. tertiary, secondary & primary, as well as those working in different specialties alongside pc. In-service training is a vital part of a national pc strategy. **This work is funded by the EU project 'The Development of Palliative Care in the Republic of Serbia' (EuropeAid/129769/C/SER/RS)**

**Abstract number:** P2-171  
**Abstract type:** Poster

### Medicine and the Arts: Using Visual Art to Develop Observation Skills and Empathy in Medical Students

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The integration of medical humanities, including the visual arts into medical curriculum is recognised as a means to enhance patient empathy, improve understanding of whole person care and aid in the construction of personal and professional values. The use of observation skills, in particular identification of key pieces of data, pattern recognition, and interpretation of significance and meaning, can be central to clinical decision-making and appreciation of patients within their own personal context. By following our eyes, feelings and ideas, we are able to gain insight into ways of looking and comprehending that have practical implications far beyond the realm of art.

This presentation will elaborate on collaborations with the Academic Programme Unit at the Ian Potter Museum of Art, Melbourne to develop a visual observation skills and empathy training project aimed at medical students completing a palliative care rotation. The programme aims to improve students' visual literacy and perception of story and narrative through visual cues thus possible raising the quality of their diagnostic and therapeutic skills. In addition it aims to improve social and cognitive skills such as empathetic communication.

The programme is structured around the use of key pieces of art to develop such objective, subjective and narrative analytical skills with students encouraged to explore various interpretations of a piece of art. Subsequent parallels are drawn with clinical case scenarios and observations

(diagnostic and nuanced interactions between patients, carers and medical staff) that patients may have encountered during their palliative care rotations. Connections are made with regards to the medical principles of differential diagnosis, the handling contradictory data and seeking to understand the patients' larger narrative.

Future plans are to expand the programme to larger cohort of students and to introduce ongoing evaluation of the programme.

**Abstract number:** P2-172  
**Abstract type:** Poster

### Coordinate My Care - Changing a Culture Requires Training

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**Aims:** Coordinate My Care (CMC) is a clinical service underpinned by an electronic solution. Its aim is to provide information that can be accessed 24/7 by multiple care providers of end of life care (EOLC) to enable seamless care to take place between the acute and community settings. CMC represents a culture change that requires training. A training program was developed and implemented in London (7.7 million).

**Methods:** The CMC training module has been standardised to include: identification of EOLC patients, how to start discussion around EOLC, consenting, care planning, advance care planning, DNAR and how to use the electronic record. All trainers are specialist palliative care nurses.

London is divided into 5 clusters. A stakeholder event is set up for each cluster to map existing EOLC resources and how CMC can support local services. Clinical Champions are identified in each locality. The CMC team offers 4 training days/100 000 population. Each locality has access to a place on one-day super user training/100 000 for clinicians who will support the sustainability in the locality. Dynamic monthly reporting allows contemporaneous feedback that completes the training cycle.

**Results:**

- 2774 CMC records created.
- Professionals creating records: GP 7%, district nurses 42%, acute 17%, hospice 34%.
- 1200 clinicians trained, 4500 to be trained by April 2013
- The training has been most successful where the trainers have had the benefit of local knowledge. The trainers need to be flexible in how/when the training is offered and to ensure that the training relates to present clinical practice.

**Conclusions:**

- CMC involves a culture change
- Training has to include end of life care skills and knowledge
- Training encourages a pathway of care
- Training emphasises sharing information and trusting other professionals' care plans
- Good practice is identified through dynamic reporting and best practice can then be shared with other localities.

**Abstract number:** P2-173  
**Abstract type:** Poster

### Singing as a Social Force in Changing Living and Dying: The St Christopher's Community Choir

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Over the past decade, there has been an increased interest regarding the impact of singing on people's health and wellbeing. A growing number of studies suggest that singing, especially within group settings (e.g. choirs), can alleviate physical symptoms and be a catalyst not only to emotional, but also social wellbeing (Clift 2001). However, the role of signing within the context end-of-life care and education has not been explored.

The belief that death and dying are social experiences is at the heart of the hospice strategy. Death is not to be hidden, but to be experienced and shared within the communities that people live. St Christopher's has therefore developed a range of initiatives to educate the local community, and promote healthier attitudes towards death and dying (Hartley, 2011).

The St Christopher's Community Choir was founded in June 2010 as part of the hospice's community education initiatives. The choir functions as an open, drop-in group and includes patients, their families and friends, bereaved people, staff and volunteers as well as members of the local community. The choir comprises of more than 60 members and is an important link between hospice and community. Also, the choir's performances both within the hospice and



public places are a powerful medium for introducing the hospice and its work to society in a non-threatening way.

This presentation shows the development of the St Christopher's Community Choir, as well as its role in changing living and dying both within the hospice and the local community.

Clift, S. (2001). The perceived benefits of singing: Findings from preliminary surveys with a university college choral society. *Journal of the Royal Society for the Promotion of Health*, 121(4), 248-256.

Hartley, N. (2011). Letting It Out of the Cage: Death Education and Community Involvement. In S. Conway (Ed.), *Governing Death and Loss - Empowerment, Involvement and Participation* (pp.129-137). Oxford: Oxford University Press.

Abstract number: P2-174

Abstract type: Poster

### Experiences of Introducing Physiotherapy Undergraduate Students to Palliative Care

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**Aims:** Physiotherapy undergraduate clinical education in Australia has typically focussed on the three clinical areas of musculoskeletal, neurological and cardiorespiratory physiotherapy. In recent years this focus has expanded to include areas such as paediatrics, geriatrics, women's health and sports medicine. Although there has been progress in introducing Palliative Care into the physiotherapy undergraduate curriculum at most Australian universities, the opportunities for practical experience are still relatively rare. The aim of this presentation is to describe the experiences of one specialist palliative care service in introducing physiotherapy students to Palliative Care.

**Methods:** In conjunction with one university, clinical placements of five weeks duration have been offered to physiotherapy undergraduate students over the past eleven years. A maximum of three clinical placements have been undertaken each year with a maximum of two students on each placement. Clinical supervision on the placement has been the responsibility of the Senior Palliative Care Physiotherapist, with support from a clinical academic at the university.

**Results:** Anecdotally, the experiences of the university, clinicians and students have been varied, though predominately positive. Unexpected resistance was met initially to the introduction of undergraduate physiotherapy students from within the Palliative Care service, however this has diminished over time. It has also been observed that students earlier in their undergraduate training adapt better to the Palliative Care environment than their more experienced peers.

**Conclusions:** Our experience has been that the introduction of physiotherapy undergraduates to a Palliative Care service is not only possible but rewarding. It is hoped that by introducing students to this clinical area, the future of physiotherapy in Palliative Care will become more secure.

Abstract number: P2-175

Abstract type: Poster

### "Do I Have to Go There?": Supporting Physiotherapists through a Rotation in a Palliative Care Service

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**Aims:** Physiotherapists new to Palliative Care are often apprehensive about working in this clinical area. Their concerns can be quite varied, ranging from fear of doing harm through to frustration with perceived limits in functional gain. The aim of this presentation is to illustrate how physiotherapists have been supported through a four month rotation in a specialist Palliative Care service.

**Methods:** In order to support physiotherapists during their four month rotation, they are provided with a range of formal and informal strategies. Care is taken at the beginning of the rotation to alert the physiotherapists to the range of strategies available. These have included: formal and informal education sessions; case presentations; regular weekly meetings with a senior clinician and observational sessions with other health professionals.

**Results:** Our experience has shown that providing a range of strategies is beneficial to physiotherapists new to working in Palliative Care. Providing such a range allows these physiotherapists the flexibility to tailor a support system that meets their own needs. Feedback obtained anecdotally indicates that physiotherapists feel more confident working in this area as a direct result of the support they receive.

**Conclusions:** The provision of appropriate support systems

to clinicians new to a particular clinical area is given. This presentation illustrates the strategies utilised by one specialist Palliative Care service to support physiotherapists through a four month rotation.

Abstract number: P2-176

Abstract type: Poster

### Working with Teams of Palliative Care in Brazil: Clinical Supervision and Reflective Practice

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The multi-professional team is essential to Palliative Care assistance. However, it is essential to develop supervision meetings, enabling reflective practice and support to health professionals. The aims of this work are: to present an experience of clinical supervision, developed in Brazil; and produce a reflection on clinical supervision and its importance on promoting health and improving the quality of services.

It is a report of structured experience developed through qualitative methodology. It was done: literature's review, and also reading of the notes in the researchers' field diary. Keywords, emerging issues and trends nuclei were builders of the analysis process. Three groups were developed, in the period between Feb.2011 and Sep.2012: with nursing staff, with Mental Health team, and a careers multi-professional task-force. The frequency were weekly or biweekly, lasting about 2 hours each meeting. Supervisors were occupational therapists and psychologist, outside the clinical team. There was weekly supervision of the supervisors. None of the meetings was used for administrative guidance.

It was observed difficulty of professionals perceive themselves as change agents on his clinical work and inside the teamwork. It was also observed a gap in the training of Brazilian professional in Palliative Care. There is difficulty in the construction of clinical reasoning, which distinguishes the subjects in the intervention. There specifics matters of practice in palliative care that can enhance the suffering of professional and team conflicts: non-improvement of the patient, professional's bereavement, workload facing the needs of the patients.

In clinical experience, health professionals are faced with many factors that must be worked on these collective spaces: listening skills, build clinical reasoning, structuring the therapeutic plan. This study reinforces the need for supervision in order to build such reflective practice.

Abstract number: P2-177

Abstract type: Poster

### Development of a Nationwide Curriculum of Palliative Medicine for Undergraduate Education in Serbia

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The number of patients with cancer and other life-limiting diseases continues to increase and as the population increases in age the need for palliative care (PC) increases. In 2009, the Ministry of Health of Serbia, published a national strategy for PC, which acknowledges the PC services to be integrated into the government health system. The strategy proposes PC capacity to increase by means of a comprehensive educational programme, formulation of better policies, increased drug availability and development of PC teams. Key to the development of PC is that of education, for current and future health professionals. The issues is to incorporate palliative medicine (PM) in undergraduate education at 4 medical schools in Serbia (University of Belgrade, Novi Sad, Kragujevac and Nis) with consensus curriculum. The Deans proposed curriculum leaders with appropriate experience in PC and teaching to participate in developing the course (curriculum, syllabus), Handbook, PowerPoint slides and Facilitator's Guide. Medical schools endorsed the documents. The curriculum of elective course of PM is based on recommendations from the European Association of PC, and on the 2003 Council of Europe recommendations on the organisation of PC. The course is developed by key international experts working on the Project "Development of Palliative Care Services in the Republic of Serbia", in conjunction with curriculum leaders. Teaching time allocated is 30 hrs (theory, seminars and

practical) in the 6<sup>th</sup> yr. The syllabus: Basics of PM, Pain and symptom management, Psychosocial and spiritual aspects, Ethical and legal issues and Communication and self-reflection. Assessed through a multiple-choice exam. The aim of the course is to introduce students to the philosophy and practice of PC, enabling them to understand the concepts and develop attitudes, knowledge and skills necessary to participate in effective and compassionate PC. This is the first consensus curriculum in medical schools in Serbia.

Abstract number: P2-178

Abstract type: Poster

### Physician's Palliative Medicine Specialization Curriculum in Czech Republic - The Experience of 10 Years

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The presentation describes the 10 years experience from the points of view: the cooperation with algeziologists, a resistance of other medical specialties and misunderstanding. Czech medical care system has had the new curriculum since the September 2011. And also free standing medical specialty - Palliative Medicine. 13 months for the physicians from several medical fields (minimally 6-7 years of clinical practice). The presentation describes contemporary range of curriculum contents and also the methods of teaching, lecturing and leading.

Abstract number: P2-179

Abstract type: Poster

Abstract withdrawn

Abstract number: P2-180

Abstract type: Poster

### A Living Community Presence: The Development of an Innovative Education Program for Volunteers to Support Patients in the Last Hours or Days of Life

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**Background:** In the UK, the majority of people die in hospital. The last hours of life can be an emotional and anxious time for patients, relatives and staff. Needs can be simple, often just someone to 'be' with patients is enough. Addressing this is a challenge on a busy ward. OPCARE 9, an EU funded project, highlighted the success of volunteer support at the bedside of dying patients in some countries but in the UK volunteering often focuses on fundraising and practical tasks, excluding volunteers from the bedside of the dying.

**Aim:** To develop a training program to enable UK volunteers to provide a 'community presence' to patients and their families when care is supported by the Liverpool Care Pathway for the Dying Patient

**Method:** A bespoke 45 hour training program was developed and piloted with 19 selected volunteers. It was delivered by 2 trainers and invited speakers over 4 full days and 9 evenings. It focussed on enhancing their personal skills and qualities, drawing on their life experiences. It covered familiarization with death and dying, the importance of listening and interacting, the significance of providing appropriate spiritual support and establishing a clear understanding of the role of the volunteer. Each volunteer also accompanied a specialist nurse to observe care given to dying patients in the hospital. Volunteers kept reflective diaries and gave verbal feedback throughout the training. A researcher and 1 trainer analyzed the diaries to identify emergent themes.

**Results:** All 19 volunteers completed the training. Feedback demonstrated that the training was interesting and enjoyable and provided effective preparation for the role. However, the volunteers indicated a preference for full day rather than evening sessions and for emotionally charged sessions to be delivered earlier in the day.

**Conclusion:** The training program developed was positively evaluated by the volunteers who felt that it had prepared them to support dying patients.

## Poster sessions

Abstract number: P2-181  
Abstract type: Poster

### Transforming End of Life Care: Evaluation of a Local 2-day Multidisciplinary Course Developed and Run by a Palliative Care Team for Non-specialist Health Care Professionals Working in an English Inner City Hospital and Community Setting

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**Aims:** With changes in National Health Service structures striving for improved integration between hospital & community services, & implementation of tools to aid End of Life Care (EoLC) in these settings, opportunity arose for a novel & innovative face-to-face teaching package. It aims to equip non-specialists with knowledge and skills to deliver the best possible EoLC. Further details are in abstract A-518-0007-00798.

**Design:** We set up a local bimonthly course for about 30 delegates. Topics cover practical aspects of EoLC including use of specific EoLC pathways & care bundles (eg AMBER & Liverpool Care Pathway), symptom control, syringe drivers, discharge management and bereavement. Delegates completed self assessment forms pre & post course rating their confidence & ability in different skills relating to the provision of end of life care on a numerical scale 1-10.

**Results:** Following 3 courses 88 delegates have attended from a variety of disciplines based in the community & in hospital. Evaluations have been positive with a median post course confidence score of at least 8/10 in all skills (precourse 5-7/10  $p < 0.001$ ). Greatest improvements were seen in understanding the criteria for initiating the AMBER care bundle (mean score 5.57 to 8.8  $p < 0.001$ ), accessing symptom control guidelines (6.06 to 9.16  $p < 0.001$ ) & understanding the rapid discharge process (5.09 to 8.56  $p < 0.001$ ). Narrative data suggest improved mutual appreciation of professional challenges. Word is spreading with delegates encouraging colleagues to attend and local commissioners have made its provision one of our team's targets.

**Conclusion:** Our novel course to aid hospital and community integration, & extend knowledge of EoLC using the nationally recognised tools as leverage, has been well received and feedback confirms its usefulness. We are now collecting data to see if the learning has translated into practice.

Abstract number: P2-182  
Abstract type: Poster

### Attitude towards Pain and Symptom Relief with Possible Life Shortening Effect: Role of Academic Background, Philosophy of Life, Relevant Knowledge and Experience

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**Research aims:** Ethical committees, involved in end-of-life decisions, include professionals with different academic backgrounds. Objective of the analysis was to investigate:

- whether preference for possibly life-shortening pain and symptom relief (PSR) over life-prolonging treatment in patients is predicted by students' academic background, and
- whether other relevant characteristics predict this preference.

**Study design and methods:** In 2012, all 1390 students of the faculties of medicine, law and philosophy at Vrije Universiteit Brussel were invited by e-mail to fill in an online, anonymous questionnaire. Dependent variable in the analyses was preference for PSR in patients even if it could shorten life versus life-prolonging treatment. Independent variables were student's discipline, philosophy of life, knowledge of end-of-life actions, experience with euthanasia or palliative sedation in a relative or friend, and gender. Significant variables ( $\text{Chi}^2 p < 0.05$ ) were included in multivariate logistic regression analysis.

**Results:** 391 completed questionnaires were received. Preference for PSR was significantly related to discipline ( $p = 0.30$ ) - being higher in medicine and philosophy students compared to law students - and philosophy of life ( $p = 0.38$ ). In multivariate logistic regression analysis only philosophy of life remained significantly associated with a preference for PSR, with those with a humanistic life-stance being more likely to prefer SR in patients ( $\text{OR} = 6.39$ ) than Catholics. Statistical power for a medium effect size was 99.9%.

**Conclusion:** Students' preference for PSR in patients over life-prolonging treatment was to some degree predicted by their philosophy of life but not by their academic discipline. Medical students were not favouring life-prolonging

treatment in patients more than law and philosophy students as opposed to the popular belief that physicians are trained to favour life-saving interventions. No funding.

Abstract number: P2-183  
Abstract type: Poster

### Blending Learning into Care through an e Learning Mentor Support Programme

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**Context:** In 2010 an English multiprofessional deanery funded the design and delivery of a blended end of life care e-learning programme in nursing and residential homes with end of life facilitator (EFE) support.

**Aim:** To increase the skills and confidence of 525 care home staff. Over 2 years the programme developed into more than an education programme. It became about changing values, beliefs, attitudes to end of life care as well as palliative care leadership and empowerment.

**Design:** The programme revolves around 6 core end of life care modules and follow up workshop delivered either on line or face to face. Each learner completes a pre and post course confidence questionnaire as well as course evaluation (which their manager also completes). Before the programme starts, during and after the programme an impact assessment/audit of deceased residents notes is carried out to review advance care planning activity. A pre and post benchmarking of end of life tools and policies is also carried out as well as hospital data admission.

**Results:** In 2 years over 800 staff completed the programme. The course is highly evaluated. Achievement of documented preferred place of death has risen from 54% to 77% with actual care home death at 89%. The programme has developed care home quality standards (completion of programme to quality monitoring) as well as an End of Life Champion Train the Trainer programme and domiciliary care agency programme. The programme has been mapped to the national Skills for Care End of Life Qualifications so that care home staff can transfer their learning nationally.

**Conclusion:** Key to the success was to design a flexible blended learning programme which meets the end of life learning and clinical leadership needs of care home staff. Lessons have been learnt as to how to sustain the learning in practice, crucial for ongoing achievement of advance care planning choices and decisions. It is important to share these lessons.

Abstract number: P2-184  
Abstract type: Poster

### Palliative Care Level of Education in Albania

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**Goal:** Presenting detailed information on the level of education on palliative care of health professionals, students of the Medical, Nursing and Social Sciences faculties; the development and extent/availability of this service in the entire country.

**Methodology:** Information collected from palliative care providers in the entire country, the faculty of Medicine, Nursing and Social Sciences on palliative care education, the background of palliative care trainings held in Mary Potter Palliative Care Center - Korça; the levels of information provided, topics included, duration of the activity and their extent.

**Results:** Acquaintance with the palliative care level of education in Albania; in the relevant faculties of the universities; the level of knowledge of health professionals on this service; the quality of the trainings held and their results.

**Conclusions:** Palliative care is a service which needs are increasingly growing for terminally ill cancer patients. The majority of health professionals either lack important information on this regard or it very scarce. 90% of health professionals working in Korca Region have already been trained in our center. All the directors of Public Health Institutions as well as family doctors have attended these trainings and will be on our focus for the future educational programs. In the near future palliative care will be introduced as a separate subject in the Medical, Nursing and Social Sciences Faculties of the Public Universities. It will also become a 1-year post-graduate course for GPs.

Abstract number: P2-185  
Abstract type: Poster

### By the Book: The Impact of a Workbook on Self-directed Learning in Medical Students

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**Aims:** Undergraduate medical education is increasingly focused on experiential learning rather than didactic teaching. Students develop skills in directing their own learning in order to progress.

During fourth-year medical students' attachment in Palliative Care, they were issued with a workbook. This contained exercises on prescribing, nausea and vomiting, opioids, death certification and communication skills. The exercises were designed to consolidate learning from tutorials and clinical experience. The students were encouraged to complete exercises in the workbook however none were compulsory. The value of the workbook in facilitating the students' self-directed learning was assessed by collecting anonymous feedback from the students.

**Methods:** Following their attachment, students were asked to give anonymous feedback on each exercise in the workbook using a numerical scale and free text comments. The students were also asked the extent to which they had used the workbook during the placement and to rate it as a revision aid.

**Results:** Feedback was obtained from 19 students. The majority completed at least some of the exercises in the workbook during their attachment in palliative care. They valued it as a tool to support learning and also rated it highly as a revision aid for exams. They found the sections on prescribing and symptom control most relevant. The exercise on communication skills was considered least useful.

**Conclusion:** Medical students will utilise tools provided to support their self-directed learning, even if these are not compulsory.

Abstract number: P2-186  
Abstract type: Poster

### Improving the Quality of Palliative Care to Patients at Home, through a Programme of Education for General Practitioners

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This project charts the evolution of a programme of palliative care education for General Practitioners (GPs) in a rural area of the UK. The aim was to increase knowledge and confidence in the subjects GPs found most challenging, and so enhance the care they are able to give to patients dying at home.

Initial discussions with GPs in 2005 about their concerns, was followed by a training needs analysis of 43 surgeries via questionnaire. The results of this were incorporated into a training programme which has been modified and refined over the subsequent years, using evaluation of both teaching and learning. The influence of legislation and Government directives has been included to ensure that content is always current, and reflects the recent emphasis on patient's being supported to die at home if they choose.

In total 135 Doctors have attended the course over the eight years it has run. Evaluations show that all participants reported a better understanding of palliative care emergencies, pain control, psychological support, and management of difficult symptoms. Pre and post-confidence questionnaires completed by 15 doctors in 2012 showed that for the majority of doctors, confidence in ability to manage dying patients increased in at least 17/20 aspects.

In conclusion, this course has been successful in addressing many of the needs of GPs in the area to empower them to give evidence-based, up-to-date care to their dying patients. Further evaluation of the enduring nature of this knowledge, and how this has altered the patient experience is needed to help quantify this success, and inform future improvements in the course design.

Abstract number: P2-187  
Abstract type: Poster

### Competence Improvement in Palliative Care in Nursing Homes - A Co-operation between Municipal Health Care and Specialist Health Care in Oslo

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In recent years, over 43% of people dying in Norway end their life in a nursing home. Many seriously ill and terminally ill patients with complex medical conditions are being transferred directly from hospitals to nursing homes. This situation creates many challenges for health care personnel in nursing homes which require an increase in competence to meet these demands. Oslo has approximately 50 nursing homes, many of which employ unskilled health care personnel and also experience a relatively large turnover of staff.

In view of this situation, a Hospice in Oslo started in 2005 to assist nursing homes in order to increase competence levels. The municipality of Oslo started a program in 2011 to elevate knowledge within palliation for nursing home personnel and over 20 nursing homes have participated. In order to succeed with the overall aim of increasing competence levels, this Hospice and the municipality of Oslo have worked together on this program.

**Method:** Competence improvement is achieved by means of study days, lectures, hospital visits and networking. Specialist nurses from the palliative team provide guidance in palliative issues together with bedside teaching for patients with special needs. The palliative team also provides supervision during patients' transition between hospital and nursing homes and provides guidance on specific nursing home resident cases when this is requested. **Results:** Co-operation between specialist health care and municipal health care is essential in order to increase the competence in basic palliation in nursing homes in Oslo. In order to achieve new knowledge, multiple methods of implementation are required.

Our experience and the method used will be presented on a more detailed basis.

**Abstract number:** P2-188

**Abstract type:** Poster

### Job Satisfaction of Nurses in Palliative Care Services

*Turin I.*

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**Background:** Society's reflex question "How can you work at hospice?" prompted me to analyze and better understand the reasons nurses choose to work and stay engaged in Palliative Care Setting.

**Aim:** The aim of the study was to investigate job satisfaction of nurses working in palliative care services, the existing correlation with organisational aspects, and to explore the main motives for nurses choosing to work in the palliative care areas of the medical system.

**Methods:** A mixed method was used: initially, in-depth interviews to understand the phenomena and generate questions for the survey, then, a specially designed questionnaire with 26 items, administered face-to-face to 43 nurses out of 45, working in our Palliative Care services (home care, inpatient, outpatient, both adults and paediatrics).

**Results:** The results show that the most satisfied nurses are those from the in-patient adult service (91,7%) and those that have worked for the organization for more than 5 years (73,9%), that nurses gain the most satisfaction from the positive influence they have on the lives of patients (93,02%), and that the continuity of their work in the organisation is maintained by the institution itself, which creates a sense of purpose, making them feel that their work is important and even indispensable (90,69%). The greatest motivating factors were: the relief of suffering, quality of work, professional and self development, the holistic approach, being part of a multi-disciplined team with potential, the smiles on the patients' faces and personally and professionally identifying with the hospice's mission.

**Conclusions:** The majority of nurses working in our palliative care service are fulfilled in their job. The factors which motivate them are directly linked to how they view their work and can be summarised as "The pleasure of coming to hospice, which is not a job but a calling".

**Abstract number:** P2-189

**Abstract type:** Poster

### Death Anxiety in Palliative Care and Other Health Care Settings

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Nurses from all specialties must deal with the death and dying of patients while also providing support to the

bereaved family. This presents personal and professional challenges and requires the nurse to be comfortable with death and dying. This paper combines findings of a number of research projects undertaken in different clinical specialties, where death anxiety in staff emerged as a significant issue.

**Aims:** The studies all sought to examine levels of fear of death anxiety and coping responses in nurses working in emergency departments, acute care, aged care and palliative care environments.

**Methods:** Most studies used mixed methods and participants were from health care services across Melbourne, Australia. Both quantitative and qualitative data were collected using questionnaires and interviews. In some studies, fear of death anxiety was examined using the 32-item Death Attitude Profile-Revised instrument.

**Results:** Differences were identified between nurse groups for anxiety about death. Aged care and acute care nurses exhibited activities and behaviours which separated and hid the dying from other patients/residents. Palliative care nurses were older and more experienced nurses and reported significantly higher coping skills than for other groups. Coping with families was rated as more difficult than coping with patients. And specific death education was regarded as the most effective intervention. Detailed results from studies will be presented.

**Conclusion:** There are differences between nurses regarding their attitudes to death and dying, depending on their specialisation, which affects clinical care. These studies suggest further work is required to develop and evaluate an intervention designed to support nurses to improve the quality of care provided to dying patients and their families.

**Abstract number:** P2-190

**Abstract type:** Poster

### Trends in Morphine Consumption at Mulago Hospital: Impact of an Integrated Hospital Based Palliative Care Service

*Turyahikayo J.S., Namukwaya E., Leng M., Kivumbi G. Makerere Palliative Care Unit, Department of Medicine, Kampala, Uganda*

**Aim:** To study the trends in morphine consumption in Mulago hospital as an impact of an integrated hospital based palliative care service.

**Methodology:** A retrospective chart review of pharmacy records from 2006-2012 was carried out. This charted the use of oral morphine across Mulago Hospital and the Uganda Cancer Institute.

**Results:** There was a 350% increase in morphine consumption over a 5 year period from 2008 with an average increase of 65 % per year. The results imply a significant difference after the MPCU became operational.

**Discussion:** To increase morphine consumption, it is imperative to target barriers to opioid use. Education and training as well as clinical modeling are all vital to dispel fears and myths of opioid use. This has been achieved in our setting through the creation and implementation of an integrated hospital based palliative care unit. Our next step is the development and implementation of clinical management protocols to support pain and symptom control.

**Abstract number:** P2-191

**Abstract type:** Poster

### Palliative Care in Primary Care

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Palliative care in Argentina it is neither available nor accessible to most patients that need it: it is estimated that only 1-5% of patients that need palliative care can be served adequately. One of the causes is that most palliative care services are in secondary and tertiary level.

In 2012 the Ministry of Health of Argentina decided to initiate large-scale implementation of palliative care through the program REMEDIAR + Redes, a training program for primary care professionals. The project is planned in two stages: faculty training and primary care professionals training.

**Objective:** To evaluate the ability of faculty from different medical schools to teach the basics of palliative care.

**Method:** An on line course, 96 hours length in 3 months. Based on constructivist teaching; 3 facilitators are available online 3 hours, 5 days per week, for both synchronous and asynchronous participation. The content, based on the IAHPC Essential List of Palliative Care Practices is organized in 10 modules, lasting 1 to 2 weeks each one.

Teachers and students will have a 2 days face to face meeting. Knowledge and attitudes are evaluated at the beginning and end of the activity

**Results:** A course for 35 faculties from 21 universities began in September 2012. Preliminary results are: few have

experience in palliative care, only half of the group participates actively, involved participants are interested and motivated, and there is little interaction between students.

**Conclusion:** Specific expertise and trained faculty are needed to teach palliative care in primary care. If the teaching process of primary care professionals is not efficient, necessary changes for proper implementation of palliative care will be delayed.

The Programa Argentino de Medicina Paliativa-Fundacion FEMEBA provides the funds for the study.

**Abstract number:** P2-192

**Abstract type:** Poster

### Developing an App for Medical Students to Revise Palliative Medicine

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**Aims and objectives:** Technology enhanced learning has been shown to be beneficial in both undergraduate and postgraduate settings and the development and use of technology in medical education has increased dramatically in recent years. 4<sup>th</sup> year medical students at the University of Leeds School of Medicine are all provided with an iPhone which is used for learning and assessment. The aim of this study was to design an iPhone app on palliative medicine that could be used to re-enforce learning and in preparation for the end of year Objective Structured Clinical Examination (OSCE) and to study how effective this source of learning was.

**Methods:** The app includes a variety of OSCE station topics including: breaking bad news, pain history and management and prescribing of medication for syringe drivers presented using video clips and text. The app was distributed to 4<sup>th</sup> year students who had completed palliative care teaching as part of the Cancer and Continuing Care Module. A questionnaire previously used to assess student's experience of technology assisted learning was given to students.

**Results:** The contents of the app were easily produced. Video played a large role within the app which is useful as a learning tool. Further qualitative and quantitative data will be presented. The main limitation was the amount of information that could be included within the format of the app.

**Conclusion:** This app is a novel and original source of revision for medical students preparing for their OSCE but also at re-enforcing learning from face-to-face teaching sessions. Apps are portable making them a handy revision and reference tool. However, more research into the use of such apps is required to assess whether new technologies can play a wider role in the education of palliative medicine.

**Abstract number:** P2-193

**Abstract type:** Poster

### Using a Bespoke DVD to Raise Health Care Professionals' Awareness of End of Life Care within the Acute Hospital Setting

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**Aims:** To make a short film to serve as an innovative way of raising awareness of end of life care within a large acute hospital as part of the UK National Dying Matters Awareness week. To use this film as an ongoing educational resource for training health care professionals (HCPs) within the hospital setting.

**Method:** The project team recruited a volunteer film producer. HCPs were invited to participate in the project, being interviewed on camera answering four questions: What small action have you taken to make a big difference in end of life care? What's hard about talking to people leading up to death? When do you think it's the right time to discuss end of life care? Have you thought about what you would want at the end of life?

**Results:** There was a positive response with 11 HCPs agreeing to take part. The participants included a Consultant Neurologist, Clinical Nurse Specialist, physiotherapist, ward sister, health care assistant, hospital chaplains and junior doctors. Over 2 hours of material was edited to a 6 minute film. Since then, 754 hospital staff have seen the film as part of educational end of life care sessions. It has also been shown to the Executives, the Improving Patient Experience Group and other senior managers. Whenever it is used, it generates discussion and interest in the subject.

**Discussions:** Success hinged on the recruitment of a skilled volunteer film producer. However, both the process of

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making the film and the reception it has had with staff since, demonstrates the value of creative film-making as a tool to promote discussion, raise awareness and change practice. **Conclusions:** The aim of the project was to promote awareness around 'dying matters' and this has definitely been achieved. The project team are now considering a sequel, perhaps filming bereaved relatives talking about their experiences of the end of life care provided for their loved ones within the hospital.

### End of Life Care

Abstract number: P2-194

Abstract type: Poster

#### Improving End of Life Care in Somerset Care Homes, Following the Use of the Gold Standards Framework Care Homes Training Programme

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**Aim:** In 2009, Somerset Primary Care Trust and Wyvern Health GP Commissioning Consortium funded GSF training for 64 Care Homes. The first 33 homes started training in June 2009, and their performance was compared with that of all the other Care Homes in Somerset.

**Method:** Data was obtained from Secondary Uses Service, the Exeter system, and the Office for National Statistics. Data on admissions from all 224 Care Homes in Somerset has been analysed, from 2 years before the project started, to 6 months after the final workshop.

**Results/admissions:** Between the start and end of the programme, both groups' admissions reduced. However, admissions reduced by 20.2% in the GSF group, and 10.5% in the non GSF group. The difference between the two groups seems to continue, and comparing the changes from the start of the programme with the final full quarter available, July-September 2010, the GSF group has maintained a reduction in admissions of 20.6%, compared to a reduction of 7.4% in the non GSF group. This represents a possible 29 hospital admissions a quarter saved by that time or 116/year.

**Place of death:** From the start of the project to the last quarter available, deaths in acute hospitals of patients from GSF homes reduced by 5.8% from 18.8% to 13.1%, and from non GSF homes by 3.9% from 32% to 28.1%. The percentage of people dying in their care home rose by 5.8% from 81.1% to 86.9% in GSF homes and by 4.5% from 67.4% to 71.9% in non GSF homes.

**Conclusion:** There was a reduction in acute hospital admissions of 20.6% in homes using GSF, compared to 7.4% in non-GSF homes. The percentage of people dying in their care home rose by 5.8% in GSF homes and by 4.5% in non GSF homes. Deaths in acute hospitals for patients from GSF homes reduced by 5.8% and from non GSF homes by 3.9%. In comparing GSF and non-GSF trained care homes over the same 2 years, the increased benefit of GSF training was apparent, including enabling more to die at home and reducing hospitalisation.

Abstract number: P2-195

Abstract type: Poster

#### Supporting People with an Intellectual Disability and Palliative Care / End of Life Needs in the Community: A Descriptive Survey

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**Background:** Based on the principles of normalisation, inclusion, participation and rights, care provision for persons with intellectual disability changed to a community based model. However contrary to these principles, anecdotal evidence suggests a trend towards a return to institutional care for such persons with end of life needs.

**Aim:** This presentation discusses findings from a study which described the incidence and experience of community nurses working with people with intellectual disability and palliative/end of life needs.

**Method:** A 26 item questionnaire was developed and administered to community nurses employed in one HSE region. Data obtained were coded and inputted into PASW 18. Descriptive analysis were conducted to describe frequencies and association between the variables and content analysis were conducted on qualitative open questions. Ethical approval was granted by the researchers' institution.

**Findings:** Overall a 32% (n=94) response rate was achieved.

Reasons for referral to palliative care included support, therapeutic intervention, assessment and end of life care. Factors impacting on provision of palliative care included nurse's knowledge and experience in intellectual disability or palliative care, previous knowledge of the family and patient, professional skills and attributes and teamwork. The majority (87.2%) of respondents reported requiring education in developing understanding and communicating with persons with intellectual disability and 64.9% requested palliative care education.

**Conclusions and implications:** From the findings it emerges that persons with an intellectual disability are less likely to remain in the community for palliative/end of life care. Significant resource are required to develop this service including education across both intellectual disability and palliative care services.

Abstract number: P2-196

Abstract type: Poster

#### Barriers and Facilitators of Timely Recognition of Palliative Care Needs by the Family Physician: A Qualitative Study

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**Background:** Patients with life-threatening diseases experience various unmet palliative care needs during their disease course. To ensure the best possible quality of life for these patients, their palliative care needs should be recognized and solved timely. Since family physicians play a central role in facilitating coordination and continuity of care they play a pivotal role in the recognition of palliative care needs. Exploring barriers and facilitators in primary practice will help to improve the quality of care and life for these patients.

**Aim:** Using perspectives of family physicians, nurses and patients we explored barriers and facilitators in timely recognizing palliative care needs of patients with life-threatening diseases.

**Methods:** We performed 18 semi structured interviews with patients with cancer, organ failure or dementia, 4 focus groups with family physicians and 2 focus groups with community nurses. All data were recorded, transcribed and thematic analysis of the data set was performed using NVIVO10.

**Findings:** Several barriers emerging in different main actors were identified, of which the most important are that: (1) the physician focuses mainly on acute and physical needs and they lack time to detect all the needs (2) other care givers do not always transfer information about their patients' care needs to the family physician and (3) patients often do not contact their physician in certain phases of the disease and tend to conceal their needs to the physician.

Pro-active communication (e.g. an exchange information book), regular contact and a good relationship with all actors seem to facilitate the recognition of care needs by the physician.

**Conclusion:** Palliative care involves multiple actors and barriers for recognizing care needs can be found in all of them. These findings are a basis to recommend strategies for family physicians and other care givers to handle the barriers in recognizing various palliative care needs in their patients.

Abstract number: P2-197

Abstract type: Poster

#### Exploring the Process of Decision Making between Multi-professional Teams, Patients and Families at End of Life

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While UK strategy supports collaborative community care and patient choice, little is known about how decisions are made between the multi-disciplinary team, patients and families who construct them. The study aimed to identify what happens in the process of decision-making at end of life, contributing understanding of the issues for patients, families and professionals. This paper explores the methodological and ethical challenges of conducting such a study involving a process of interaction with complex groups, and in challenging end of life contexts.

A multiple case study design, n=15, using a qualitative approach was adopted for use in a large NHS Trust in Northern Ireland. The purposively selected cases were

processes of decision making made by patients, families and multi-professional groups, around place of care. Methods included:

1. Non-participant observation of professional decision-making interactions.
2. 5 minute debrief interviews with professionals.
3. Semi-structured individual post decision and contextual interviews.
4. Documentary review of professional notes.

Challenges included:

1. Complex, time consuming research governance process: due to ethical concerns about patient vulnerability and multiple applications to independent, charitable and statutory sectors.
2. Access to participants was improved by an introductory pilot period which facilitated familiarization with the research process, improved professional ownership, identification and recruitment of patients.
3. Researcher credibility and skills in palliative care were beneficial.
4. Capturing real-time observations demanded co-ordination and flexibility. Debriefing supplemented observations where non-planned communications occurred. Balance required between high researcher profile with staff and avoidance of burden.

Real-time, intensive research designs in community palliative care are methodologically feasible but require adequate time and appropriate researcher skills and experience.

Abstract number: P2-198

Abstract type: Poster

#### Do the Different Scales of Performances Correlate with the Duration of Follow-up in Turkish Advanced Cancer Population

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**Aim:** Palliative care is an important aspect of cancer management. There are many defined scales to measure the patients' performances like Edmonton Symptom Assessment Scale (ESAS), Palliative Performance Scale (PPS) and Karnofsky Performance Status Scale (KPS). However, the accuracy and predictability of scales might vary from countries to countries. Therefore, each scale should be evaluated for the validation of any given society. Here, we aimed to evaluate the predictability of some palliative performance scales in Turkish patient population living in a Northern city of Turkey.

**Materials and methods:** One year ago a multidisciplinary palliative therapy study group was formed in our University to evaluate the advanced cancer patients on weekly basis. The study included the patients followed during this period. A printed form was used to evaluate each patient. The form included the patients demographic, social, and disease features and 3 performance scale measurements as well (KPS, ESAS, PPS). Each patient was followed either in outpatient department or by telephone interview on weekly basis. The data was collected retrospectively and analyzed with Pearson correlation test using SPSS 13.0 programme. P value < 0.05 was considered significant.

**Results:** The study included 64 patients with the mean age of 64.9 years  $\pm$  11.6. n: 43 (67.2%) was male and n:21 (32.8%) was female. Patients were followed by 53.7 $\pm$ 50.9 days (mean $\pm$ SD). The duration of follow-up was positively correlated with the scores of KPS and PPS (r: 0.584 and r: 0.567 respectively and p < 0.01 for both), whereas negatively correlated with the scores of ESAS (r: -0.544, p < 0.01). Highly significant correlation between KPS and PPS score was found (r: 0.932, p < 0.01).

**Conclusions:** The performance scale analysis with KPS, PPS and ESAS in palliative care setting of terminal cancer patients well correlate with duration of survival. Either scale can be used effectively in palliative care setting.

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Abstract type: Poster

#### End of Life Care: Creating a Model Regarding Existential Support for Patients and their Families in Specialized Palliative Care

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**Background:** According to WHO's definition of palliative care, the main goal is to improve patients' and their families' quality of life when the patient is facing a life-threatening

illness. Patients and their families often express the need for existential support and a need to talk about life issues.

**Aim:** To offer a patient-centered end of life care that assures all patients the same opportunity to discuss the most important existential issues by creating a new model for offering existential support.

**Method:** In collaboration with specialists of the hospital's research department and members of the clinical staff, a standardized care plan on existential support was created, as well as, a "hands-on" tool containing useful information on existential issues.

**Results:** The care plan includes goals and "to-do-suggestions" at specific occasions, from enrollment to the end of life. It also specifies who holds the responsibility for different forms of existential support. This method offers an individualized support from all members of the multi-professional team, including, when appropriate, external support from representatives of different religious communities.

**Conclusion:** The intention was to improve the quality of care by creating a model for working with existential support. Identifying and alleviating existential suffering is - by the use of a standardized care plan - just as important as diagnosing and relieving physical symptoms for patients in advanced palliative care. Offering each patient the opportunity to talk about end-of-life issues (EOL), might enable a sense of comfort and closure for the patient at the end of life.

**Abstract number:** P2-200

**Abstract type:** Poster

### The Attitude and the Opinion of Physicians about Palliative Care for Terminally - III Cancer Patients

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**Aims:** Palliative care (PC) is defined as "a humanitarian need" by WHO. However, the institution of PC varies among different countries depending on their cultural, social, economic and health policies. The attitude of physicians on the necessity of PC carries of paramount importance in the success during the establishment of PC facilities in Turkey. Therefore, we aimed to evaluate the opinions of physicians dealing with cancer patients on PC.

**Materials and methods:** The study was designed as a cross-sectional and descriptive one and included the physicians dealing with cancer patients primarily in a provincial state hospital. A questionnaire with 46 items corresponding the socio-demographic features of the physicians and the opinions about the PC was prepared. The questionnaire was delivered to the physicians. The completed questionnaires were returned back and the data was analyzed with Chi-square test using SPSS 18.0. Statistical significance was considered at  $p < 0.05$ .

**Results:** 86 physicians out of 115 (74.8%) completed and returned the questionnaires. 68.6% was male with the mean age of  $37.9 \pm 8.5$ . 15.1% of physicians experienced cancer in their first-degree relatives. Only 33.7% had palliative care education during their trainings. While 82.6% of physicians treat patients with PC need, only 15.1% thinks PC service is available in the hospital. 62.8% thinks the most important symptom is pain and 66.3% believes that the aim should be the improvement of quality of life of patient and families. 60.5% are willing to enter an education program dealing with PC.

**Conclusions:** Although the majority of physicians treat patients with PC need, only one-third has the relevant information. Since many of the physicians would like to get informed, a multidisciplinary educational program might improve the quality of service provided by physicians to terminal cancer patients.

**Keywords:** Palliative care, physicians, attitude and opinion.

**Abstract number:** P2-201

**Abstract type:** Poster

### Imminence of Death among a National Cohort of Hospital Patients in Scotland

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**Background:** There is growing interest in policies to promote end of life care in hospital settings. Some attempts have been made to estimate the numbers of hospital patients that might be in need of palliative care, but there is little understanding of what portion of the hospital population is in the last stages of life - and therefore of how best hospital services can be oriented to end of life needs.

**Aim:** To establish in one jurisdiction (Scotland) the likelihood of death within 12 months, of all patients in hospital on a given census date.

**Design:** Record linkage study of patients in all 25 of Scotland's teaching and large general hospitals on the night of 31 March 2010.

**Results:** We identified 10,743 hospital inpatients on the census night, of whom 3,098 (28.8%) died within the next 12 months. 1,001 patients (9.3%) died during the recorded period of admission which accounted for 32.3% of all deaths within one year. We established how many had died at 7 days (2.9%); 30 days (8.9%); 3 months (16%); 6 months (21.2%); 9 months (25.5%) and 12 months (28.8%).

Propensity to die was closely related to age and also to gender: men of all ages were more likely to die within 12 months than women (30.4% vs. 27.5% -  $p=0.001$ ); and between the ages of 60 (22.6%) and 85 (45.6%) each increase of 5 years in admission age was equivalent to 4.2% higher risk of death ( $R^2 = 0.95$ ). The most deprived patients were twice as likely to be admitted (SIMD09 Q1: 2,936, Q5: 1,515) but were not more likely to die (Q1: 29.8%, Q5: 28.0%  $p = 0.215$ ).

**Conclusion:** We are not aware of any other study of this kind, since the required record linkage is not readily available. The data indicate the large numbers of patients nearing the end of life that are in the hospital in-patient system at any one time. Such data could assist in advocacy for these patients and should influence end of life care strategies in hospital.

**Abstract number:** P2-202

**Abstract type:** Poster

### A National Survey Exploring Views and Experience of Health Professionals about Transferring Patients from Critical Care Home to Die

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**Background:** Progress has been made towards enabling patients to die in their preferred place of care. However, it is not clear how this might apply in the context of those dying in critical care. The aim of the study was to determine experience of, and attitudes towards, transferring critical care patients home to die by conducting a national survey targeting critical care staff.

**Methods:** An online survey was developed informed by the literature and analysis of six focus groups with Health Care Professionals (HCPs) from critical care units, primary care and patient representatives to assess 1) experience and 2) views. The lead consultant and lead nurse of 409 critical care units in the UK were invited, by e-mail, to take part.

**Results:** A total of 180 HCPs completed the online survey (response rate 24%). Around a third (36.1%) of respondents reported experience with transferring a patient home to die. The majority (89%) of respondents agreed with the statement that transferring patients home to die is a good idea in principle, while 36% agreed that it would be unethical to prolong a patient's life to facilitate a transfer. 82% agreed that transfer is important as patients should be able to die in their preferred place of death. Thirteen percent agreed that a transfer was not worth the risk of dying in the ambulance whereas 27% responded 'neutral' to this statement. Statistically significant differences for some views were found for physicians and nurses, as well as differences between those who had transferred a patient home and those who had not.

**Discussion:** This study is the first to explore views of health care professionals about transferring patients from critical care home to die. Respondents' views were generally positive, particularly about honouring preferred place of death but reservations were expressed in terms of ethical concerns and the risk of dying on route to home. Views varied according to profession and previous experience.

**Abstract number:** P2-203

**Abstract type:** Poster

### Barriers and Facilitators for General Practitioners to Engage in Advance Care Planning: A Systematic Review

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**Background:** It has been widely acknowledged that general practitioners (GPs) are well placed to actively initiate the process of advance care planning (ACP). Although both patients and physicians support the idea of ACP, the prevalence of ACP discussions remains low.

**Objectives:** The objective of this systematic literature review is to identify the factors that hinder or facilitate GPs to engage in ACP discussions with their patients about care at the end of life.

**Methods:** Four electronic databases (PubMed, CINAHL, EMBASE, PsycINFO) were searched for studies published from 1990 to 2011. Further relevant studies were identified by contacting first authors of included studies, known experts in the field, searching through relevant journals and reference lists.

**Results:** Eight qualitative studies (semi-structured interviews and focus groups) and eight quantitative studies (cross-sectional studies) were included. All identified barriers and facilitators were categorized as GP characteristics, perceived patients factors or health care system characteristics. Stronger evidence was found for following barriers: lack of skills to deal with patients' vague requests (GP characteristics), difficulties with defining the right moment (GP characteristics), the attitude that patients should initiate discussions (GP characteristics), fear of depriving patients hope (perceived patient factors). Stronger evidence was found for following facilitators: gathered skills (GP characteristics), foreseeing problems in the future (GP characteristics), skills to deal with patients initiating discussions (GP characteristics), personal convictions about who to involve in ACP discussions (perceived patient factors), a longstanding patient-GP relationship (health care system characteristics).

**Conclusion:** Initiation of ACP in general practice can mainly be improved by targeting GP-related barriers and facilitators, but changes in health care systems factors may also be required.

**Abstract number:** P2-204

**Abstract type:** Poster

### Primary Palliative Care for People with Intellectual Disabilities; A World to Win!

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**Aims:** To explore size and content, developments and barriers in the palliative care for people with intellectual disabilities (ID's) living in primary care.

**Methods:** The project contained of an epidemiological exploration, individual and focus group interviews and an expert meeting.

**Results:** The registration, concerning people with ID and concerning palliative care for them is ambiguous or non-existing. The (focusgroup) interviews revealed 4 main themes in which there is care and/or policy, but very often hindered by all kinds of obstacles. The themes and subthemes are:

- \* client is the leading person: communication with the client, optimizing the participation in the care process, defining someone who is in control;
- \* connection between practice and policy: vision as a starting point, financial requirements are necessary, sharing and distributing care between several health care providers is not that easy;
- \* multidisciplinary arrangements; necessary but often missing, integration of the worlds of the care for people with ID and palliative care, special attention for transitions in care;
- \* dimensions in palliative care: proactive care is urgently needed, fulfilling the needs on all four dimensions of palliative care.

**Conclusion:** Care providers often try as hard as they can. They don't know the way, don't know each other and find it difficult to integrate the two worlds. Respondents indicate three main topics for research and practice improvement in the near future:

- \* early identification of the person with ID in need of palliative care;
  - \* improvement of the organisation of care, including transfers
  - \* the client perspective is leading
- A WORLD TO WIN!

Abstract number: P2-205  
Abstract type: Poster

## Continuous Subcutaneous Infusions - Are We Certain Patients Are Receiving the Treatment We Prescribe?

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**Introduction:** Continuous subcutaneous infusions (CSCI) are commonly used to maintain symptom control in the UK once the oral route is no longer available. There are over 15,000 potential combinations of drugs that can be administered via CSCI. In 2006, a national survey of UK practice identified a list of drug combinations that were administered via CSCI. The authors of this work concluded that compatibility and stability data were available for less than half of the most frequently used combinations. In 2010, analysis of an in-house CSCI database identified the ten most frequently used combinations of drugs. The current availability of CSCI compatibility and stability data to support local practice is unknown.

**Aim:** To identify the chemical compatibility and stability of locally used frequent combinations of drugs administered via CSCI.

**Method:** A literature review was performed to identify chemical stability and compatibility data for combinations of drugs that may be administered via CSCI. The results of the literature review were compared to the list of frequently used combinations identified from the in-house database.

**Results:** A total of 68 combinations have reported chemical compatibility and/or stability data. Ninety per cent refer to two-drug combinations, with only 10% applicable to three-drug combinations; there were no reports for four or more drug combinations. Chemical compatibility and stability data are available for only 33% of the identified frequently used combinations.

**Conclusion:** In order to ensure high quality, safe and effective therapy, studies reporting on the chemical compatibility and stability of commonly used drug combinations administered via CSCI are urgently required.

Abstract number: P2-206  
Abstract type: Poster

## Using Data from COUINS to Inform Innovation that Drives up and Sustains Quality in End of Life Care across Healthcare Boundaries

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In the UK, the Commissioning for Quality and Innovation (CQUIN) framework allows Trusts to define standards and measure the quality of care provided in a standardised format against specific targets. Such data helps to highlight gaps in care provision, and encourages Trusts to develop robust action plans to improve the quality of care. Currently 54% of patients die in an Acute Hospital. One CQUIN target in an Acute Trust in NW England is that 70% of patients known to the Hospital Specialist Palliative Care Team (HSPCT) are transferred to their preferred place of care (PPC). Routinely collected data can be used to explore preferred place of care outcomes for palliative care patients. As part of the HSPCT routine data collection, CQUIN reports are produced and analysed monthly. This presentation reports on the data collected over a period of 11 months (April 2011 - February 2012). 714 patients were reviewed. Of those 498 (69.75%) did achieve their PPC, which means that the target was met. An analysis of those 30% where the target was not met revealed two main reasons: - patients were discharged from the HSPCT back to the Treating Team prior to discharge from hospital or they deteriorated and died in the hospital. More work is needed to improve the outcomes for the 30% of patients who did not achieve their PPC. The HSPCT is working with the National End of Life Care Team and Marie Curie Cancer Care to undertake 3 innovative projects; As one of 4 pilot sites completing an audit of deaths in hospital (QIPP KPI 2) As one of 25 pilot sites in the National TRANSFORM Programme. A partnership programme with Marie Curie Cancer Care, working across boundaries to improve discharge planning. All of the projects involve investment in personnel and service provision, increased education and training of all grades of staff, improved documentation, structures and processes across sectors to improve the patient experience and enhance the Trust's reputation both locally and nationally.

Abstract number: P2-207  
Abstract type: Poster

## Abstract withdrawn

Abstract number: P2-208  
Abstract type: Poster

## Place of Death Is Associated with Holiday Periods: Implications for End of Life Care

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**Background:** Mortality was found to be associated with specific holiday periods. However, no study has investigated whether similar link exists in place of death (PoD), which is important for effective service planning and service organisation at the end of life care.

**Aims and objectives:** To explore the association between PoD and holiday periods.

**Study design and methods:** A whole population observational study design, using all deaths in 2001-2010 in England extracted from the National Death Registration Database. PoD was described as percentage of deaths in individual locations (Hospital, non-hospital communal establishments, home, and elsewhere). The independent association between holiday period (including three days before and after Christmas, New Year and Easter period) and place of death was evaluated using log-binomial model, adjusting for confounding factors (age, gender, year of death, marital status, region and index of multiple deprivation) and clustering effect within geographical unit.

**Results:** A total of 4,567,639 death records was analysed, of which 2.2% died in Christmas, 1.4% in New Year, 1.9% in Easter, and 94.5% in normal period. Hospital deaths accounted for 57.6% of all deaths, followed by non-hospital communal establishments (22.2%) and home (19.0%). Compared with the normal period and hospital death, patients are more likely to die in home during New Year (Adjusted proportion ratio (APR): 1.03; 95%CI: 1.01-1.04) and Christmas (APR: 1.02; 1.01-1.03), and slightly lower chance of home death during Easter (APR: 0.97; 0.97-1.00); deaths in non-hospital communal establishments are more likely in Christmas (APR: 1.02; 1.01-1.03), and less likely in New Year or Easter periods (APR: 0.98; 0.97-1.00).

**Conclusions:** Place of death did vary by holiday periods. Christmas has consistent lower chance of deaths in hospital. Healthcare organisations may need to take into consideration of the holiday effects[1] on PoD when planning and deliver end of life care service.

Abstract number: P2-209  
Abstract type: Poster

## The Hospice Friendly Hospitals Programme in Ireland

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**Background:** The Hospice Friendly Hospitals (HFH) Programme in Ireland is a multi centre intervention to develop end of life care capacity, advocate for patients and families and create systems level change in the delivery of hospital care at the end of life. The programme has been developed and supported within the Irish Hospice Foundation (IHF).

**Aim:** To construct a narrative history of HFH in its first five years (2007-12) drawing conclusions to influence its future development and sustainability.

**Design:** Documentary analysis of programme documents, reports, minutes of meetings, media outputs, promotional and educational materials; qualitative interviews with HFH staff and stakeholders (n=42); field and ethnographic observations.

**Results:** We identified key milestones in the development of HFH from as early as 1996, to 2012. The programme consisted of four main components: design and dignity/the physical environment; communication/competence and compassion; integrated care/planning and co-ordination; patient autonomy/an ethical approach. Major contributions were made in the production of standards for end of life care in hospitals and in a baseline 'audit' of end of life care in Irish hospitals. Total funding in 2007-12 was c10m Euros.

**Conclusion:** HFH is an ambitious, multi-faceted programme that has involved over 40 acute and community hospitals and has developed in partnership with the Health Service Executive. Whilst elements of the four programme components struggled to achieve impact, significant successes occurred in the roll out of communications training, in standards development, in the use of symbolic

resources at ward level and in aspects of the audit. The programme now moves into a phase of more limited funding, when it will seek to 'mainstream' its activities within the participating hospitals - aiming at achieving sustainable impact.

Abstract number: P2-210  
Abstract type: Poster

## The Knowledge and Barriers of the Advanced Cancer Patient Signed Advanced Directives in Taiwan - A Nationwide Survey of the Public, Physicians and Nurses

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**Research aims:** The Natural Death Act has been legalized for ten years in Taiwan. The aim of research was to find the relative important predictors of pre-signed advanced directives by advance care planning (ACP).

**Study design and methods:** This study used the triangulation method to collect quantity and quantitative data based on general population, cancer patients and families, medical staff. After twenty sessions of focus groups, to comprehensive interview with participants by random sampling from multi-centers. And then we made a cross-sectional questionnaire survey from 18 medical centers or local hospitals, using unequal proportion two-stage system random sampling. A total numbers of 1,613 participators who met the criteria and were analyzed.

**Results:**

- 1) The fewer patients that are informed of the terminal illness, the worse their families feel about revealing the disease.
- 2) For the behavior intention of provide or sign an advanced directives, the effective predictors explain 30.7%-60.3% of variances. In addition to patients' families, medical staff, general public and patients who have greater knowledge of cardiopulmonary resuscitation (CPR), choosing life quality rather than survival time for end of life therapy, and having positive attitude by himself/ herself about signing an advanced directives, will intend to discuss or sign the advanced directives.
- 3) For the behavior intention of provide or accept for hospice care. The predictors accounted for 24.5-43.8% of total explained variance.

**Conclusions:** The research result will provide these obstacles and design different strategy as educational practice materials for constructing a social-cultural model for end-of-life care that will respect concepts of Chinese filial piety. This model could also be developed as a reference for ACP clinical practice guideline. (Research funding from Bureau of Health Promotion, Department of Health, Taiwan)

Abstract number: P2-211  
Abstract type: Poster

## Place of Death after Stroke - Views of Health Care Professionals on an Acute Stroke Unit

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**Introduction:** Stroke is the third commonest cause of death in the United Kingdom (UK) and causes significant symptoms and disability. In the UK, acute stroke care occurs in hospital. Previous research suggests that most stroke patients die in hospital; families appreciate stroke unit expertise and rarely consider that patients could die at home.

**Aims:** To determine what healthcare professionals (HCP) on a stroke unit believe constitutes good end of life care and if barriers exist to its implementation.

**Method:** 15 HCP from an acute stroke unit were purposively sampled. Semi-structured interviews were undertaken to examine specific care domains, including place of care. Interviews were recorded, transcribed and analysed using framework analysis.

**Results:** Participants believed it is important for dying patients and their families to have privacy, a comfortable and dignified environment and not to be moved between

wards. HCP reported requests from families for patients to die at home were rare and believed patients were often too poorly to travel home. HCP had experience of getting patients with other diagnoses home to die. Perceived barriers to discharge include lack of family support, absence of community nasogastric feeding and delays in funding, commencement of care and delivery of equipment.

**Conclusions:** Families and patients rarely request discharge home to die. Reasons may include: patient/family choice, impaired capacity, cognition and communication, rapid deterioration, prognostic difficulties, families' expectations, lack of family, delay in delivery of equipment or package of care, unawareness that patients could die at home.

**Recommendations:**

Further research into preferred place of care/death after stroke

Encourage patients with capacity to discuss place of care

Discuss dying patients care at multidisciplinary meetings

Facilitate patient communication

Improve links with primary care, social care, community

palliative care and volunteer organisations

**Abstract number:** P2-212

**Abstract type:** Poster

### Multidisciplinary Management of Patients near the End of Life Could Be Better

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**Aims:** Recent guidance from the Liverpool Care Pathway for the Dying Patient (LCP) in the United Kingdom states that the diagnosis of dying and the implementation of the LCP should be a multidisciplinary process. We set out to determine how well this was done.

**Methods:** The care of all patients who died over a six-week period, on ten medical wards (253 beds), was studied retrospectively. Deaths were identified through the bereavement centre. Case notes were reviewed. One doctor, nurse and therapist from the MDT caring for each patient were then questioned.

**Results:** Three of the 48 deaths identified were excluded as these occurred only hours after transfer to the wards; therefore not all MDT were aware of them. 84% of nurses, 68% of therapists and 49% of doctors approached had received formal training in recognising dying patients. All concurred that 32 of 45 deaths (71%) were not unexpected. Where surprise was expressed about a death; for doctors and nurses this was noted more in the cohort of trained staff. All doctors felt involved in decision-making, despite receiving relatively less formal training. In contrast, many nurses (56%) and therapists (45%) reported feeling that their opinions were under-valued. Occasionally, non-medical staff themselves felt that their opinion was not necessary. Opinions were varied as to whether and when the LCP should have been started. 33 (69%) of patients were on the LCP at the time of death. Only five patients had the capacity to participate in discussions. Of them, two had been awaiting a home care package, one had been awaiting transfer to hospice and two had chosen to die in hospital.

**Conclusion:** Not all MDT members are consistently included in LCP decisions. Many deaths are not unexpected and therefore good end-of-life care can be prepared for. More patients might have the opportunity to participate in decision-making before they deteriorate if MDTs could work better together.

**Abstract number:** P2-213

**Abstract type:** Poster

### Diagnosing Dying: A Systematic Review of the Literature

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**Aims:** This paper is a report of a systematic literature review to identify how patients are judged by clinicians as being in the final hours or days of life. The aim of this review was to address:

- How do clinicians diagnose dying?
- What factors influence clinical decision-making?
- What criteria have been identified as integral to conferring a diagnosis of dying?

• Can any related tools, triggers or guidance for clinicians be sourced?

**Methods:** A systematic literature review to synthesise the available evidence about diagnosing dying. We carried out a search using multiple electronic databases and hand searched key texts to find suitable systematic reviews and primary quantitative and qualitative papers for review. The following data bases were searched: the Cochrane Central Register of Controlled Trials (CENTRAL) on *The Cochrane Library*, MEDLINE (1950 to 2011), EMBASE (1980 to 2011), PsycINFO (1980 to 2011), CINAHL (1982 to 2011), Web of Science (- 2011). The search yielded a total of 2073 hits, 331 titles and abstracts were screened, 42 papers were retrieved and reviewed and 24 articles were included.

**Results:** The review team have extracted data and quality appraised the 24 included papers. This analysis is on-going and definitive results will be available to present by the time of the conference. Initial analysis reveals; evidence of significant psychosocial and physical characteristics which indicate dying is imminent; decision making around diagnosing dying remains focussed towards cure orientated treatments rather than systematic planning for end of life care and inequities exist in the care of dying patients particularly amongst those dying from non-cancer related deaths.

**Conclusions:** There remain issues around diagnosing dying and the evidence suggests this impacts on decision making and care at the end of life.

**Abstract number:** P2-214

**Abstract type:** Poster

### Interventions Dying Care and Spiritual Support in Nursing Care for Patients Suffering From Death Anxiety in the Final Phase of Life

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**Research aims:** Death anxiety causes distress in patients. Dying Care and Spiritual Support belong to suggested nursing interventions for problem resolution. The aim was to find out which activities of the NIC Dying Care and Spiritual Support interventions are performed by Czech nurses in patients with death anxiety in the final stage of life.

**Study design and methods:** Quantitative research, structured questionnaire using Likert scale. Variables: type, workplace, nurses' religious belief. A group of 468 nurses, 43.7% believers, workplace: hospice, oncology, geriatrics, Institute for long-term patients, Home for the Elderly, Home care. Statistical analysis: chi-squared test using Bonferroni correction, Mann-Whitney and Kruskal-Wallis tests.

**Results:** In Dying care interventions, nurses always performed: Assist with basic care, as needed (79.5%), Monitor pain (79.3%) and Provide frequent rest periods (71.6%), regardless of workplace ( $p > 0.05$ ). There was a significant relation in Support the family's efforts to remain at the bedside (48.7%;  $p = 0.011$ ), Facilitate obtaining spiritual support for patient and family (34.8%;  $p < 0.0001$ ) and Modify the environment, based on patient's needs and desires (27.4%;  $p < 0.0001$ ). These were reported mostly by nurses in hospices.

From Spiritual Support, nurses often performed Treat individual with dignity and respect (83.5%), Assure individual that nurse will be available to support individual in times of suffering (55.3%), regardless of workplace or faith. The activity Be available to listen to individual's feelings (50.0%) was dependent on the workplace (hospices;  $p = 0.042$ ) and faith ( $p = 0.007$ ).

**Conclusion:** Czech nurses see great importance in caring for biological needs. Dignity is appreciated as a cover value of spiritual support in a wider existential dimension. Activities of nurses in hospices are based on the concept of accompaniment. Supported by IGA UP grant (No FZV\_2012\_003) and grant ESF CZ.1.07/2.2.00/28.0181.

**Abstract number:** P2-215

**Abstract type:** Poster

### Trajectory and Determinants of the Caregiving Burden of Family Caregivers of Terminally Ill Cancer Patients in Taiwan

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**Aims:** The various kinds of caregiving works tasks may increase the caregiving burden. The effect of caring for a dying cancer patient on caregiving burden has been explored primarily with small sample sizes or short-term follow-ups in western countries, but has not yet been investigated in Taiwan. The purposes of this study were identify the trajectory of the caregiving burden of family caregivers (FCs) of terminally ill cancer patients in Taiwan,

and investigate the determinants of the caregiving burden of FCs, in a large sample and with longer follow-ups.

**Methods:** This longitudinal survey study was conducted with 226 FCs who had a relative with terminal stage cancer. The Caregiver Reaction Assessment (CRA), the Symptom Distress Scale (SDS), the Senses of Coherence (SOC), the MOS Social Support Survey (MOS-SSS) were administered during follow-up until the time of patient's death. This study initially analyzed the proximity in time to the patient's death as a continuous variable to assess its association with the CRA scores, using a generalized estimation equation (GEE).

**Results:** The study shows showed that the caregiving burden of caregivers did not increase significantly as the patient's death approached. Time of death came closer, the results indicated that this deterioration of a caregiving burden reflects the patient's increasing symptom distress ( $\beta = 0.11$ ,  $p = 0.05$ ), high intensity of total assistance in caregiving ( $\beta = 0.44$ ,  $p = 0.0001$ ), the gradual loss of confidence in caregiving ( $\beta = 0.60$ ,  $p = 0.003$ ), the financial difficulty of FCs ( $\beta = 3.81$ ,  $p = 0.03$ ), lower social support ( $\beta = 0.16$ ,  $p < 0.0001$ ) and weak SOC ( $\beta = 0.13$ ,  $p = 0.01$ ).

**Conclusion:** Caregiving burden was a non-significant change from the time of the patient's death in Taiwan. This study contributes to the family caregiving literature by using longitudinal data to confirm that the confidence in caregiving, social support, and psychological recourse are important predictors of caregiving burden.

**Abstract number:** P2-216

**Abstract type:** Poster

### Reversing the Irreversible: Antibiotic Prescribing in the Last Week of Life?

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**Aims:** To examine the prescribing pattern of systemic antibiotics in the last week of life within a network of Specialist Palliative Care Inpatient Units in the United Kingdom.

**Methods:** A retrospective review of 20 consecutive deaths from five separate Specialist Palliative Care Inpatient Units over a defined period of time in 2012. Patient records were analysed and the use of systemic antibacterials was recorded within the last week of life, last 48 hours of life and at the point of death. Indication, aim of treatment, route of administration and prescriber details were all recorded.

**Results:** A total of 99 patient records were reviewed and analysed. Over a third of patients (38%) in the last week of life, a fifth of patients (21%) in the last 48 hours of life and a modest number of patients (7%) at the point of death were on antibacterial therapy. Reversing sepsis (66%) and symptom control (42%) accounted for the commonest aims of antibacterial therapy. Interestingly both patient (21%) and family wishes (10%) were also important aims of treatment. The route of administration of therapy consisted of oral (76%), enteral tube (5%) and intravenous delivery (26%). A time limited trial of antibacterial therapy was recorded in only 45% of cases.

**Conclusion:** This study reveals that a significant number of patients within a hospice setting receive antibiotic therapy at the end of life, with the most common stated aim of treatment to reverse sepsis. Firstly this suggests that the prescribers do not view antibacterial therapy as an aggressive modality of care, which may be influenced by both patient and family wishes. Secondly, the perception that sepsis is reversible may be unrealistic and suggests diagnosing death remains difficult. A prospective study will be undertaken by the authors, including qualitative research methods, to explore further the prescribing pattern of antibiotics at the end of life.

**Abstract number:** P2-217

**Abstract type:** Poster

### An Update on Use of Opioids in Terminal Patients and Survival

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**Background:** Opioids are drug frequently used in palliative care. However, a common thought among some physicians is that those drugs hasten of death. Few studies have addressed the relationship between survival and of opioids use. The aim of the present work was to thoroughly review published data on this issue.

**Methods:** We reviewed all studies about the effect of opioids use on survival from 1987 to 2012. Methods

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included database searching (Pubmed, MEDLINE), snowballing, specialized books and personal contact with physicians in palliative care.

**Results:** Eight studies fulfilled the inclusion criteria: five retrospective, one prospective and two cohorts, one of them multicenter. These papers were designed with the aim to assess the impact on survival of opioid use in hospice. In these studies there was no statistically significant difference between the survival of patients with high doses of opioids or dose increases during the last days of life. In addition there was no difference between applying double dose and risk of decreased survival.

**Conclusion:** It has not been demonstrated that opioids used to treat symptoms in terminal patients shorten the survival

**Abstract number:** P2-218

**Abstract type:** Poster

### **ATLANTES Research Program: "Human Dignity, Advanced Illness and Palliative Care". A Project within the Institute for Culture and Society (ICS) of the University of Navarra**

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**Background:** Late stage illness and the prospect of death raise profound questions within modern culture. Palliative care is one response to such concerns in the form of advanced medicine for end-of-life care. In 2012 the Institute for Culture and Society (ICS) embarked upon the ATLANTES Research Program.

**Aim:** To improve scientific and public understanding of the work of palliative care. The overall objective of this five-year program is to promote in society a positive attitude toward the care of patients with advanced, irreversible illness, from a perspective based on the dignity of the person and the role of medicine.

**Method:** ATLANTES will adopt perspectives from history, psychology, sociology and anthropology to illuminate the understanding of palliative care. It will also encompass contributions from public health, geography, communication studies and education.

**Results:** ATLANTES will promote reflection on fundamental aspects of palliative care as well as the implementation of strategies to promote it at institutional, professional and societal levels. Among its sub-projects will be a study of the intangibles in the interaction between palliative care and the individual; the anthropological and spiritual foundation of palliative care; a ranking of the development (and an associated Atlas) of palliative care in Europe and Latin America; education in palliative medicine, a workshop on "The message of palliative care" and a "Think Tank" on ethics and advanced illness.

**Conclusion:** ATLANTES will approach these issues in a manner consistent with the work of an academic institution: scientific investigation, professional training and dissemination of the knowledge acquired. This will be done in ways which are consistent with the institutional characteristics and Christian perspective of the University of Navarra, and with a clear willingness to co-operate with other institutions that work for similar objectives, as well as those who may adopt differing perspectives.

**Abstract number:** P2-219

**Abstract type:** Poster

### **Czech Public Awareness about Palliative Care**

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**Introduction:** The topic of palliative care is not yet in the Czech Republic sufficiently discussed. The research try to attempt to identify current levels of awareness of palliative care within the Czech population.

**Aims:** The research aimed to identify what are the current levels of knowledge of palliative care and what factors contribute to this knowledge. It also asked a number of additional questions relating to who respondents think should receive palliative care, what they think palliative care should consist of, when they would want information on palliative care and whether respondents feel that in the Czech society there is sufficient discussion of issues surrounding death and dying.

**Methods:** The research was carried out through a postal survey. 2 000 individuals in Czech were identified at random from the phone book. To ensure geographical representation stratified random sampling was used. In total, 785 responses were received.

**Results:** Overall the majority of respondents reported some knowledge of palliative care, with under a third reporting no

knowledge. Only a very small number of respondents reported a high level of knowledge of palliative care. The vast majority of respondents feel that palliative care should be offered to all those who have terminal illnesses. The majority of respondents cited pain relief as important in end of life care with many stating this as their first, most important service. The second most common service requested for end of life care was family support, including respite services, support services and someone for family to talk to. Respect or dignity were also commonly cited. More than half of respondents stating that we do not discuss death and dying enough.

**Conclusion:** The survey findings confirm many of the existing views and policies within palliative care and point to possible directions and challenges for future development.

**Abstract number:** P2-220

**Abstract type:** Poster

### **What Kind of Palliative Support Do Nursing Professionals Need in Different Hospital? A Study about End of Life Care in Acute Hospital Settings Using PASKAL Questionnaire**

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**Background:** In Germany the majority of palliative patients spend time in hospital in the final year, and nearly 50% die in hospital. Due to the German system with different types of hospitals there are differences in the structural and process quality in End of Life Care. The range of difference and improvability up to now remains unclear due to a missing valid measuring instrument.

**Objectives:** The aim of this study is to create a valid instrument which is able to measure the palliative skills of nursing professionals and the conditions of dying in hospital. PASKAL questionnaire will provide a possibility to identify local strengths and weaknesses and the kind of palliative support needed.

**Methods:** The study is designed as a quantitative, descriptive survey based on a questionnaire which consists of 48 items. For the pretesting a teaching hospital (TH) and general hospital (GH) were chosen. The questionnaire was addressed to all nurses of different wards including the intensive care units.

**Results:** The questionnaire was addressed to 1005 nurses (790 TH; 215 GH). 170 questionnaires returned, 16.3% of the TH and 19% of the GH. Beside of major factors in both sites such as the need of inpatient palliative care, the lack of resources including time, staff and suitable room and inadequate and medical and nursing interventions which are seen as an additional burden for the patient there were many differences in knowledge and skills about end of life care. Especially in general hospital there seems to be a lack of training and teaching in palliative skills.

**Conclusion:** In conclusion our pretest shows that there's a special need for structured training in the Care of the Dying, supplemented by a guideline-based support. With the validation of the questionnaire we will be able to identify the special need of this support.

**Abstract number:** P2-221

**Abstract type:** Poster

### **Enhancing Knowledge and Attitudes of Fourth-year Medical Students on Code Status Discussions and End-of-Life Care Decisions through Teaching Conferences Using Feature Films**

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**Background:** Cinemedication has become increasingly popular in medical education with the majority of its use in teaching about psychosocial aspects of illnesses and specific symptom presentations as well as areas such as professionalism and therapeutic managements. Doctor-patient communication is also a key area that involves a great deal of art, emotion, and humanistic facets. Using such creative strategy to encourage students to think about the dying process and personal choice in end-of-life care can enhance teaching.

**Methods:** A teaching conference for the medical clerks incorporated discussing about the feature film "Wit" designed not only to enhance student knowledge of the stages and process of grief and the complexity of human reactions when facing end-of-life situations, but also to engage students in thinking about the importance of

quality of life in palliative care. Our session focused on code status discussions and end-of-life care decisions. The feature film "Wit" complemented the didactic portion of the teaching conference by depicting clinical scenarios when it would have been timely and appropriate for doctors to initiate discussions on advance care planning and did not and how this eventually led to the kind of end-of-life care that the patient received. To assess the efficacy of this approach, a set of standardized questions were given once at the beginning, and once at the completion of the session.

**Results:** The 4<sup>th</sup> year medical students indicated that their understanding of death and dying and their comfort levels as regards code status discussions and end-of-life care decisions in clinical practice increased significantly.

**Conclusion:** We used the feature film "Wit" to teach medical students about death and dying and code status discussions and end-of-life care decisions. The results of the subjective assessment of this approach indicated that it was successful in accomplishing our objectives.

**Abstract number:** P2-222

**Abstract type:** Poster

### **Using the Medical Research Council (MRC) Guidance to Develop a 'Complex Intervention' for Advance Care Planning (ACP) in Care Homes for Residents Nearing the End of Life (EOL): Results from Phase 1**

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ACP has become increasingly important in terms of its perceived role in improving care planning for people nearing EOL. The aim of ACP is to enable people to die in their place of choice and have care coordinated to reduce unnecessary hospital admissions and burdensome interventions towards EOL. Improving the process by which future care is planned is pertinent to care home residents, as many residents view the care home as their home and may wish to live and die there. Recent guidance in the UK has promoted investment in the use of ACP, the effects of which may enable more residents to stay in their preferred place of care.

ACP is often articulated in terms of orders such as DNAR and 'Do not hospitalise'. Although evidence has shown a relationship between the presence of documented orders and improved outcomes such as reduced hospital admissions from care homes and relative/carer perceived satisfaction with care provided, the process by which this occurs has not been well described. ACP is a complex process and relies on a number of interactions: with multiprofessionals/relatives/carers/residents.

**Aims:** To present phase 1 of the development of a complex intervention for ACP:

Map current practice of ACP in care homes in Liverpool. Develop a consensus model.

Develop quantitative 'core metrics' to inform the ongoing monitoring of ACP.

**Method:** An iterative process of discussion, process mapping and consensus building (using Nominal Group Technique) will be engaged to develop a 'complex intervention' for ACP within care homes, in accordance with the MRC guidance.

**Results:** From phase 1 will be presented, outlining recommendations to aid further development of the ACP intervention and provide a context from which to evaluate care delivery in the care home setting.

**Conclusion:** A consensus driven process for ACP incorporating best evidence from the available literature, expertise from multiprofessionals and stakeholders will be developed for pilot evaluation within care homes in Liverpool.

**Abstract number:** P2-223

**Abstract type:** Poster

### **Heart Failure and Palliative Care**

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**Aims:** The objectives of this audit were to identify if the following standards were met:

- (1) Patients are provided with information regarding their diagnosis and disease management.
- (2) End of life care issues are being approached and discussed with patients as part of their heart failure management plan.
- (3) Patients were being referred to palliative care services appropriately according to referral criteria.

Standards used within the audit were based upon local and



national published clinical guidelines.

**Methods:** Case note review of 42 patients admitted to a district general hospital with a diagnosis of heart failure. Patients were identified via the heart failure nurse database during the period January 2011 to April 2012.

**Results:** Of the population studied 40 patients (95%) were informed of their diagnosis however evidence to demonstrate discussion regarding current and future disease management was lacking. Discussion in relation to prognosis, death and uncertainty of disease pathway was only achieved in 4 patients (10%) of the population studied. One patient was referred to the hospital specialist palliative care team according to referral criteria however 40 patients (95%) would have been appropriate palliative care referrals. **Conclusions:** Comprehensive heart failure management should incorporate palliative care from diagnosis through to end of life. There is evidence to demonstrate several strengths within early heart failure management. However, the evidence also suggests that we need to consider how to improve and raise awareness amongst clinicians regarding when to refer patients to palliative care services and how to establish palliative care input amongst patients with a diagnosis of heart failure. Several recommendations are made to accomplish this.

**Abstract number:** P2-224  
**Abstract type:** Poster

### Changed Attitudes among Surgical Nurses Caring for Dying Patients in Cancer - A Pilot Study of an Educational Intervention on Existential Issues

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**Aim:** To test the feasibility of an educational intervention about existential issues for nurses in surgical care, and to describe care attitudes towards patients dying of cancer. Specific aims were to explore the effects on nurses' estimated confidence in communication and reflections on existential issues.

**Methods:** The intervention included five 90 minute sessions with theoretical group lectures and self-studies about the topics; life and death, freedom, relations and loneliness, and meaning. All registered and enrolled nurses at one rural hospital who were interested in participating in the study were invited. 42 surgical nurses at three wards were randomly assigned to an education or non-education group. All nurses completed questionnaires at equivalent time intervals: at baseline before the intervention, directly after, and 3 and 6 months later. 11 nurses in the education group participated in face-to-face interviews directly after the intervention and after 6 months. Non-parametric tests were used to analyze changes, differences and relations between the education and non-education groups. Interviews were analyzed with qualitative content analysis.

**Results:** Results concerned significant short-term and long-term changes. Nurses reported increased confidence and decreased powerlessness in communication as well as increased feelings of value in caring for dying patients 3 and 6 months after the intervention. In addition, they described enhanced awareness on existential issues and increased reflection.

**Conclusion:** This study indicates that an understanding of the dying patient's situation, derived from enhanced awareness and increased reflection, precedes changes in attitudes towards communication after participating in an educational intervention on existential issues. This small-scale study indicates positive outcomes but the intervention must be tested on a larger scale to be solid and reliable.

**Abstract number:** P2-225  
**Abstract type:** Poster

### Transforming End of Life Care in Acute Hospitals Project

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**Aim:** This poster will demonstrate the development & implementation process for Transforming End of Life Care in Acute Hospitals Project as led by the Specialist Palliative Care Team covering two acute hospitals in the North West of England.

**Background:** Over 50% of people die in acute hospitals in England, many of whom do not currently receive optimal end of life care. For this reason the importance of improving end of life care in hospitals was highlighted in the 2008 End of Life Care Strategy. The 'Route to Success in End of Life Care - achieving quality in acute hospitals' was published in 2010 as the first step

towards a national improvement programme.

**Method:** The presentation will detail the improvement methodology undertaken throughout the development and implementation of the project plan and as recommended by the Advancing Quality Alliance (AQuA) and supported by the NHS Institute for Improvement and Innovation (NHS Ili).

It will also demonstrate the outcome measurement process and audit methodology.

The project is underpinned by the Sustainability Model and Guide published by the NHS Ili.

**Additional content**

The poster will provide information about the five key enablers contained within the Transform Programme:

- Advance care planning
- Electronic Palliative Care Co-ordination Systems (EPACCS)
- AMBER care bundle
- Rapid Discharge Home to Die Pathway
- Liverpool Care Pathway for the Dying Patient

**Abstract number:** P2-226  
**Abstract type:** Poster

### Terminal Care Protocol Implementation and Impact on Clinical Staff

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**Background:** Terminal care protocol was the first protocol introduced in our unit, leading to organizational and practices changes.

**Aim:** To identify the perceptions, attitudes and impact on clinical staff of the implementation of the terminal care protocol.

**Methods:** Qualitative study, data collected through 2 focus groups with staff in home care team (n=8) and inpatient unit team (n=8), 3 months after the introduction of the protocol. Coding by 2 both researchers and thematic analysis was performed.

**Results:** Five domains were identified: participatory education, family as caregivers, clinical team, moment of protocol initiation and monitoring process with themes and subthemes. Staff initially expressed resistance in using the protocol due to fears of excessive documentation and comfort with current practice but the educational process had a key role in overcoming fears by changing the perception on the protocol and allowing staff to become an active part in implementation process by adapting the medication toolkit and documentation. The protocol offered the opportunity to change the practices especially in the area of spiritual and religious care and better structure the process of care. It led to a perceived better doctor-nurse collaboration and joint decision making. Family as caregivers perceived the initiation of the protocol as giving up the fight and expressed worries in assuming the role of giving medication subcutaneously. Staff expressed concern that they won't be able to recognize in due time the terminal stage leading to not applying the protocol at the right moment.

**Conclusions:** This study shows the need of recognizing staff and family members resistance in implementation of the terminal care protocol especially in a culture where the family controls the flow of communication. It also highlights the importance of the education throughout this process.

**Abstract number:** P2-227  
**Abstract type:** Poster

### Can Comprehensive Specialised End of Life Care Be Provided at Home? Evaluation of an Innovative Consultant-led Community Service in England

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**Background:** The UK, along with other developed nations, faces a challenge in providing specialist hands-on palliative care for a growing number of people who prefer care at home. The Midhurst Macmillan service is a consultant-led, multi-disciplinary team that aims to provide round the clock care and advice at home, in community hospitals and in care homes. The team provides a wide range of palliative interventions, including IV procedures, paracetamol and intrathecal analgesia. In one year (2008-2009), the service received 389 referrals of which about 85% were patients with cancer, from a population of about 155,000 served by

19 general practices.

**Method:** A mixed methods study was commissioned by Macmillan Cancer Support with three purposes: to assess whether the Midhurst service is meeting its original aims; to gather evidence for funding decisions; and to assess the applicability of the Midhurst model to other areas. We used data from NHS sources, surveys of GPs and bereaved carers, and interviews with health care professionals, patients and carers.

**Results:** During one year 283 patients died under the care of the service. Bereaved carers reported receiving good or excellent support from Midhurst. The mean cost of the service itself is about £3,000 per patient, with £1,900 being the mean cost of Midhurst service interventions on cancer patients in the last year of life. When individual patients are compared, the costs of the Midhurst service are similar to hospice services, taking substitution of NHS costs into account.

**Conclusion:** The quality, flexibility and holistic nature of the care provided by Midhurst appear to allow GPs and hospital consultants to refer patients earlier in their illness. Outcomes include satisfaction with care at home, fewer emergency attendances, decreased hospital stays and 71% of patients dying in their own home. We suggest that this model may have application elsewhere in providing consultant-led specialist palliative care at home.

**Abstract number:** P2-228  
**Abstract type:** Poster

### The Role of Arts for Social Engagement in Palliative Care: The St Christopher's Social Programme

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As part of its vision to offer high standard palliative and bereavement care to terminally ill people as well as to those close to them, St Christopher's is leading a number of community-based projects. These projects aim to introduce the hospice's work to the public, as well as to dispel myths and change attitudes towards the hospice, death and dying by enabling the development of relationships between local community members, hospice patients, and their families and carers (Hartley, 2011, Hartley 2012).

In 2011 St Christopher's introduced 'The Social Programme' which consists of a series of weekly arts and music-based social events or activities, including: the St Christopher's Community Choir, Pottery and Quilting Groups, a Pizza and a Curry night, as well as the Dame Cicely Saunders Concert Series and other live music events. All of the programme activities are open to the public and take place within the common social space of the hospice throughout the week. The Social Programme provides opportunities to connect people at all stages and from all walks of life. All of the activities introduce the hospice, as well as issues around death and dying in a creative and dynamic way, by enabling people to become active members of the hospice's community.

This presentation introduces the St Christopher's Social Programme. It provides an outline of its events and activities as well as its role within the hospice and its potential for social engagement and change. Also, ideas for the development of similar initiatives in other end-of-life contexts are provided.

**References:**

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**Abstract number:** P2-229  
**Abstract type:** Poster

### Can Holistic Interventions Improve the End of Life Care of People with Severe Chronic Obstructive Pulmonary Disease (COPD)? A Systematic Review

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**Background and aim:** A palliative care approach is suggested to meet the unmet needs of people approaching the end-of-life with COPD. We aimed to review the effectiveness of holistic interventions compared to usual care for people with severe COPD.

**Methods:** We searched 11 international databases, three trial repositories and contacted a panel of international experts for published, unpublished and in-progress randomised controlled trials (RCTs), quasi-RCTs and

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controlled clinical trials (CCTs) of holistic interventions for patients with severe COPD in any healthcare context. Date range January 1990 - March 2012; no language or geographical restrictions. Quality assessment and data extraction followed Cochrane Collaboration methodology. Health-related quality of life (HRQoL) was the primary outcome. We used a piloted data extraction sheet and undertook narrative synthesis.

**Results:** From 2,866 potentially relevant papers, three trials met our inclusion criteria: two RCTs (United States, Australia), and one CCT (Thailand) studying a total of 216 patients. Critical appraisal identified a moderate or high risk of bias. All interventions were led by nurses acting in a co-ordinating role. The community-based intervention in Thailand significantly improved HRQoL at three months compared to (limited) usual care (St George Respiratory Questionnaire: intervention: 30.3 ± 19.4 vs control 52.4 ± 21.3 p < 0.001). Significant effects in the US trial were confined to 'Physical functioning' and 'General health' sub-domains of Medical Outcomes Study Short-Form-36 at three, but not six-months. There were no significant changes in the Australian trial.

**Conclusions:** We were unable to find robust trial evidence about urgently needed interventions to address the physical, psychological, social and spiritual needs of people with severe COPD approaching end-of-life.

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Abstract number: P2-230

Abstract type: Poster

### Volunteering in End of Life Care - Presenting and Exploring the Changing Landscape

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This paper poses a number of important questions regarding the current trends and future challenges for volunteering in end of life care within the UK (1). It gives a unique perspective from an organisation which has undergone a large change programme regarding identifying new possibilities and the potential for a more effective utilisation of volunteers across end of life health and social care service provision. Using a large London hospice as a case study, the change management programme is presented and described, highlighting important areas such as recruitment and selection, appropriate training and education, and effective and necessary support and supervision structures. Some individual stories are added, as well as the content analysis of a qualitative evaluation study, in order to give a more personal sense, and a broader perspective, of the changing benefits and rewards for individuals choosing to volunteer as part of the changing landscape of good quality end of life care. These benefits and rewards include offering back to work possibilities for those who are unemployed, or a first step on the employment ladder for those with little or no academic qualifications. It is an important question for end of life care in general, and hospice care in particular, as to whether or not the volunteer programme that is offered is "fit for purpose" (2) both within the current climate and as part of an altered future. The model utilised and developed as part of this particular organisation will be shown to be suitable across a variety of institutions, cultures and countries (3).

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(2) Conservative Party. Policies and manifesto for the general election. London: Conservative party UK; 2010.

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Abstract number: P2-231

Abstract type: Poster

### Health Professionals' Experiences of Using the Liverpool Care Pathway for the Dying Child Pilot Document in a Hospice and a Community Outreach Setting

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**Background:** The Liverpool Care Pathway for the Dying Child (LCPC) is a multi-professional integrated care pathway that provides an evidence-based framework for the delivery of care to children in the last hours or days of life. The LCPC Pilot Document (LCPC-PD) was introduced in a children's hospice and a community outreach team in the UK in 2006. A developmental study is currently underway to develop

the LCPC Model Pathway (LCPC-MP).

**Aim:** To explore health professionals' experiences of using the LCPC-PD, to inform the development of the LCPC-MP.  
**Method:** 24 health professionals (21 nurses, 2 healthcare assistants and 1 counsellor) who had contributed to the 26 pathways completed 2009-2012 were recruited purposively. Focus groups (6) and individual interviews (2) were conducted, audio-taped and transcribed verbatim. Data were analysed thematically using a framework approach.

**Results:** End-of-life care in both settings was nurse-led and medical professionals' involvement was limited. Diagnosing dying in children was challenging and some nurses lacked confidence in starting the LCPC-PD and in having conversations with parents about their child's plan of care. The LCPC-PD was viewed as best practice, but also as a checklist that parents may perceive as limiting the individuality of their child's care. Supporting education had been limited, underpinning misunderstandings in completing the LCPC-PD.

**Conclusion:** Medical professionals must participate in the multidisciplinary decision to commence the LCPC-MP, and support nurses in diagnosing the dying phase. This will be a challenge in the current nurse-led culture. Communication goals must be emphasised in the LCPC-MP to ensure parents understand their child's plan of care. A rigorous education programme must underpin implementation of the LCPC-MP, to ensure the robust documentation of care provided to children in the last hours or days of life. Project funded by Alder Hey Imagine Appeal.

Abstract number: P2-232

Abstract type: Poster

### Experiences and Health Care Needs during the Last Year of Life of Older People with End Stage Renal Disease (ESRD) Managed without Dialysis in Thailand

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**Background:** Symptom experiences and unmet health care needs are an important issue of concern in older patients with (End Stage Renal Disease) ESRD managed without dialysis in Thailand. It has been argued these patients are a neglected group and as a consequence likely to have unmet needs with respect to healthcare and suffer from symptoms that could be better managed.

**Objectives:** To explore experiences and health care needs during the last year of life of older people with ESRD managed without dialysis from the perspective of bereaved relatives in Thailand. To develop and adapt a form of the VOICES questionnaire for use with a Thai population.

**Methods:** A mixed-method exploratory phased design (instrument development model). Retrospective, exploratory interviews have been undertaken to collect data about older peoples' experiences of ESRD managed without dialysis from the perspective of bereaved relatives. Purposive sampling was used to recruit participants from the renal units of two hospitals in Thailand between September-December 2011. Semi-structured interviews with 12 bereaved relatives of elderly ESRD patients managed without dialysis between 5-10 months after death were conducted. Interviews were digitally recorded, transcribed and analysed through Framework Analysis.

**Results:** The experiences and health care needs of older people with ESRD managed without dialysis were explored under four themes (sub-themes) including

- 1) symptom experiences (physical, psychological and spiritual aspects),
- 2) impacts,
- 3) symptom management and
- 4) health care needs and utilization (health service provision, home visiting, spiritual need and financial support).

**Conclusion:** The qualitative finding revealed important information about symptom experiences and unmet needs of older people with ESRD managed without dialysis in Thailand.

Abstract number: P2-233

Abstract type: Poster

### A Survey of Inputs and Outputs of Hospice at Home Services in England and Wales

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**Background:** Hospice at Home (H@H) is a recognized service provided by hospices across the UK. Whilst those delivering H@H allege that it has an important role in providing care to people at home who are approaching the end of life there is little evidence regarding the detail of the care delivered, its impact and whether this varies between services who share the name of H@H.

**Aims and methods:** A recent survey of care delivered by 76 hospice at home services in England and Wales over a 3 month period begins to answer this question and build an evidence base regarding H@H. It has collected data describing inputs and outputs of just over 4500 completed episodes of care. Anonymised data was collected by the individual services and forwarded to a national organization for collation and examination. Some initial examination of the data has yielded early results. Further analysis is planned.

**Results:** The amalgamated results demonstrate that H@H does have an important role in caring for people in the last days and weeks of life. 87% of patients who die under the care of H@H die in the place of their choice; 76% of these patients died at home. The inputs for the service are relatively small in terms of resource, suggesting a service for investment in the future. However inequalities exist particularly around diagnosis. Another limitation of the service is its relatively low reach in relation to the number of people who could benefit from it.

**Conclusion:** The survey identifies further actions required on the part of H@H services, their national association and other players concerned with improving the experience of people facing the end of life who wish to remain at home. Its findings suggest that hospice at home could be a valuable service for people who are dying and their carers in the future, reflective of the priorities of UK End of Life Care Strategy and the preferences of individuals. It identifies areas for further work and investment, including further research.

Abstract number: P2-234

Abstract type: Poster

### Advanced Cancer Patients. Treatment during the Last Month of Life

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**Aim of the research:** Many advanced cancer patients, during the last month of life, initiate news treatments with unclear clinical benefit.

This sometimes delay the involvement of palliative care teams.

There is little published literature. Previous studies show various data:

- Chemotherapy: Hoberg, 2011, 118 patients, 56.7%. Nappa, 2011, 397 patients, 23%. Sanz Ortiz 2011 303 patients, 55.6%.

- Radiotherapy: Wallace, 2011, 253 patients 10.6%.

- Tansfussional suport: 19.5%.

The aim of this study is to determine the prevalence of treatments carried out during the last month of life, and its impact on survival.

**Methods:** Retrospective, descriptive study. Review patient deaths in Palliative Care Unit since 1/7/2010 to 30/6/2011.

Variables: Age, sex, tumor location. Review treatments during last month: Chemotherapy, radiation therapy, surgery, transfussional support, byphosphonates and hormone therapy.

Survival according to the presence or absence of treatment.

**Results:**

**Patients:** 237.

**Age:** mean 73.1 (SD 13.5, range 25-93).

**Sex:** 62% male.

**Tumor location:** lung 19%, colon 10%, bladder 7%, stomach 7%, CNS 5%, pancreas 5%, liver 5%, rectum 5%, breast 5%, bile ducts 4%.

**Follow-up time:** between 29 and 38 days.

**Statistical method of analysis:** P. Kruskal-Wallis.

**Treatments:** chemotherapy 17%, radiotherapy 2%, surgery 4.2% (stents 2%, gastrostomy 0.5%, transurethral resection 0.5%, pleurodesis 0.5%, lymphadenectomy 0.5%, abdominal and pleural drainage 1%), transfussional support 14%, biphosphonates 6%, hormone therapy 3%.

No longer survival was observed in patients who received treatment.

**Conclusion:** The absence of differences in terms of survival calls for more research aimed to identify prognostic factors that help us to choose the best indication and benefits of the treatments carried out during the last month of life.

Abstract number: P2-235

Abstract type: Poster

### "Allow your Voice to Dance till Death." Music Therapy at the End of Life

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**Description:** Analysis of some essential and touching moments taken from the backstage of an extraordinary

amatory film, already on youtube, concerning a program with terminally ill patients and their relatives.

#### Aims:

- 1) Helping people to retrieve relational ways of aesthetics by taking them to new qualities of feeling and building together.
- 2) Promoting musical intelligence, to open relational states of mind able to make possible the aesthetic contextualization of pain, of irreducible symptoms and of the sense of imminent loss.
- 3) Creating a privilege context of relief and peace.

**Method:** VoxEchology - from performance to therapy is a social-musical training created by the author. It is centred on searching the oneness of voice and body along with their reflections (Echo), as well as on applying musical intelligence to human relationships.

**Results:** The constant modifications and adjustments of musical experiences reflected, in a positive manner, on the common idea of a bio-psycho-social helplessness usually associated to death. A musical proto-theatrical frame allowed the participants to recover the dignity of dying and to be aware of the sacredness of the end of life time and of a different way to manage symptoms.

**Conclusion:** By walking away from the sense of ridicule, making music for the development of a Relational Musical Intelligence naturally helps people to get close to the idea of the closure of a life cycle as it is in live music performance and to free a sense of love and social cohesion unequalled: an ideal container in which people can put joy, pain and hope.

Abstract number: P2-236

Abstract type: Poster

### The Big Five Revisited - Wound Management Education in a Kenyan Hospital

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**Aims:** Following an invitation of the palliative care unit (PCU) in Kenyatta Hospital 2 palliative care experts (nurse, researcher) spent one week in Nairobi in order to discuss feasible and budget-friendly ways of management of malignant wounds. The Kenyan PCU team has been working as a wound management (WM) consultancy team throughout the hospital and strives to expand their outpatient service at the PCU to a WM advisory center.

**Methods:** The Kenyan team organised a one-day seminar with various speakers on WM for hospital staff (nurses) including pre-/posttest, anatomy & physiology of the skin, evidence & treatment of malignant wounds, wound assessment and wound care product information. This also introduced the German team to hospital staff. In the next few days, the German & Kenyan nurses were invited to assess patients with malignant wounds in several wards, discuss wound care options with the staff and to show how to change the dressings. The team also saw outpatients at the PCU and visited a patient at her home.

**Results:** Five major challenges emerged throughout the visit. These included attitude (use of rescue medication before & during dressing changes, not wearing a surgical mask), prevention and treatment of malodour & bleeding, use of available material, creative approach (self-made charcoal compresses), and treatment goals (treatment of patients with severe malignant wounds who were not informed of their prognosis). There was a vivid discussion about pros and cons of WM options and the best possible management of certain problems. An evaluation at the end of the visit indicated that this was an important step to improve the knowledge of WM on non-palliative wards and towards the establishment of a wound advisory center.

**Conclusion:** As a next step of this cooperation a regular or on-demand WM discussion should be established (consultation via email or Skype).

**Funding:** Verein zur Betreuung und Begleitung Schwerstkranker und Sterbender e.V., Bonn

Abstract number: P2-237

Abstract type: Poster

### 'Diagnosing Dying' Delphi: Gaining Consensus?

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**Background:** Recognising the imminently dying phase (last hours or days of life) is a key part of providing end of life care. However, accurate recognition can be challenging and

there is little empirical evidence on this process, including the factors considered by healthcare staff.

**Aim:** To seek consensus on key factors considered by hospice staff when recognising the dying phase.

**Method:** A Delphi survey building on previous qualitative research. Experienced multi-disciplinary hospice staff (the Delphi experts) from UK hospices were asked opinion on questions derived from core qualitative themes using a web based survey. Questions included physical factors, patient actions, depth of relationship with patient and assessment of potentially reversible causes for deterioration. Using the original qualitative research as the foundation, 2 Delphi rounds were performed.

**Results:** Round 1: 69 staff from 9 hospices participated (64.1% >5 years hospice experience). Asked 'What factors do you consider indicate that a patient is entering the dying phase?' 250 individual responses were received. Strong agreement was seen for consideration of potentially reversible causes for deterioration and importance of knowing the individual patient to better recognise progressive changes. Key physical factors included appearance, breathing changes, conscious level and fatigue. Round 2: 44 staff participated (67.4% >5 years hospice experience). Further clarification was sought on factors identified in round 1 including: potential reversible causes (hypercalcaemia /infection /opioid toxicity /medication side effects) facial appearance (glazed eyes /pinched nose/colour changes) & patient actions (agitation /withdrawal). **Conclusion:** Recognising the imminently dying phase is complex and a variety of factors are considered. This Delphi has gained consensus on aspects of this process, which could be used for further research or development of educational tools.

Abstract number: P2-238

Abstract type: Poster

### The Role of 'Breathing Changes' in Recognising the Imminently Dying Phase

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**Background:** Recognising when patients are approaching the imminently dying phase (last hours or days of life) is an important aspect of providing end of life care. However, this recognition can be challenging and multiple factors need to be considered. In a study to explore the processes by which hospice staff recognise the dying phase, the importance of 'breathing changes' was frequently encountered.

**Aim:** To describe the significance of 'breathing changes' in recognition of the imminently dying phase.

**Method:** An ethnographic qualitative study, guided by grounded theory, performed in 2 specialist hospices using retrospective case-note analysis of the last 7 days of life, observation of clinical meetings and semi-structured interviews with hospice staff. This was followed by a Delphi study seeking consensus on key themes and factors identified from the qualitative research, asking opinion from regional and national hospice staff.

**Results:** From case-note analysis, 'breathing changes' was the most commonly documented group of physical factors identified. The frequency of case-note entries relating to breathing increased towards the last 48 hours before death. Multiple descriptions of breathing were found, e.g. rapid/slow/irregular breathing, chest secretions, cheyne-stokes breathing, apnoea episodes, increased dyspnoea. During interview, participants agreed the importance of 'breathing changes' but found difficulty in describing specific aspects. The Delphi study confirmed strong agreement for the importance of breathing changes. Cheyne-stokes breathing followed by irregular breathing pattern and shallow breathing showed strongest level of agreement. Increased dyspnoea showed lowest agreement.

**Conclusion:** 'Breathing changes' appear to be a significant physical factor in recognising the dying phase. This study has helped clarify the relevance of certain aspects of breathing, but further research to improve specific knowledge is needed.

Abstract number: P2-239

Abstract type: Poster

### Experience of Life- and Death Anxiety among Patients with Severe COPD

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Anxiety often appears together with dyspnea in patients with severe COPD. Considering the provoking

symptomatology and the high mortality rate in COPD, it is plausible to believe that these conditions trigger death related anxiety. There is a lack of recognition of the existential needs in conjunction with the COPD disease.

**Aim:** The aim of this study was to explore severely ill COPD patients' experiences of anxiety and their strategies to alleviate anxiety.

**Design:** This qualitative in-depth interview study explored perceptions of experiences of anxiety and strategies to alleviate anxiety. Interviews were analyzed using a thematic content analysis approach, involving interpretive coding and identification of themes.

**Setting/participants:** People suffering from COPD (stage III or IV) were recruited from a pulmonary outpatient clinic in West Sweden. A purposive sampling was used with respect to participants' gender, ethnicity, age, psychosocial background and physical function. Thirty-one (31) patients were included.

**Results:** A clear majority had experienced anxiety associated with the COPD disease. Analyses indicated three major themes:

**Death anxiety** which included: Fear of suffocation awareness of death, fear of dying, and separation anxiety.

**Life anxiety:** the prospect of living with breathlessness and other COPD symptoms created more anxiety than thoughts about dying from COPD. Patients experienced fear of living and loss of meaning, relationships, and independence. **Counterweight to anxiety** was different coping strategies and a joy that defied the vulnerable situation.

**Conclusions:** How to treat existential anxiety is a challenge, because there is no easy way to "cure" it. The support from palliative care service to COPD patients must be extended. Future investigations of how to optimal support to COPD patients with anxiety are warranted.

Abstract number: P2-240

Abstract type: Poster

### Invisible Workers, Hidden Labour: Emotional Support Provided by Health Care Assistants (HCAs) Caring for Dying Patients - Their Views and those of Bereaved Carers

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**Aims:** In the UK HCAs comprise 30% of the nursing workforce and are unregulated. They commonly care for the dying at home. Lack of status and recognition has led to them being described as 'invisible workers'. Few studies have described the full extent of their work. We aimed to explore their role by interviewing HCAs and bereaved carers who had experienced their care.

**Method:** Semi-structured interviews were undertaken with 10 HCAs from three diverse services in England. Analysis enabled development of a series of prompts used in subsequent interviews with 34 family carers 3-9 months post bereavement. Thematic analysis of these interviews is nearing completion.

**Results:** HCAs described their role as practical work and providing emotional support, including: relieving the burden of caring, encouraging self-care for carers and listening to patient and carers' concerns. HCAs valued building relationships and providing continuity of care. Initial findings from bereaved carer interviews indicate that they were mostly very satisfied with HCAs care, acknowledging: practical help, the reassuring presence of the HCA, sensitivity and spontaneity in recognizing their needs; listening to patient and carers' concerns and ongoing involvement after death, including follow up visits and attending funerals. Some bereaved carers specifically recognized and valued the emotional support that HCAs gave. It was particularly appreciated when HCAs had developed an ongoing relationship with patients and family members. Conversely, if HCAs did not show sensitivity or failed to engage with them during caring activity, bereaved carers were critical and discontent. This rarely occurred. **Conclusion:** HCAs offer a wide variety of skills in their work with dying patients and their carers, including practical and emotional support. Their work is highly valued by bereaved carers and its full extent should be recognized and acknowledged by the services in which they work.

**Funder:** Dimbleby Cancer Care

Abstract number: P2-241

Abstract type: Poster

### Characteristic of Patients Received Hematopoietic Stem Cell Transplantation and Occupational Therapy

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**Introduction:** In Japan, estimation of the number of cancer rehabilitation cases began in 2009. Occupational therapists are involved in many facilities in the field of palliative care. However, there have been few reports regarding occupational therapy (OT). Here, we surveyed the attributes of patients who received hematopoietic stem cell transplantation (HSCT) and compared patients followed by OT with patients not received OT.

**Subjects:** The subjects were 273 HSCT patients who received treatment between March 2005 and October 2011 at Shinshu University Hospital. 161 patients followed by OT. 121 patients not received OT.

**Methods:** The attributes of patients before HSCT were examined. We compared about attributes (age, sex, disease classification, the survival situation, the survival days, transplant type, recurrence, Performance status (PS), Karnofsky performance status scale (KS), Hematopoietic cell transplantation-specific comorbidity index (HCT-CL) Total, acute Graft versus host disease (GVHD)) between two groups. The Kaplan-Meier method was used to examine the survival curve from the day of transplantation to the last day of survival.

**Results:** Disease classification (p=0.000), the survival days (p=0.000), transplant type (p=0.000), recurrence (p=0.001), HCT-CL Total (p=0.033) were significant difference between two groups. The 5-year survival rate of OT group was 44% (95% confidence interval 0.3241 - 0.5468%). The outcomes were as follows: 121 patients were discharged to home (75%), 31 patients died (19%), and 9 patients switched to another physician.

**Discussion:** OT group was many severe cases. The 5-year survival rate for HSCT patients was low. Rate of death was high at 19%, and we found that there were many opportunities to perform OT in end-stage patients. In future studies, we plan to examine the effectiveness of OT in end-stage patients.

**Abstract number:** P2-242

**Abstract type:** Poster

## Improving End of Life Care in Community Hospitals - GSF!

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**Aim:** Improving end of life care in Community Hospitals using the Gold Standards Framework Dementia Care Training Programme. Community Hospitals have an important role in the community. Many elderly people are transferred to community hospitals from the Acute Sector following often long stays in an acute ward. Although some would choose the community hospital as their preferred place of care/death, others can spend a long time in the community hospital awaiting assessments and placement to care homes or to return home.

The programme followed the same format as other GSF Programmes. And the aim was to improve the coordination and planning of care, putting systems in place to ensure:

1. The Right Person
2. The Right Care
3. The Right Place
4. The Right time
5. Every time

This Quality Improvement Programme involved 28 community Hospitals in the South West of England. The programme is currently being evaluated and the hospitals are preparing for Accreditation in 2013. Further details of both quantitative and qualitative changes will be available.

- Results so far are showing improvements in communication and collaboration with care homes, primary care teams and acute hospitals.
- More patients are being offered Advance Care Planning discussions and being given the opportunity to express their preferences in relation to place of care.
- All staff in the hospitals have become more aware of end of life care issues and there is an improvement in the assessment of patients and the identification of those in the last year or so of life.
- Community hospitals play a key role in rural areas - and is the preferred place of death for some.

The use of the adapted GSF Training Programme for Community Hospitals has helped improve the quality of end of life care in rural areas, and enable more to live and die well as they would wish. These hospitals are progressing to accreditation and further integration in cross boundary care.

**Abstract number:** P2-243

**Abstract type:** Poster

## Improving End of Life Care in Acute Hospitals, Using the Gold Standards Framework Acute Hospital Programme

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**Context:** Most people die in hospital but most would prefer to die at home. Communication with hospitals and others is often poor, leading to cross boundary gaps in care and inappropriate hospitalisation. GSF is widely used in the community, but integrating GSF into Acute Hospitals was the missing link.

**Aim:** The aim of the GSF programme is to improve the quality of care provided for all people in the final year of life, improve coordination and collaboration within teams and across boundaries of care, and to enable more to live and die at home and decrease hospitalisation. Phase 2 GSF included 8 acute hospitals, ranging from 1-3 wards per hospital. A comparative evaluation was carried out before and after the 9 month intervention of the GSF training programme.

**Method:** An independent evaluation and analysis from eight hospitals participating in Phase 2 GSF included:

- Staff Survey
  - Organisational Survey
  - After Death/Discharge Analysis (ADA)
  - Qualitative data from a focus group
- Results (details to be supplied):**
- The key results included improvements in staff knowledge and confidence in most areas of end of life care
  - Increased identification of patients nearing the end of life
  - Increased advance care planning discussions
  - Improved communication with primary care teams
  - There have been modest improvements in use of rapid discharge processes and use of care pathways for the dying.
  - Some evidence of reduced length of hospital stay.

**Conclusion:** The GSF Acute Hospital programme has enabled hospitals to improve quality of end of life care, at grass roots level, through organizational/ cultural change and at some patient level outcomes. The programme offers hospitals the opportunity to broaden awareness of end of life care, develop and educate all staff, improve cross boundary care and communication and to move onto to deepen levels of sustainability through objective accreditation. This enables better integrated cross-boundary care.

**Abstract number:** P2-244

**Abstract type:** Poster

## Using Tools and Pathways to Improve Generalist End of Life Care in the Community

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**Aims:** To improve the standard of end of life care provided by generalist community nursing services through adapting hospital tools and pathways for patients who are in their last hours or days or whose recovery is uncertain.

**Methods:**

- Refinement and implementation of the Liverpool Care Pathway (LCP), a widely recognised pathway for dying patients, across seven generalist community nursing teams working in a diverse and densely populated urban area
- A feasibility study of the use of the AMBER care bundle, a hospital tool developed by Guy's and St Thomas' NHS Foundation Trust for patients whose recovery is uncertain.

- Results:**
- In the nine months following implementation of the LCP 88% of identified community nursing end of life patients who died at home received care supported by the Liverpool Care Pathway (N=105)
  - In the same period 73% of identified community nursing end of life patients died in their preferred place of care (N=148)
  - During the AMBER care bundle feasibility study the Nurse Consultant working in community nursing used the care bundle in the management of six patients. The potential benefits of the AMBER care bundle in the community were:
    - \* Improved cooperation and communication between services
    - \* The promotion of open and honest discussion with patients and those who care for them
    - \* Help for generalist staff working with patients whose recovery is uncertain who are not known to specialist palliative care services

**Conclusion:** The LCP has provided a systematic and measurable approach to end of life care for the generalist community health services in the area. Its use by community nurses appears to be sustained in the nine months following

implementation.

The successful implementation of the LCP has opened the door for further development, including the implementation of the AMBER care bundle. The feasibility study indicates that the AMBER care bundle has the potential to be adapted to improve care in the community for patients whose recovery is uncertain.

**Abstract number:** P2-245

**Abstract type:** Poster

## The Views of Palliative Patients and their Families on their Needs for Palliative Care Services in Medjmurje (County of Croatia)

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In Croatia there are limited professional palliative care services. Patients and their families face many difficulties when coping with advancing illness but the primary health institutions, hospitals and nursing homes are unable to provide adequate care.

**Aims:** This study looked at ascertaining the palliative care needs and views of patients with incurable illness, and their families, within the county of Medjmurje in Croatia and asked for their ideas about the development of a palliative care service.

**Methods:** A qualitative study was undertaken, including five semi-structured interviews for the patients and five focus groups for the family members.

**Results:** The patient's main concerns were of a psychological nature and talked of the inability to do day-to-day activities due to fatigue. Families talked of practical issues, such as problems with providing 24 hour care. Both patients and family members acknowledged the lack of a specialised palliative professional help.

Poor communication with health professionals was stressed by both patients and families and they talked of the problems that ensued as there was little collaboration amongst service providers.

**Discussion:** Recommendations from this study include the need for more education on palliative care management and advanced communication skills training for health professionals, including improved collaboration between service providers needs. Increased care would help families to provide care for the patient and the establishment of palliative care teams would provide additional help and increase the quality of patient's life. The study has encouraged a local charity to continue to develop support by volunteers for patients and their families.

**Abstract number:** P2-246

**Abstract type:** Poster

## Professionals' Perceptions on the End of Life Care (EoL): Implementation of the Spanish Version of the Liverpool Care Pathway (LCP) in Spain and Argentina

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Health professionals' perceptions on EoL can influence communication with patients and families. Although in Palliative Care (PC) death is expected, emotions of varying intensity are generated. The fears and difficulties encountered in facing this subject will be different according to previous personal experiences. The LCP proposes a quality programme of care for people at EoL. Both in Argentina, PALLIUM and in Spain, Cudeca, are implementing a Spanish version of LCP.

**Aim:** Describe the perceptions of professionals concerning EoL, and the influence of the LCP in a Latin-American (LA) cultural context.

**Specific aims:**

- 1- Identify the implementation of the LCP (version 12) in Argentina and Spain.
- 2- Analyse the meanings that professionals assigned to care the dying, communication, teamwork, documentation and the attitudes to EoL.

**Method:** A cross sectional exploratory description study of two hospitable team of PC trained in the use of the LCP in Argentina and Spain, by structured questionnaire and 1 open question about perceptions of needs and conditions of professionals using the LCP in both countries.

**Results:**

-In Spain all participants work in PC units of the Andalusian

Plan for PC. Argentina does not have a National Plan of PC. 2 -Module 1: identified associations:

- advances in the intervention in EoL;
  - expectations of training in the use of the LCP;
  - doubts and fears in the application of the LCP;
  - the position of awareness in the interventions.
- Module 2-Spain n:23 Argentina n:112. Consensus: respect of the patient/providing comfort/relief of pain/symptom control. In Argentina there was a lack of training in PC, obstacles and resistances from other health professionals are described; the importance of documenting: Spain (87.5%) vs. Argentina (41.6%).

**Conclusion:** The study gives, for the first time in LA context relevant data regarding support to EoL and perceptions in the context of the implementation of the LCP, not commonly used in our situation.

Abstract number: P2-247

Abstract type: Poster

### PAMPA Program: The Liverpool Care Pathway (LCP) Implementation in Argentina

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The Liverpool Care Pathway (LCP) was largely recognized in Europe as a guide for the care of the dying, providing high quality end of life (EoL) practice. Excellence in care provision is based, not only on its institutional framework but also on its cultural context. Argentina is a large South American country positioned at Level 4 (approaching integration) in the global map of Palliative Care (PC) development. However, PC services are still quite unable to reach the vast majority of patients who might benefit from them. For the last 4 years we have been working in the translation and cultural adaptation for the LCP into the Latin American (LA) cultural context. In 2012 we received two grants from The National Cancer Institute and from the National Ministry of Health. The aim of this presentation is to show the implementation overview audit we realized the lack of the best practices in almost 65% of the goals of excellence from de LCP. Then we started a pilot and post pilot phase including: all patients and families assisted by our teams at the 3 settings (n200), continuous f the PAMPA (Programa Asistencial Multidisciplinario Pallium) based on the LCP at two teaching hospitals and the Pallium (NGO) Home Care. In a retrospective base multidisciplinary education programs for care of the dying (20 sessions), family members interviews(3), staff perceptions surveys on the EoL issues(n 112), and professionals focus groups(4). The process was supervised for the Marie Curie Palliative Care Institute Liverpool (UK) and the data was analyzed by their website software program. The outcomes show that the goals of excellence were achieved in more than 95% and the awareness about the care of the dying was notably improved in the qualitative analysis. This is the first project focused on the EoL care best practices in LA. Our challenge consists on the use of the LCP in our language and cultural context. This requires continuous insight, critical decision making and clinical skills.

Abstract number: P2-248

Abstract type: Poster

### Meningioma - Nonmalignant Histological Lesion with Slowly Progressive Severe Clinical Course - A Case Report

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**Introduction:** Meningiomas are mostly histologically benign lesions, which mainly affect elderly patients. Sometimes they spread to the bone and destroy it, but also they can cause hyperostosis.

**Case report:** The patient was 27-year-old when two meningiomas were diagnosed. The first one in posterior cranial fossa was removed surgically - meningioma WHO gradus I. The second one in the right temporal region was operated three months later. The histological examination confirmed an atypical meningioma WHO gradus II. The patient was treated with radiotherapy one month after surgery. About one year later, the bone flap after craniotomy was explanted for osteomyelitis. After its healing for three months cranioplasty was performed. The patient was operated for fistula in the scar after cranioplasty next month. Recurrent tumour in the right temporal region was removed after two years. Further recurrence of the tumour in the both posterior cranial fossa and in the right temporal region was removed separately at an interval of one month. Last (the ninth) neurosurgical operation was performed for repeated recurrences of tumour in the right temporal region one year

later. At the age of 35 years all treatment options of neurosurgical and oncological therapy were exhausted. About two years later, the family was not able to take a care of the disabled patient who was transferred at hospice in Rajhrad after three months of her residence at health resort of chronically ill patients. The patient was treated symptomatically including adequate analgesic therapy. Mental support of the patient was necessary as well as the patient's family. The patient died at the age of 38 years. **Conclusion:** Nonmalignant histological lesions such as meningiomas can present severe clinical course significantly enhanced by long time factor. It is essential to take all-embracing care of a patient including psychotherapy.

Abstract number: P2-249

Abstract type: Poster

### "Dying Healthy" - How Alternative Therapies Support Reintegration of Psycho, Social, Spiritual and Biographical Parts in the Dying Process

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Alternative therapies such as creative therapies (e.g. music, art) aromatherapy, manual therapies (e.g. massage, shiatsu) or mind-body therapies (e.g. guided imagery) are widely used in hospice and palliative care. Aim of this study was to explore the (therapeutic) effects and significance of alternative therapies for seriously and terminally ill people at the end of life.

Elements of Grounded Theory and Intuitive Inquiry served as a methodological framework for this qualitative explorative study. A total of twenty multi perspective, qualitative interviews were conducted with managers (n=7), complementary practitioners (n=8) and doctors (n=5) in six German inpatient hospices. There were also focus groups (n=6) with multi-professional team members. Interviews and focus groups were tape-recorded, transcribed verbatim and analysed using Grounded Theory methods.

Empirical data shows that alternative therapies do not only have effects on a physical level (e.g. decrease of pain and changed pain perception) but also on psychological, social and spiritual levels. In the course of an illness not only physiological, but in particular emotional, social or spiritual parts of an individual get hurt or become separated. Multidisciplinary palliative care staff report, that alternative therapies play an essential part in reintegrating these separated parts into the individual biography during the dying process.

Even if people die of physical illness, the dying process itself should not be considered as an illness. Instead, dying can be understood as a healthy process (of life), which allows the individual to reintegrate separated parts in the biography. To support the dying in these processes of reintegration it needs therapies respectively therapists, which address and respond to bio-psycho-social and spiritual levels.

The research project was funded by the "Stifterverband für die Deutsche Wissenschaft".

Abstract number: P2-250

Abstract type: Poster

### Physiotherapy and Motor Skills in Palliative Care

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**Background:** The problem of physiotherapy in palliative care has been discussed until relatively recently, therefore, the current knowledge of this issue is limited. In many hospices in Poland, team members are not able to specify goals to be fulfilled in the course of the rehabilitation undertaken, while physiotherapists face difficulties in clear determination of their role in palliative care.

**Objective:**

- The aim of the present study was analysis of functional changes in all aspects of life (motor fitness, somatic condition, mental condition) in advanced stages of malignant diseases during rehabilitation process included in home assistance.
- To analyse the physical activity of the terminally ill patients in the range of basic everyday activities-Barthel Index.

**Material and methods:** The research was performed on group of 20 patients in their terminal phase of cancer, who finished 6 months of physiotherapy. All of them were involved in palliative homecare treatment. The physiotherapy was performed twice a week in the patient's home, for the duration of 6 months. None of the patients

was included in any other rehabilitation programme-district outpatient unit, nor was he subject to psychological therapy.

**Results:** The physiotherapy improves the quality of life of the patients throughout increasing the level of functional activities: transfer training -28%-III and above 50% in VI months of the rehabilitation programme, bath-133%-II months, gait re-education-38%-VI months, stairs-50%-II months.

**Conclusions:**

- The results indicate that motor rehabilitation improves the quality of patients' life by increasing the level of functional efficiency, manifested as an improved ability to be self-sufficient.
- Applied in the thesis Barthel Index is a useful and functional model of grading typical everyday activities. It is also an effective qualifier of the basic areas of therapists' work.

Abstract number: P2-251

Abstract type: Poster

### Palliative Care in Reach of the Vulnerable Psychiatric Patient

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**Objective:** An explorative research among professionals, patients and relatives on palliative care for people with a psychiatric disorder. Inventarisation of further research questions among patients, relatives and experts in mental health, general health and palliative care.

**Design and method:** Four groups of clients were formed and all of them included in the five parts of the project:

- Focus groups with different medical professionals to gather information about their experiences in treating psychiatric patients in a palliative phase.
- A questionnaire among professionals were they were asked about the amount of patients treated in the past year with a psychiatric disorder and the need for palliative care.
- Interviews with professionals about their experiences with these patients.
- Interviews with patients about their experiences in receiving palliative care
- Focus groups with relatives.

**Results and conclusions:** Offering palliative care for patients with a psychiatric disorder is essential, further research needs to be done for embedding this care in fields of health care. Health professionals are developing different methods and courses e.g. a specialized palliative care unit for psychiatric patients and a manual for providing palliative care for these patients but all of them are in a premature phase. Medical professionals presented clear ideas about the contents of these methods and the obstacles they faced when treating these patients, especially in communication. Professionals with different backgrounds need to work together in these cases which makes treating the patients complex.

Abstract number: P2-252

Abstract type: Poster

### The Role of Advance Care Planning in an Inpatient Hospice: Is it Too Late?

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**Background:** Advance Care Planning (ACP) is a process where future healthcare preferences are discussed based on personal values. Discussions are preferably conducted with patients themselves. Our hypothesis is that it is too late to initiate ACP in hospice, especially since average length of stay is 25 days. Our aims are to study the rate of completion of ACP discussions with these patients, understand the barriers to ACP and review the outcomes.

**Methodology:** This is a prospective observational study carried out between June to October 2012. ACPs were conducted by a trained facilitator with patients who were cognitively intact, with no collusion and were agreeable for discussions. For patients who were unable to participate, ACP was carried out with their surrogates, usually close family members by default. Descriptive statistics and reasons for unsuccessful ACPs were collected.

**Results:** 169 patients were studied. 50% were cognitively impaired; of which majority (88%) were recent in onset. 36% of patients were cognitively intact. The remaining 14% could not be assessed due to uncontrolled symptoms or inability to communicate. 23% of all patients completed their own ACP, of these, a fifth died within 1 week. Other than cognitive impairment, collusion (6%) and uncontrolled symptoms (7%) precluded ACP discussions. 5% had no ACP

## Poster sessions

even via surrogate due to rapid decline. Only 17% had ACP before admission.  
129 patients died during this period and care preferences were respected in all except for preferences to pass away at home, only 2 out of 13 were achieved.  
**Conclusion:** 57% of patients could have potentially participated in their own ACP discussions as barriers such as cognitive impairment, uncontrolled symptoms and collusion can be avoided or addressed earlier in disease trajectory. This will reduce surrogate-led discussions and honor patients' true preferences.

## Epidemiology

**Abstract number:** P2-253  
**Abstract type:** Poster

### The Evaluation of Palliative Patients' Care in Emergency Services in a Hospital without Palliative Care Center

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**Research aims:** Emergency departments (ED) are units focused on dealing with acute diseases or injuries while the palliative care focuses on increasing the quality of life by relieving pain. Although the role of palliative medicine is gaining importance in ED, emergency physicians carry this task with limited skills and training. The aim of the study is to find out the course of cancer patients, in need of palliative care, when they were admitted to ED in a province that had no palliative care units.

**Study design and methods:** The cancer patients that were admitted to ED of an university hospital, between January 2012 and September 2012, were evaluated. The data were analyzed through SPSS 15.0.

**Results:** It was seen that total of 125 cancer patients have been admitted to ED between January 2012 and September 2012. The number of patients that was in need of palliative care was 52 (41.6%). The mean age of the patients was 61, there were 32 male and 20 female patients. Considering the cancer types, lung cancer was mostly seen (23%) and the second was the gastric cancer (21.2%). The average number of a patient's admission to ED in an 8-month period was 8.7. In terms of the complaints of these admissions, the first was the pain (34.6%) and the second was dyspnea (25%).

**Discussion:** Meo et al. have emphasized that an emergency physician needs to be competent in pain control, in elimination of other possible symptoms, and on main issues of palliative care such as breaking bad news or specifying prognosis. It has become a necessity, especially in those hospitals that have no palliative teams.

**Conclusion:** This study shows that the palliative patients constitute an important group of patients, in the admissions to ED in our province. We suggest that emergency physicians' skills and training should be increased until the hospital has its own palliative care units.

**Abstract number:** P2-254  
**Abstract type:** Poster

### Prolonged Dwindling; An over Simplification of Dying for Centenarians?

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**Context & aim:** Centenarians are the fastest growing demographic in the world. The number is projected to increase worldwide from 317,000 in 2011 to 3,224,000 by 2050. To develop and improve services for this group requires understanding on variations in cause of death by place of death. We aimed to test a classification of cause of death and variations by place of death to inform the provision of end-of-life care services.

**Methods:** A whole population observational study using death registration data for people aged 100+ years and died 2001-2010 in England. Descriptive analysis of cause of death and contributing causes of death to examine models of dying and comparative analysis of variations by place of death.

**Results:** Participants 33, 581 people average age 101 at time of death (range 100-115 years). Majority widowed (85%) and died in a care home (61%). Many died in hospital (28%); few died at home (9.8%). Three models of dying conceptualised: 1. Acute death on chronic illness. Main acute cause of death pneumonia (18%) with contributing chronic circulatory

disease e.g. heart failure  
2. Chronic cause of death. Main chronic causes of death cardiac disease (15%), dementia (5.6%) and cancer (2.9%)  
3. Acute cause of death e.g. myocardial infarction (2.8%)  
**Conclusions:** The models of dying challenge the prominent trajectory of dying in old age of 'prolonged dwindling' presenting an alternative conceptualisation of dying with many dying from an acute event while living with contributing chronic disease. The trajectory of prolonged dwindling is questioned as too simplistic. Greater recognition of acute events in this age group and place of death in care homes indicates service implications for wider provision of advance care planning and health service support to care homes as the main providers of end-of-life care to centenarians.  
**Funder:** NIHR Health Services and Delivery Research programme (project no. 09/2000/58).

**Abstract number:** P2-255  
**Abstract type:** Poster

### Identifying Advanced Chronic Patients in Need of Palliative Measures in the General Population and Health Services: A Prevalence Study

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**Aims:** To establish prevalence of advanced chronic patients in need of palliative care in the County of Osona (Spain).

**Methods:** Cross-sectional and observational prospective cohort study. 3 out of 11 primary care areas (32% of population) were selected to participate, as well as settings in these areas - general hospital (1), socio-health centre (1), nursing homes (4). The NECPAL CCOMS-ICO tool was applied to advanced chronic patients; those with 'surprise question' positive (SQ+) were identified; patients with SQ+ and, at least, 1 additional positive parameter, were considered as NECPAL+ and all of them followed-up for survival for 1 year, as well as general mortality occurred in the county.

**Statistical analysis:** number of observation, median, standard deviation, percentages and OR were calculated. Sensibility, specificity, PPV, NPV and AUC ROC for advanced chronic, SQ+ and NECPAL+ categories will be assessed regarding mortality at 3, 6, 9 and 12 months.

**Results:** 100% of centres participated. Total population was 49164 (>65y=21.4%). Between Nov 17<sup>th</sup> 2010 and Oct 25<sup>th</sup> 2011, 1064 persons (2.06%) were identified as advanced chronic; 750 (1.45%) as SQ+, and 684 (1.33%) as NECPAL+. PS+ persons are: medium age 82, 62.5% women; 31.73% show advanced frailty, 23.47% dementia, 12.7% advanced cancer (cancer/non cancer=1/8); 64.7% live at home and 22.1% live at a nursing home. 89.9% show general clinical indicators of severity and progression (nutritional decline: OR=5.79, functional decline: OR=4.9, admissions>2: OR=4.44, geriatric syndrome: OR=3.63). Only 17.7% of professionals considered identified persons in need of palliative care. Survival and mortality follow-up has just finished in Oct 25<sup>th</sup> 2012. Final analysis will be available in Mar 2013.

**Conclusion:** To determine prevalence is crucial for planning and implementing palliative care programmes with a public health, community and population-based approach.  
**Source of funding:** Department of Health, Government of Catalonia.

**Abstract number:** P2-256  
**Abstract type:** Poster

### High-grade Brain Tumors: A Challenge for Palliative Care Teams

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Patients with high-grade gliomas (HGG) represent a clinical challenge, due to their poor prognosis but also because of their severe functional and cognitive impairment. Increasing concern has been focused on quality of life of these patients and psychosocial burden of their caregivers. Objectives and methods To describe and analyze adult patients with HGG referred to the palliative care (PC) department of a tertiary hospital without inpatient palliative care unit (PCU), between March of 2008 and September of 2012, by the retrospective analysis of clinical process. Results Ninety six

patients were referred to PC mostly by neurosurgery (46,9%, n:45) or medical oncology (43,8%; n:42). The main reason for request was symptom control (54,2%; n:52) and care organization (44,8%; n:43). We observed 88 patients (8 died and 1 was transferred to another care facility before observation). The median age was 63 years (25-80) and 60,2% patients were male (n: 53). Half patients (n: 44) were first evaluated as outpatients and 47,7% (n: 42) as inpatients, observed by our PC mobile team. The main caregiver was the spouse (60,2%, n:53), followed by patients offspring (25,0%, n:22) and other family member (6,8%, n:6). At the first observation nearly 90% of the patients had a low performance status (ECOG 3-4). The most prevalent problems were motor impairment (80%), altered state of awareness (68%), pain (49%) and dysphagia (49%). Seventy-one patients died (80,7%): 34 in our hospital, 25 in a PCU and 12 at home. Ten patients were transferred to another department or medical institution and 7 are still in follow-up. The median overall survival was 7 weeks, IC95% (5,2-8,8). **Conclusion** Despite the complexity of problems, present since the diagnosis, HGT patients are referred to the PC too late. Focused not only in symptom relief but also in the psychosocial and existential problems of patients and caregivers, PC could probably reduce even more the burden associated with this disease.

**Abstract number:** P2-257  
**Abstract type:** Poster

### Are Palliative Care Patient Satisfaction Surveys with Low Response Rates Biased? A Randomised Study

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**Aims:** It is necessary to ask patients about their experiences of palliative care in order to identify problems, but due to advanced disease the response rate is often low. The aim was to investigate (1) the impact of questionnaire length and of sending reminders on patient participation, and (2) whether patient surveys of palliative care with low response rate are biased towards higher or lower satisfaction with care.

**Methods:** A unique Danish registry allows identification of incurably ill patients in the palliative care phase: These patients are entitled to free medicine, and are registered when this is granted following application from their doctor. We were allowed to contact consecutive cancer patients receiving this allowance. We randomised 998 of these patients between:

- (A) a long satisfaction with care questionnaire (16 pages) without a reminder and
- (B) a short questionnaire (2 pages) followed by a reminder to non-respondents after two weeks.

The validated FAMCARE-P16 patient satisfaction questionnaire was included in both versions, and the proportions of satisfied/dissatisfied patients (excluding 'Don't know') were compared between arms A and B using Chi-square tests.

**Results:** The participation in A was 21% (97 out of the 457 who were alive when contacted) and 41% (188/458) in arm B. Based on the temporal pattern we estimated that the participation would have been approximately 31% in B without the reminder. There were no significant differences in any of the 16 FAMCARE-P16 items between arms A and B. **Conclusion:** Low participation is an almost unavoidable methodological problem in research involving patients at the end of life. The short B questionnaire (2 pages instead of 16) affected participation as much as the reminder (each increased participation with 10 % points). This study suggested that low participation does not lead to strong bias: there were no significant differences in satisfaction between arms A (21% participation) and B (41% participation).

**Abstract number:** P2-258  
**Abstract type:** Poster

### A Study of Patients Reported to the Swedish Register of Palliative Care 2009 as Departed in Cancer But Not Registered in the Swedish Cancer Register

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**Background:** The Swedish Cancer Register (SCR), an old and reputable health data register, contributes a large amount of data used in research. The quality of the research using SCR data depends on the completeness and validity of the

register. In Sweden, every health care provider is obligated to report newly detected cases of cancer to the SCR regardless of the diagnostic basis. An unpublished report revealed that 19% of the patients in the Swedish Register of Palliative Care 2008 (SRPC) whose cause of death was cancer were not registered in the SCR. This study aimed to clarify whether there is an under-reporting of patients with cancer to the SCR or an over-reporting of cancer as cause of death to the SRPC. In addition, this study looked at the distribution of under or over-reporting related to age, sex, type of cancer, diagnostic basis, and department responsible for cancer diagnosis. **Material and method:** Of the 10,559 patients whose cause of death was cancer as reported to the SRPC (2009), 1394 patients (13.2%) were not registered in the SCR (1958-2009). Medical records from a representative sample of 203 patients were collected and reviewed. **Results:** The medical records for 193 patients were obtained; of those, 183 (95%) patients should have been reported to the SCR. Among these, radiologic investigation was the most common basis for diagnosis and there was a significant overrepresentation of cancer of the pancreas, lung, liver, and bile ducts. **Discussion:** The study cannot quantify the completeness of the SCR. The findings indicate that 12.5% of patients dying of cancer in palliative care are not reported, that specialized hospital departments diagnose the vast majority of the unreported patients, and that routines for how to report patients to the SCR based on radiological findings have to be revised.

## Ethics

**Abstract number:** P2-259  
**Abstract type:** Poster

### Palliative Sedation and Organized Palliative Care in Flanders (Belgium): From Palliative Sedation Research to Palliative Sedation Guidelines (and Back)

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**Background and aims:** Especially in a country in which euthanasia is a distinct possibility, it is of crucial importance that information on and expertise regarding other, less drastic 'options of last resort' is widely shared. This paper intends to show how the Flemish Palliative Care Federation through research, education and the development of guidelines has been trying to offer clarity and direction regarding the practice of palliative sedation. **Design & methods:** Starting from a brief overview of the different (conceptual, ethical, prospective-clinical, review, questionnaire) internationally published studies on palliative sedation in which the Flemish Palliative Care Federation actively participated (1999-2012), we show how this research led to a better understanding of palliative sedation and to the development, in close cooperation with the different working groups of the Federation, of specific guidelines and brochures in order to share these insights. **Results:** Through numerous lectures and workshops (1999-2012) and the development of a shared conceptual framework (brochure, 2006), guidelines on palliative sedation (2010, <sup>2</sup>2012), a practical summary of the guidelines (2012) and a leaflet on palliative sedation for the general public (2012) essential insights regarding i.a. terminology, the importance of proportionality, and the threefold distinction between euthanasia and palliative sedation (intention, act, result) have been widely shared. **Conclusion:** Palliative sedation continues to cause a great deal of controversy in many countries, especially because of a lack of expertise and of adequate information, the latter both at the level of the general public and of health care professionals. The research done by the Flemish Palliative Care Federation and the guidelines and information sheets developed (English translation available) can offer valuable inspiration to address these issues.

**Abstract number:** P2-260  
**Abstract type:** Poster

### Changes in Opinions and Attitudes towards Advanced Directives (AD) in the Primary Care Staff. 5 Years after the First Survey

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A Domiciliary Palliative Care Team starts a collaborative project with the Primary Care in 2006. **Aims:** To describe attitudes towards the Advance Directives (AD) of the Primary Health Care staff in our area. To describe changes 5 years after. **Methods:** Descriptive-qualitative study. **Setting:** Urban and rural **Subjects:** Center's staff. Who organized 5 focus groups. The chairperson introduced the AD concept, and informed about ethics and legal frames as well as the registration process of AD. The chairperson leads the dialogue. The observer registered the main questions about AD. An anonymous survey was given to attendants. We repeated the study 5 years later. **Measurements:** n°requested AD, n°delivered AD, n°assessed AD, Physician, Nurse. AD Knowledge, Request AD, Delivery AD, Assessment AD, Usefulness AD, difficulties of general population towards AD, Diffusion AD, Have you drafted your own AD. **Results:** N= 42 surveys, 69 in 2006, Attendants: Physician: 54% (2006) 51% (2011) Nurse: 46% (2006) 49% (2011). Practically all (98%) knew the existence of an AD document, but only 50% knew the complete contents of the AD. The AD knowledge increased in last 5 years with significant (p=0.0311). A request of AD was recided by 38% of attendants and 29% delivered AD document to the patients. There's a trend of increased demand of AD statistically significant (p=0.007) in last 5 years. Only 22% of attendants assessed the patient in some AD aspects (8.7% in 2006) without statistical significance. Practically all the attendants (98%) thought that AD was useful or very useful in their clinical practice. Practically all of attendants (93%) believed that the AD must be diffused among the general population. **Conclusions:** There's a better knowledge of the AD among the Primary Health Care Staff in last 5 years, although that knowledge is not total. There's an increased demand about AD by patients in last 5 years. Most professionals believe that the AD is useful in their clinical practice.

**Abstract number:** P2-261  
**Abstract type:** Poster

### The Spread of Palliative Care into the European Continent: A Meeting of Different Care Traditions

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**Aim:** Palliative care is spreading rapidly across the world but little is known about the socio-cultural factors influencing this process. We explore how the ideas of palliative care are received in different national contexts and how these relate to already existing approaches towards care at the end of life. **Method:** A qualitative survey on cultural issues in EoL care was sent to experts, European palliative care associations, and conferences targeted at palliative care professionals. Those who participated in the survey were asked to refer us to other relevant experts through a process of snowball sampling. The responses were analysed using content and discourse analysis. **Results:** We received 168 responses, mainly from academics (39%) and clinical practitioners working in an academic context (23%) from 19 countries in Europe and beyond. Respondents engaged enthusiastically with the survey's focus. The palliative care model was received differently when introduced in different national contexts. It has acquired an influential position mostly through integration into health systems. The priorities identified for developing palliative care were consistent with the culture-specific concerns relating to the end of life. In all countries, the adoption of palliative care changed debates about the end of life in national contexts and introduced a new ethos of care. However, respondents had little knowledge of the ways in which palliative care is developing beyond national borders, except for the option of euthanasia in some countries, and some high-profile media cases. **Conclusion:** When the ideas of palliative care started spreading to other countries it led to various reinterpretations of indigenous care traditions, and in the process, palliative care itself was modified. Agreement on standards and best practice for the further improvement of palliative care need to be informed by these ideas and practices that live in contemporary societies. **Funding source:** EU FP7

**Abstract number:** P2-262  
**Abstract type:** Poster

### Ethical Dilemmas in Nursing Homes Related to End-of-Life Processes: Differences with Other Clinical Settings

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**Aim:** To determine what health professionals that work in Nursing homes think on ethical issues related to end-of-life processes and what are the main differences regarding other professionals from different areas such as hospitals or primary care. **Methods:** Observational, descriptive and cross-sectional study between nurses who developed their work in primary care, hospitals and nursing homes. An ad hoc questionnaire was developed according to the aim of the study. We performed a descriptive analysis of the main variables, and ANOVA test was used for comparing the different groups. **Results:** Significant differences were found in the assessment of the ethical issues between different types of nurses. Nursing homes nurses showed higher scores on questions related to respect the wishes of the patient and family. On the other hand, the no-resuscitation orders are more implemented in hospitals than in the other settings of the study. Nurses of all settings, especially from hospitals, showed little knowledge about advanced directives. The most frequent ethical dilemmas in nursing homes are related to communication with the patient or family. **Conclusion:** In appearance, it seems to be more respect to patients and families wishes in nursing homes, than other clinical settings, but overall, our results show that the principle of autonomy often is not respected.

**Abstract number:** P2-263  
**Abstract type:** Poster

### Knowledge and Ethics: A Poststructural Discourse Analysis of Patients and Carers Views of Quality Palliative and Supportive District Nursing Care

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**Background:** Palliative and supportive care (P&SC) services increasingly aim to incorporate patients' and/or carers' views to improve quality of care. District nurses (DNs) (UK community nurses) play a key role in providing P&SC but less is known about the views of patients' and carers' with P&SC needs receiving DN care. **Aim:** To explore patients' and carers' perspectives on the quality of P&SC DN care. **Design and methods:** Qualitative design, using in-depth semi-structured interviews with patients and carers receiving DN care. Patients were recruited from DN caseloads and hospice day care centres, where possible they nominated a carer. Inclusion criteria: over 18, able to consent, and (for patients) receiving DN care, and requiring P&SC. Interviews were audio-recorded and transcribed. Poststructural discourse analysis techniques were used to examine how knowledge of DN services affect care. The study gained ethics and governance approval. Data were collected in 2010-2011. **Results:** Twenty-six patients and thirteen carers participated. Lack of knowledge on DN services emerged as a key theme. Patients' and carers' knowledge of DN services were entirely formed by media representations and/or current care. They were unaware of potentially beneficial services and were unable to envisage the development of DN care as their illnesses progressed; lack of knowledge about DN services governed patients' and carers' decisions about future care. **Discussion:** Poststructural analyses demonstrate how lacking knowledge detrimentally structures care. By not conveying knowledge, DN services become unethical and quality care is precluded by restricting patients' and carers' ability to access care beyond existing discourses on district nursing. **Conclusion:** If care is to be ethical, practitioners, managers and third parties need to disseminate knowledge of DN P&SC services in a variety of ways to ensure that knowledge rather than a lack of knowledge is informing decisions about care.

Abstract number: P2-264  
Abstract type: Poster

## Physician Assisted Suicide: Are Health Care Professionals More Liberal when Self-concerned - Differences between Palliative Care and Pain Specialists

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**Background:** In 2011 the guidelines for end-of-life (EOL)-care in Germany were changed. The phrasing of physician assisted suicide (PAS) changed from „unethical“ to “not one of the physician’s duties“. Since no study has been performed on physicians attitudes. Also no comparative study of different groups of health care professionals has been performed.

**Objectives:** To determine palliative specialist’s opinions about legalisation of physician assisted dying (PAS) and euthanasia comparing this with palliative nurses and pain specialists.

**Design:** Questionnaire (see Seale 2009). All 450 participants of a Palliative Congress and 100 participants of a pain symposium.

**Results:** A total of 358 questionnaires were returned, 100 from palliative specialists, 180 from palliative/hospice nurses, 35 from laypersons, and a sample of 37 pain specialists. In total 8% of the palliative specialists were in favour of euthanasia in case of life limiting diseases and 14% in favour of PAS. In case of non-malignant diseases all figures were lower, however, still more than 2% supporting euthanasia and PAS. In all questions physicians were more reluctant than nurses or laypersons. The same was true for religious or male respondents. A regular care for dying patients did not influence the results. Overall pain specialists supported euthanasia and PAS more than palliative people. When asked the same questions for EOL for the respondents themselves the acceptance of PAS increased.

**Conclusion:** This is the first study to compare different health care professionals and to ask for attitudes towards patients or themselves in Germany. The results are in line with former studies. However, taking all polls and studies together it seems that the support of PAS declines with the experience in EOL care, general population > physicians >> pain specialists > palliative nurses > palliative physicians. This is also the first study to show that acceptance of PAS is greater when self-concerned.

Abstract number: P2-265  
Abstract type: Poster

## To Treat or Not to Treat - Nurses Experiences of Giving Palliative Chemotherapy to Patients with Incurable Cancer

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Both the number of available drugs for palliative chemotherapy treatment (PCT) and indications for their use are expanding. Treatments are determined by the oncologist, based on the patient’s condition, experience of treatments, and expected effectiveness, and to some degree, patient preferences. Nurses administering PCT often have an established contact with a patient, and thus play an important role as s/he can see variations in the patient’s performance status. The nurse’s observations may raise questions about benefits and burdens with PCT and have the potential to influence if the planned PCT should be given or not. Knowledge about nurses’ assessments of patients receiving PCT is lacking, therefore the purpose of this study was to explore dilemmas experienced by nurses giving PCT to patients with incurable cancer. This was explored by qualitative interviews with 17 experienced nurses working at eight chemotherapy units. Nurses were asked to relate experiences of situations in which PCT was prescribed, but they felt the patient had deteriorated too much to receive treatment. These stories were analyzed with a narrative method. Analysis revealed three alternative types of stories in which PCT was administered, involving ethical dilemmas for the nurse:

- 1) nurse with initial concerns about PCT, and nurse’s assessment that outcomes were negative;
- 2) nurse with initial concerns about PCT, and nurse’s assessment that outcomes were positive; and
- 3) nurse with no initial concern about PCT, but afterward assessed outcomes as negative.

The nature of the outcomes and their ethical implications will be discussed.

Abstract number: P2-266  
Abstract type: Poster

## Euthanasia, Physician-assisted Suicide and Legal Issues of Palliative/Hospice Care in Opinion of Medical Students

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**Background:** In Poland euthanasia and physician-assisted suicide are illegal, and they belong to crimes prohibited by criminal law. Futile therapy is still not defined in Polish law, and physicians haven’t got any legal conditions to provide or withdraw of it. Nevertheless the Act of Law on Patients’ Rights and Patient Ombudsman provides patient’s right to die in peace and dignity, which is in opposition to futile therapy and patients’ right to die.

**Aim:** The aim of the study was to review students opinions on legal issues concerning end of life care, in particular euthanasia, physician-assisted suicide, futile therapy.

**Methods:** Statistical analysis of the responses obtained from a questionnaire directed to the last year medical students.

**Results:** 188 students of medicine from Medical University of Gdańsk took part in this survey.

Some participants of the study would accept euthanasia, physician-assisted suicide and futile therapy if they were legal and in accordance with the will of the patient (41%, 19% and 20%, respectively). On the other hand, 38% of medical students wouldn’t accept these solutions.

Less respondents would take part personally in euthanasia (25%) and in physician-assisted suicide (14%) and 50% of students wouldn’t accept their engagement in euthanasia, physician-assisted suicide and futile therapy. In opinion of half of all respondents euthanasia should be legalized under certain conditions, but more than 40% of participants of the survey believe that it should remain crime.

**Conclusions:** Medical students opinion on euthanasia, physician-assisted suicide and futile therapy depends on their personal engagement in this solutions.

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Abstract type: Poster

## When World Views Collide - The Ethics of the Staff and Volunteer Interface

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The ethics of volunteering in hospices constitute a little considered area and yet can lead to tensions for organisations, staff and volunteers, in addition to patients and families.

The aims of this session are to explore a number of questions around the:

- § ethics of volunteer involvement in hospices from the organisation’s perspective
- § issues which arise when volunteers and paid staff work alongside each other.

§ impact on the patient’s, staff, volunteers and the organisation when these situations are not addressed. Many hospices rely heavily on volunteers to provide a range of activities, including care and support to patients and families. It is accepted that in palliative care, many challenges can arise from inter-disciplinary working. Different professions have different ethical frameworks, individual values and world views which can lead to disagreement and conflict within the team. Add to this mix volunteers who may bring not only personal principles, but those of their own professional life and the potential for tensions increase significantly. When seen within the complex ethical context of palliative care, this can pose challenges, for organisations and individuals.

The key tenets of medical and nursing ethics - to do good and do no harm, maintain confidentiality and treat people as individuals apply easily also to the role of the volunteer. There are recognised ethical principles governing the involvement and management of volunteers - are these understood and valued as highly as those of paid professionals? Why is the interface between staff and volunteers so complex? What are the risks to patients and families when these are not acknowledged or addressed?

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Abstract type: Poster

## Attention Pattern Based on the Dignity of the Patients: Agreement Degree of Doctors in Specialized Training

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The dignity of the patients is an intangible concept and difficult to define. Chochinov H has reported different arguments defined by patients themselves that delimits what influences an individual’s sense of dignity. The patients who showed a fully agreement with the different arguments of dignity ranged between 87 and 50%.

**Objective:** Describe the degree of agreement of doctors in specialized training about values comprising the concept of dignity.

**Method:** Structured survey concerning 22 values of the dignity inventory, given to residents of our university hospital. The degree of agreement on these 22 values was asked, using a scale of Likert, in two different ways: first as the importance from the personal point of view and second as the degree of implementation in clinical daily practice. This survey was conducted in 2009 and 2012 after implementing a training program in bioethics.

**Results:** A total of 29 and 55 residents took the survey in 2009 and 2012 respectively. The maximum degree of agreement regarding personal importance and point of view of the 22 values of dignity was ranged between 82 and 7% in 2009, and between 93 and 27% in 2012 (p < 0.05).

The maximum degree of agreement on the implementation of the 22 values in clinical daily practice ranged from 46 to 0% in 2009, and between 87 and 16% in 2012 (p < 0.05).

**Conclusions:** Medical residents have assessed the importance of the 22 arguments about dignity lower than the data provided by patients themselves. Some personal values identified by doctors in training were applied with difficulty in daily practice. There is a trend of increase in the degree of agreement in the last survey. The data we confirm the importance of formation programs in bioethics during the period of specialized training. In the final presentation, the itemized data on the 22 specific survey questions will be presented.

Abstract number: P2-269  
Abstract type: Poster

Abstract withdrawn

## Family & Care Givers

Abstract number: P2-270  
Abstract type: Poster

## Inaccuracies in the Assessment of Body Image of Cancer Patients by Families

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**Aims:** To analyze the correlation between body image in cancer patients evaluated by family members and patients body mass index (BMI).

**Methods:** A cross-sectional study was conducted from June to August 2012 with 140 family members of cancer patients. Patients height and weight were measured to obtain the BMI real. With the Scale of silhouettes of Stunkard adapted, family members rated the BMI actual, previous and ideal patients and the general population. We obtained the domains idealization, distortion and dissatisfaction with body image. Statistical analysis was performed using the Pearson correlation.

**Results:** Most family members were female (82.8%), aged 30 to 49 y (55%), with a mean schooling of 10.5 y (SD = 3.3). Breast cancer (18.6%), colon (9.3%), uterine/ovarian (8.57%), prostate (8.57%) cancers and leukemia/lymphoma (8.57%) were the most frequent diagnoses. The BMI real was measured between 18.5 to 24.99 (52.9%) and 25 to 29.99 (28.6%). In the analysis of Pearson, there was a positive correlation of moderate to strong across all BMI, with statistical significance. The domain idealization showed a desire of family members that the patients weigh more (41.4%) or had the same BMI prior to illness (41.4%) (p < 0.001, CI = -2.66 - 0.81, r = 0.71). In the field distortion, all family members showed distorted body image of the patient, underestimating body size (43.6%) or overestimating it (53.4%) (p = 0.006, CI = 0.50 to 2.93, r = 0.61). As to dissatisfaction, the majority (58.6%) showed a desire that patients increase their body size (p < .001, CI = 2.08 to 4.67, r = 0.52).



**Conclusion:** Dissatisfaction and a distorted of body image of the patients can indicate expectations and evaluations sometimes unrealistic and inaccurate, which can be a source of conflict between family and patients. Such distortions require the proposition of interventions that adjust expectations in order to improve the unit of care (patient with cancer - family).

**Abstract number:** P2-271

**Abstract type:** Poster

### Providing Palliative Care at Home: How Are our Main Caregivers?

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**Aims:** Knowing the profile of the main caregivers, the support and the level of caregiver burden (CB) in our home palliative care programme.

Assessing whether there would be some relationship between the symptoms of the patient and the CB.

**Design and methods:** Descriptive study during the period from July to October 2012. We included all those caregivers who were identified as the main carer and had no exclusion criteria: age below 18 years and diagnosis of psychiatric illness. All of the patients had to be able to do the Edmonton Symptom Assessment System (ESAS) so they had to have ability to communicate effectively and they could not have cognitive failure and/or delirium. We used the Spanish Zarit scale to study the level of CB. Descriptive statistics were computed for the sociodemographic variables, the results of Zarit and all scale variables measured of the ESAS were calculated. We calculated the  $\chi^2$  test and the Pearson's correlation.

**Results:** The sample consisted of 50 caregivers, 82% were female, the mean age was 54( $\pm$ 15,2) years, 56% were the partner and 42% the children. 64% had no previous illness. The caregivers had been caring the patients for a median of 11 months and they spent a mean of 21,2( $\pm$ 5,8) hours a day caring the patient. 86% had no kind of social assistance, although 60% had some support of relatives or friends. In our sample, the average total score on Zarit was 50,6( $\pm$ 14), so 26% of the caregivers had "mild burden" and 32% "severe burden".

We have found no significant  $\chi^2$  value among the categorical variables. There are no significant Pearson's correlations between the Zarit and the different symptoms of ESAS.

**Conclusion:** The situation of our caregivers is worrying and similar to others studies in palliative care.

Although it appears that there was no relationship among the different variables, it's true that the sample is too small, so it's necessary to do more research with bigger samples and even do some prospective research.

**Abstract number:** P2-272

**Abstract type:** Poster

### Development of an E-learning Programme for Formal Family Meetings in Palliative Care

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**Background:** Several studies have demonstrated the benefit of formal family meetings in the palliative care setting. It is imperative that professionals are competent in conducting formal family meetings. A survey of staff in 2 specialist palliative care units (presented at EAPC Congress, Lisbon, 2011) found that only 20% of staff felt very confident in conducting formal family meetings and 52% thought that staff training was a priority for improving practice in the future.

**Objective:** A collaborative working group from the two centres undertook to develop a staff training programme for formal family meetings in palliative care.

**Methods:** Feedback from a pilot workshop in November 2011 highlighted the need to split the training programme into 2 parts: an E-learning programme outlining the principles of planning and conducting a formal family meeting; and a face to face workshop on communication skills training. The structure of the E-learning programme was decided based on agreed learning outcomes and a review of other relevant E-learning resources. The content was based on a comprehensive literature search and evidence-based guidelines.

**Results:** The E-learning programme comprises 5 sections: the role of each discipline in formal family meetings; the role of the chairperson; pre meeting planning; the structure of the meeting; post meeting debriefing and follow up. Each section contains a podcast and a video clip, followed by a

quiz to ensure that the participant has understood the concepts.

**Conclusions:** The E-learning programme will be used to train palliative care professionals on the principles underlying formal family meetings. This will be followed by the development of a face-to-face workshop to provide communication skills training for formal family meetings. It is hoped that this will help to address the education need identified by staff and increase both staff confidence and competence in carrying out this very important intervention.

**Abstract number:** P2-273

**Abstract type:** Poster

### Family Involvement in Hospital Care for Patients with Cancer in Indonesia: Lessons Learned from a Country with an Extended Family Structure - A Cross Sectional Study

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**Background:** Family involvement can contribute to the quality of life of a patient with cancer. As this is already part of the Indonesian culture, studying family involvement in caring for a patient with cancer in this country can provide important information for other countries.

**Objectives:** To determine which problems of patients with cancer were assessed and addressed during hospitalization in Indonesia and by whom.

**Methods:** Based on the Problems and Needs of Palliative Care short version, a patient as well as a nurse questionnaire were developed on involvement in caring aspects. As well nurses as patients filled in this questionnaire. Per problem, involvement in assessing and addressing them was asked. Descriptives were used.

**Results:** One hundred and nineteen hospitalized patients with cancer and 142 nurses participated. The patients stated that their capacity to perform activities of daily living (ADL), their physical and psychological problems were very often assessed (> 84%) and addressed (>90%). ADL were most often addressed by a nurse (80%), followed by physical (73%), spiritual (63%), social (54.4%) psychological (50%), and autonomy problems (49%). Physical problems were also often addressed by their doctor (77%); non-physical problems much less. Family involvement in caring was high, especially for problems with ADL (89%) and financial problems (89%). Nurses mentioned that they only assessed non-physical problems if the patient mentioned them spontaneously. Furthermore, almost all nurses stated that they addressed physical problems (96%), ADL (96%) and psychological problems (93%).

**Conclusions:** Nurses as well as the family have prominent roles in cancer care in Indonesian hospitals. The extended family structure plays a role by the prominent influence of family in daily hospital care. More information is needed on patient satisfaction with care and on family caregiver burden.

**Abstract number:** P2-274

**Abstract type:** Poster

### Challenges of Engaging Carers to Accomplish Assessment of their Support Needs in End of Life Care

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**Background:** End of life care (EOLC) at home is heavily dependent on the efforts of family carers. They often suffer adverse effects from care giving and thus EOLC policy recommends their needs should be assessed. However there has been no examination of the realities of accomplishing carer assessment in practice.

**Aim:** To identify challenges posed in EOLC in engaging with carers for assessment of their support needs. This formed part of a work program on implementing a carer support

needs assessment tool in practice.

**Sample:** Two UK hospice home care services (HHCs): 23 staff members (service managers, qualified nurses, health care assistants) and 6 family carers recruited via HHCs.

**Methods:** Focus groups and telephone interviews, digitally recorded and transcribed verbatim. Thematic analysis using framework approach.

**Results:** Health care professionals (HCPs) identified many challenges in assessing carers in practice. Three main themes were identified. The first related to accessing carers to assess: barriers included contact with carers being via patients who could block access, carers not being physically present during HCP home visits and changes in the main carer or carers at different times during the patient's illness. The second theme was the challenge of accepting the label of 'carer' not just for those supporting the patient but also for patients themselves, particularly in earlier stages when they was no 'hands on' care. Thirdly, health care professionals had to balance managing the needs of patients as well as carers. While their remit included both, referrals for input were for patients who were their priority.

**Conclusion:** Current UK health policy recommends carers should be assessed with little evidence on how this should be achieved in practice. This study offers important insights into the realities of carer assessment in practice and provides important contextual information for further development of policy guidance on carer assessment.

**Abstract number:** P2-275

**Abstract type:** Poster

### A Support Group Programme for Family Members: An Intervention during Ongoing Palliative Care

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**Introduction:** Patients with life-threatening illness are often cared for by their family members. Studies show that family members don't feel prepared enough and have adequate knowledge for the caregiving role. In an intervention family members were invited by the caring team to take part in a support group programme during ongoing palliative care.

**Aim:** This is an abstract for a doctoral thesis including 3 studies with specific aims:

I) describe experiences of taking part in the programme (n=10),  
II) describe experiences of support group programme design (n=29),  
III) investigate effects of the programme (n=125)

**Method:**

I), qualitative interviews

II), telephone interviews

III) questionnaires including assessments of preparedness, competence, reward, hope, anxiety, depression and health.

**Result:** Family members experienced confirmation, insight, sense of belonging and a moment of rest. The programme was experienced to cover topics of immediate interest. Family members taking part in the programme felt significantly more prepared and competent for caregiving and also felt more rewards of caregiving. No changes were found for hope, anxiety, depression and health.

**Conclusion:** Family members felt supported and the participation provided relief in their day to day life. They felt more prepared and competent for caregiving and experienced more rewards after participation.

**Clinical implications:** The results should provide encouragement in the challenging work to develop and deliver interventions, with the explicit purpose of supporting family members in palliative care.

**Abstract number:** P2-276

**Abstract type:** Poster

### The Impact of Family-centered Care in Reducing Stigma and Discrimination in the Management of HIV/AIDS in Children

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**Stigma** has been one of the major barriers for HIV+ children in accessing medical care. **Discrimination** occurs when a distinction is made against a person that results in his or her being treated unfairly or unjustly on the basis of their belonging, or being perceived as belonging, to a particular group; this may worsen the stigma and lead to poor family support, denial, failure to disclose of HIV status, denial for

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social support, experience loneliness, depression and increased rate of HIV transmission. A case study of an HIV positive male child aged 11 years old whose mother died from AIDS when he was 3 years old: his father abandoned him after discovering his HIV status. The child has been suffering from multiple skin infections, chest infections and generalized body weakness. Currently he is living with his grandmother. Through Family-Centered Care which enabled the involvement of the whole family, care and treatment plans were established. These included: home visits, psychosocial support, return to schooling and enrolment in the antiretroviral therapy program. Currently the child's health has significantly improved; he has returned to school and has attended grieving sessions as part of psychosocial support. Family-Centered Care plays a pivotal role in the management of children living with HIV and facing challenges of stigma and discrimination. It is easier to address the issue of stigma by involving the whole family.

**Abstract number:** P2-277  
**Abstract type:** Poster

### How Can We Support Parents to Adult Children with a Seriously Ill Disease?

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**Aim:** There are much research about being a parent to an under aged child but very little of being a parent to an adult child being seriously ill and who might die. How can the parent cope with this situation and which support is needed?  
**Method:** Qualitative interview study with a quantitative part. Thirty parents will be included in the study. They are sent an information letter and a consent blank. Those who consent to participate are offered an in-depth interview with the interval at 0, 9 and 18 month including two questionnaires about support and sense of coherence. The interviews will be analysed by content analysis and the questionnaires with descriptive statistics.  
**Results:** The study will begin in November 2012 and the first analysis of the interviews is available in January 2013 of the parents experience of having a seriously ill child, their involvement in the situation and the support they need.  
**Learned:** This study can give knowledge of how it is to be a parent to an adult child both in existential, practical and social dimensions.

**Abstract number:** P2-278  
**Abstract type:** Poster

### Cancer Patients in Homecare Settings: The Profile of Greek Caregivers

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**Introduction:** The role of family is very important and act as a strong support system for the cancer patient in Greece. In many cases, the relatives have assumed all the responsibilities and decision making on behalf of the patient and often interfere in ethical issues such as truth telling and informed consent.  
**Aims:** Describe the caregiver's profile of cancer patients in Greece.  
**Methods:** The sample comprised 95 family caregivers of people with cancer attending two regional hospitals as inpatients for active treatment or visiting hospital's pain management specialist as outpatients for consultation and prescription of analgesics. Eligible participants were the main family caregivers of patients with cancer who met the inclusion criteria and who attended the above-mentioned departments of the hospital during a 2-month period. Participants completed a self-reported questionnaire that included items about demography such as caregiver's age, gender, marital status and educational background.  
**Results:** The majority of participants in current study were women (79.3%). The age group with the largest representation in the sample was between 19-40 years old (47.6%). Most of them are holders of a bachelor or higher degree (46.3%), married (59.8%) and they are relatives of the patient (72.0%). It is important to mention that in the group of relatives are included patient's children.  
**Conclusions:** In a recent literature review, across the set of studies reporting demographics, the majority of samples were comprised caregivers who are females with an average age of 56 years old, in a spousal relationship and who are fairly well educated. In this study, there is evidence that in

Greece, relatives such as patients' children are involved in higher rates than in other mentioned studies. Probably this fact decreases the average age of the sample. Apart from these differences, the gender and education level are according current data from other countries.

**Abstract number:** P2-279  
**Abstract type:** Poster

### Religious Symbolism in the Experience of Brazilian Families of Children with Cancer in Palliative Care

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**Aim:** Understand the role of religion for families of children with cancer in palliative care.  
**Method:** Ethnographic case study, involving five families of children with cancer in palliative care, monitored at a teaching hospital in São Paulo State-Brazil. Data were collected through open interviews with the parents, based on a guiding question: the role of religion during palliative care delivery to children with cancer; and participant observation, which contributed to understand the sociocultural context. Data were organized according to Seidel's proposal and analyzed according to the foundations of interpretative anthropology.  
**Results:** It was observed that religion is important for the parents to understand and elaborate their grief; and that religious belief permeates the families' experiences as the supporting pillar for parents and children. Religion was a coping strategy the families used in palliative care delivery, allowing them to elaborate a meaning for the suffering inherent in the death of their child. We observed that the parents were able to tolerate the suffering, possibly because they associated this process with religious resources capable of giving meaning to their emotional experiences. Some of these experiences are similar, but the contact with death was singular and influenced by plans, rules and instructions that ordered these families' behavior.  
**Conclusion:** The study results were relevant for palliative care delivery to children as, by apprehending the meanings of religion for the families through their "lenses", we identified aspects that can guide the planning of this care, based on the principles of palliative care, reinforcing the need for individual, multiprofessional and interdisciplinary care, based on the families' experience during the process of death, dying and grief.

**Abstract number:** P2-280  
**Abstract type:** Poster

### Bereaved Carer's Experience of Caring for Patients Dying at Home

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**Aims:** The aim of the study was to understand the impact of caring for a dying patient at home has on carers, by exploring the experience of bereaved carers.  
**Methods:** Purposive sampling was used to identify the bereaved carers. All the bereaved carers who were interviewed, were under the umbrella of, and identified by the local hospice bereavement service. In each case, the patient had died 6 to 7 months prior to the interview. The participants were interviewed using semi-structured interviews and the phenomenological approach was used to provide an insight into the living experience of the carers. The Heideggerian hermeneutic interpretation allowed the lived experience to be described, with the researcher's experience, values and beliefs acknowledged.  
**Results:** 8 bereaved carers were identified and interviewed, 6 female and 2 male (aged between 35 and 65). The study showed the familiarity of the home environment created a real sense of normality, dignity, autonomy and control for both the carer and the patient. 5 common themes were identified:  
1. Special times; focusing on closeness of the relationships, acceptance of dying and the comfort of the familiar home environment.  
2. Care all consuming; resulting in exhaustion, frustration, resentment, guilt and loss of relationships.  
3. Conflict; raising issues of autonomy and control, lack of open communication, impact of changes to home environment, involvement of care agencies and financial burden.  
4. Clockwatching; descriptions of a rollercoaster experience and periods of "listening to every breath"  
5. Coping mechanisms and strategies; influenced by patient

and carer personalities, and acceptance of death. Participants' responses were more positive and emphatic about being at home than the literature suggested.  
**Conclusion:** This study demonstrates the impact on carers of caring for dying patients at home, affecting both the caring process and bereavement, highlighting the need for a comprehensive carer assessment.

**Abstract number:** P2-281  
**Abstract type:** Poster

### Itinerant School for Carers: Training for Family Members Is Crucial in End of Life Care

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**Aims:** To identify training needs for those caring for palliative care patients at home and to put into service an education program aimed at them, in the patient's own home, through a travelling carers school.  
**Methodology:** Qualitative study through conversation techniques, such as semi structured interviews and focus discussion groups, so that content analysis can help us know people's subjective views and perceptions.  
**Unit to Study:** those family members caring for a relative with palliative care needs.  
**Sampling through convenience, with voluntary character**  
**Results:** Those caring for people with palliative care needs have family ties with the patient. Oncological pathology is more prevalent than non oncological pathology. Among carers, patience is identified as their greatest asset and emotional control techniques as top priority, specially in situations of pain and distress. They identify as equally important training needs related to the management of patient's basic care needs (personal hygiene, getting them to use the toilet, etc.) specially in the bed bound.  
**Even though carers believe to have good control over prescribed medication, we observe their intuitive management of analgesia, as with other care interventions, since they have not been trained to give basic daily care which makes symptom control more difficult.**  
A recurrent problem carers put forward is that they tend to get very attached to the patient, rather than detaching from them, which makes their attending groups or schools away from home impossible for them.  
**Conclusion:** As one of the interviewees said: "... caring for her now means giving my own life up, she is going through a rough time and I am not there with her ... her pain, her suffering are my own, there is no difference". This care's statement sums up why this type of training close to the patient is necessary.

**Abstract number:** P2-282  
**Abstract type:** Poster

### Families' Experiences of Assisted Suicide in Switzerland: A Qualitative Study

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**Background:** In Switzerland, helping with Assisted Suicide under certain conditions is not prosecuted. Family involvement in assisted suicide and experiences of bereavement afterwards are understudied and the results from the few published studies are rather contradictory.  
**Aims of the study:** To explore family involvement in decision making prior to assisted suicide and to examine their ways of coping during the bereavement period.  
**Methods:** A qualitative pilot interview study was conducted on 11 relatives of eight patients who died following assisted suicide between January 2007 and May 2009 in Southern Switzerland. The principles of Grounded Theory analysis were adopted.  
**Results:** The majority of family members faced moral dilemmas during the decision making phase. Their main concern was breaking the "thou shalt not kill" rule, by helping the patient, regardless whether they were in general agreement with it. Respect of the patient's autonomy helped relatives overcome this dilemma. During the decision making phase two types of involvement of the

interviewed were identified: "passive" and "active". Passive when relatives were in disagreement or the decision making challenged them at a moral level. Active when assisted suicide was proposed to the patient by a relative and/or the relative contributed to the legal procedures. The relatives reported feelings of isolation during and after assisted suicide. Family members reported fear of social stigma and tended not to disclose assisted suicide after the death beyond to these already involved.

**Conclusions:** Bereaved families are confronted with moral dilemmas, isolation and secrecy in the management of assisted suicide in Southern Switzerland. These features maybe underestimated and not adequately addressed by the health care professionals. Management of assisted suicide requests should require consideration of families needs, in addition to those of the patient.

Abstract number: P2-283  
Abstract type: Poster

### Approaching the family in Palliative Care Research - A Case Study Facing Methodological Challenges

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**Aims:** Better understanding family carers' perspectives has become a widely recognized research area in palliative care, especially in the home care setting. Some methodological challenges remain to be unsolved: In most studies data are collected from one family member, identified as the "main carer". Following such an approach the characteristics of families as complex networks run a risk of being disregarded.

**Methods:** This problem arose in an ethnographic study on recognizing dying in palliative home care. Observational data of dying trajectories (n=16) were supplemented by interviews with bereaved family members and professional carers. We decided to incorporate a case study dealing with the issue of sampling. The case of Mrs. M., a 56year old woman who died from breast cancer was selected and additional interviews with all bereaved family members available and the hospice volunteer (n=6) were conducted. Interviews were transcribed verbatim and analyzed by using a coding procedure to work out core themes as basis for comparison of perspectives.

**Results:** We found major differences in the perspectives on the dying trajectory among the people interviewed. A systemic perspective offered insight into the fragile balance between hope and fears within the family, represented by different members of the family, according to their emotional involvement as well as personalities. It became obvious that no one single interview would have represented a certain family perspective covering the others. Instead the different perspectives complemented one another.

**Conclusion:** The results raise important issues for future research in family carers in palliative care. To consider the family as a complex system affords sensitive research designs, which might be put forward best in collaborative interdisciplinary research groups.

Abstract number: P2-284  
Abstract type: Poster

### Respite for Parents Caring for a Child with Incurable Illness

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**Background:** Family remains in our society the main care provider in case of a child with an incurable illness, struggling to insure that all effort is done for achieving the longest possible life for the child and the best quality.

**Aim:** To identify the respite needs of parents of children with incurable illness assisted by our palliative care service.

**Method:** Prospective study, survey of parents who have had children in our care during January-June 2012. A purposely design questionnaire with 32 items with multiple choice, Likert rated and open ended questions was administered through a face to face interview. Data were analyzed with SPSS 13.0.

**Results:** Data were collected from 101 subjects, parents caring for a child with incurable illness. Response rate was 100%. In 97% of cases the main carer was one of the parents. 66,34 % of the parents are involved in the care of their children between 13 and 24 hour/day. 11,88 % are involved between 9 and 12 hours/day. The time for self-care allocated is reduced; thus for 61,39% of the parents 1 hour/day is the maximum time for self-care. 55,45% of the parents affirmed that they felt neglected due to lack of time for self-care. In

the same time, 80% of respondents benefit of support from the family when they are tired. 33,66% of the parents have abandoned the working place so they can take better care of the ill child, 33,66% didn't abandoned the work place and for 32,67% the illness of the child was the possibility to become employee as personal assistant of the child.

**Conclusions:** Regarding the cultural, social factors and existent public health system, there was identify a complex spectrum of respite needs for parents of incurable ill children. This study brings evidences for respite needs and families expectations regarding this type of service. Also, this research makes recommendations regarding the modalities of answering to the respite needs of the parents caring for incurable ill children.

Abstract number: P2-285  
Abstract type: Poster

### Initial Referral to Palliative Day Care Brings Fear and Anxiety to Family Caregivers: Findings from an Irish Qualitative Descriptive Study

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**Aim:** This presentation focuses on a theme identified within a study to describe family caregivers' experiences of supports received in an Irish palliative care day centre. The presentation discusses participants descriptions of how initial referral and first attendance at day care brought fears and anxieties to family caregivers.

**Background:** An emphasis on home care for patients with advanced disease (DoH&C 2001) has meant that family caregivers' are taking on greater responsibilities. Palliative day care can have a significant impact on alleviating some of the carer's stress and burden. However these carers should be able to access the service without fear. The paucity of research exploring Irish caregivers' experience and a need to develop this service prompted the study.

**Methodology:** A descriptive, qualitative approach was utilised. Following ethical approval six purposively sampled family caregivers' were interviewed. Data was analysed using Braun and Clarke's (2006) thematic analysis framework.

**Findings:** Participants' described the referral and transition to palliative day care and the worries and fears encountered. They anticipated a more 'hospital' atmosphere and were afraid of seeing a lot of very sick people. They worried about the reaction of their loved one. Once they had arrived they welcomed the homely environment of day care and participants were relieved and glad to be able to share the "heavy weight" of responsibility with the staff of the palliative day care unit.

**Conclusion and recommendations:** Referral to palliative day centre caused initial fear and anxiety for participants. However, following the first visit the support provided was valued by participants'. Participants suggested additional ways to ease transition into the service might include, meeting a staff member beforehand, or having an opportunity for family member to visit day centre in advance.

Abstract number: P2-286  
Abstract type: Poster

### Training of Family Members/Relatives and Caregivers during 2010-2012 LASKA Irena, KOLECI Gerla, GEGOLLARI Entela, STASA Eda

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**Goal:** The presentation of the trainings held to provide useful information for family members/caregivers of patients of Mary Potter Palliative Care Center.

**Methods:**

1. Interviews with family members /caregivers of patients prior to the training.
2. Needs assessment on the importance of these trainings
3. Data analysis form the interviews held prior and after the trainings
4. The feedback of the patients regarding the quality of care provided by their caregivers after the participation in our trainings

**Results:**

1. 21 trainings have been organized with 240 family members/caregivers of patients participants during 2010-2012
2. The trainings focused on the importance of the delivery of drugs in the right dosage and time.
3. Communication with the patients
4. Management of emergencies
5. The proper care to prevent the creation of pressure sores,

provision of a good diet and the care during the last 48 hours

**Conclusions:** These trainings are very important for the impact they have on the care provided to the patients at home. The work with groups has helped them face together issues and situation that they have found common for everyone. Sharing experiences, thoughts and suggestions on optional solutions of similar problems has been a very good help to them.

**Keywords:** Patient, family member/caregiver of patient, trainings.

Abstract number: P2-287  
Abstract type: Poster

### Older Parents' Experiences during a Serious Illness Trajectory and after the Death of an Adult Child: A Qualitative Study

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Increased life expectancy enhances the likelihood that older people face a serious illness in an adult child and even will outlive their child. We aimed to explore the lived experience of these parents and the underlying processes that are of interest.

A qualitative study using narrative interviews was used to elicit accounts of 20 parents (≥70 years). Data were analysed with support of NVivo 9, based on the principles of grounded theory.

The cancer diagnosis in their adult child exposes parents to a multitude of intense feelings which are often contained in the presence of their sick child, in order not to stimulate the others' suffering. Most parents want to resume their parental responsibilities by means of 'being there', which can take many forms and intensities. The exercised form of parenting is influenced by several factors i.e. their relationship history, the degree of care dependency and the marital status of the adult child. Envisaged parenting is complicated by their uncertainty of what is appropriate in the situation where the partner of the adult child is frequently taking the position they once occupied, and by their lack of status as older parents.

The death of an adult child is a life-altering event for older parents. Feelings of survivor's guilt and self-blame coexist with an increased awareness of their own impending death. A consistent theme is the older parents' holding on to their memories and continued encounters with their deceased child. They have a need to talk about the deceased child and his/her life but do not always have the opportunity to do so.

Aged parents carry deep burdens from the prospect of losing their adult child. There is also evidence that they want to stay involved, but need to reconstitute their parent role. Mutual protection is an important phenomenon in this context wherein health care providers could play a role by stimulating open communication between both the adult child and the older parents.

Abstract number: P2-288  
Abstract type: Poster

### Older Parents' Experiences Following a Serious Illness Trajectory of an Adult Child: A Review of the Literature and Recommendations for Future Research

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Given the increasing life expectancy, the likelihood increases that health care providers are confronted with older people having an adult child with a life-limiting illness. This literature review aimed to

- (1) explore the experiences of older parents in relation with their position and role as a parent of an adult child with a life-limiting illness,
- (2) detect gaps in the existing literature and to make recommendations for future research.

Studies were identified by searching four electronic databases including: Web of Science, MEDLINE, CINAHL and Google Scholar. In total, 29 published studies were included. Few studies describe the experiences of older people having an adult child with cancer, or having an adult child who died from cancer. From the moment the cancer diagnosis is disclosed, parents are confronted with a reawakening of the parental nurturing which clashes with the autonomy of the

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adult child. Even after the adult child is deceased, older parents retain the image of themselves as parents. The included studies are merely descriptive and give no concrete recommendations for health care providers in daily practice. No intervention studies were found. In the current literature little is known about this topic. Limited research exists to provide concrete recommendations for health care providers in daily practice and helpful family-centered interventions. There is need for more in-depth research to understand the lived experience of these parents and what health care providers can do to assist these older people.

## Medical Sociology

Abstract number: P2-289  
Abstract type: Poster

### From 'Friendly' to 'Inclusive': Responding to the Needs of our Gay, Lesbian, Bisexual, Transgender and Intersex Community

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The international palliative care community has proposed that the provision of palliative care is a basic and international human right. Palliative care services are generally created with the needs of mainstream society in mind, and although these services attempt to accommodate everyone, the unique challenges of serving marginalised populations can make this difficult.

With this in mind, it is necessary to have a coordinated and planned response to service delivery for all patients, carers and families. By attempting to learn about the patient's background, significant support can be given to the patient and their family. This can make an enormous difference in the building of relationships with the patient and carer and with their community as a whole.

In Australia, one of the social determinants of health leading to patterns of health inequity is that of sexual orientation and gender identity. Research demonstrates that GLBTI people have poorer health outcomes than the general population because of the discrimination they experience. The actual or perceived discrimination from many services also means that GLBTI people are more likely to avoid or delay seeking care.

One of the larger minority communities in our catchment area is the Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) community. Melbourne Citymission Palliative Care (MCMPC) has recently taken part in a pilot accreditation process for a *Rainbow Tick* - a program developed to address the health inequities for GLBTI people by allowing us to understand and respond to the needs of our GLBTI patients in a systemic manner. The main thrust of the process is to allow services to move from 'friendly' to 'inclusive' practice and be able to provide evidence of the same.

This paper will outline MCMPC's experience and outcomes of this pilot GLBTI accreditation process, as well as the processes put in place to ensure we can evidence 'inclusive' rather than 'friendly' practice.

Abstract number: P2-290  
Abstract type: Poster

### Extending Palliative Care to Marginalised Population Groups - Our Muslim Community

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It has been proposed by the international palliative care community that the provision of palliative care is a basic and international human right. Palliative care services are generally created with the needs of mainstream society in mind. Although these services attempt to accommodate everyone, the unique challenges of serving marginalised populations make this difficult, and cultural barriers can add to these challenges. It is necessary to have a coordinated and planned response to service delivery in palliative care for all Culturally and Linguistically Diverse (CALD) clients, carers and families. By attempting to learn about the client's religious and cultural background, significant support can be given to the patient and their family. This can make an enormous difference in the building of relationships with the client and carer and with the community as a whole.

As part of our quality process, we reviewed our statistics and it was apparent that the provision of palliative care to our Muslim community did not reflect the level of service provision that taken up by other CALD communities in our catchment area. Anecdotally we saw that this could be due to a number of factors but we did not have any evidence to support these possibilities.

Consequently, Melbourne Citymission Palliative Care (MCMPC) chose to investigate the reasons behind this apparent lack of referrals for palliative care, and the barriers that might be inhibiting these referrals. With this knowledge, we hope to be able to better offer timely and appropriate care to our clients from the Muslim community and establish closer relationships with the Islamic community. For our staff, knowledge of customs and rituals around death and dying will be important, and for the community the dispelling of rumours around palliative care will potentially lead to an increase in referrals from this community.

Abstract number: P2-291  
Abstract type: Poster

### Biographical Disruption - A Descriptor for the Experience of Advanced Colorectal Cancer?

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**Aim:** Biographical disruption is thought to occur in response to chronic illness, where the person's taken for granted assumptions of everyday life and their relationships are disrupted and restricted. The aim is to explore to what extent those with advanced colorectal cancer (CRC) describe biographical disruption; if they conduct biographical work to manage their sense of self; and how this changes over time.

**Methods:** The study adopted a qualitative longitudinal design, employing in-depth interviews with 16 participants with advanced, metastatic colorectal cancer. Narrative and thematic analyses were employed to capture the major issues and themes at each time point and longitudinally to explore how the participants' experiences evolved over time.

**Results:** Not all the participants experienced threats to their sense of self as a result of the disruption caused by the cancer. Firstly, there were those who experienced disruption which threatened their sense of self over the course of the study. Secondly, there were those that experienced disruption, but did not describe a threat to their sense of self. However, biographical work was carried out in both groups. Participants in the former group were attempting to restore a sense of the self whereas those in the latter group were working to maintain it. In the earlier interviews participants used the 'you' voice to assign themselves a collective identity. In later interviews they wanted to define an after death identity.

**Conclusions:** The findings suggest that biographical disruption should not be used as a standard framework for describing the experience of illness. One way participants conducted biographical work was by reflecting on their legacy and negotiating how they were going to be remembered after their deaths. Further research should explore the benefits of an early intervention to support people with CRC to plan for the future. This PhD studentship was funded by the Economic and Social Research Council

Abstract number: P2-292  
Abstract type: Poster

### Living with Lung Cancer: A Longitudinal Interview Study with Patients Participating in the FRAGMENTIC Trial

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**Research aims:** Advanced lung cancer patients are under-represented in oncology trials and very little is understood about their experiences of clinical trials. FRAGMENTIC is the largest lung cancer study in the world and is investigating the effects of Fragmin (a self-injected anti-coagulant) in patients with lung cancer. This current study (QUALFRAG) is a qualitative sub-study of the FRAGMENTIC trial. The study aims to explore patients' experiences of participating in the FRAGMENTIC trial and of living with advanced lung cancer.

**Study design and methods:** Twenty semi-structured interviews were carried out with 10 patients over three time points. Patients were recruited from the intervention (n=6) and control (n=4) arms of the FRAGMENTIC trial. The data were analysed using Interpretive Phenomenological Analysis methodology.

**Results:** This paper reports on key themes relating to patient

copying and adaptation. Patients described their efforts at symptom management and lifestyle changes, gave examples of how they rationalized and reappraised their symptoms and demonstrated a mix of more 'passive', fatalistic coping strategies as well as strategies pursued to give patients feelings of agency and control over their lives. Patients also identified coping resources at individual, social and institutional levels which helped them to adjust to, and manage their illness.

**Conclusions:** These results increase our understandings of how advanced lung cancer patients learn to manage and make sense of their illness and the key resources which help them to do so. These findings have theoretical relevance to the social and psychological literature on coping and practical implications are identified for health and social care providers.

Abstract number: P2-293  
Abstract type: Poster

### 10,000 Palliative Care Consults

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**Aims:** The Palliative Care Consult Service (PCCS) in this 544 bed community based, tertiary care teaching hospital (one in a system of 8 hospitals) was established in 2003 and completed over 10,000 consults by the end of 2011. The purpose of this study is describe outcomes from 10,000 consults and demonstrate how the palliative care (PC) service database informed administrative, clinical, and research decisions leading system-wide growth in the hospice and palliative care program.

**Methods:** A PC nurse practitioner was responsible for maintaining the PCCS database in an Excel file. The PCCS provided computer and internet services to support data entry and database maintenance.

**Results:** Volumes have been stable for the past 3 years at approximately 1,600 per year or approximately 3.3 per adjusted occupied hospital bed per year. Currently 56% of consult requests originate from medical units, 31% from intensive and coronary care units, and 6% from the emergency department. These percentages varied with the addition of intensive care beds and the opening of the Acute Palliative Care Unit (APCU), the latter leading to a 45% PCCS growth rate the following year and growth in the systems own home hospice program. The mean number of days to consult varied and decreased over time for both ICUs and medical unit patients.

**Conclusions:** The database provided evidence of growth and volume to justify opening the APCU, adding PC clinicians, an outpatient PC clinic, a PCCS for extended care facilities, and demonstrated ample volume to support a palliative medicine fellowship. When hospital databases do not provide the detailed data needed to efficiently track and analyze PCCS process and outcomes, a PCCS maintained database is an essential component of clinical and administrative management. The study was hospital funded.

Abstract number: P2-294  
Abstract type: Poster

### "How Would you Like it to Be Around You when You Are Dying?" Perspectives from an International Group of Museum-visitors: A Trans-disciplinary Collaboration

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Data is lacking on how the general public conceptualizes a "good death" at this time in history. This presentation provides such data generated from an international general public. An architect, ER, interested in crossing disciplinary borders, initiated a unique project which teamed 5 pairs of artists and craftsmen together. Each pair then created prototypes related to space for difficult conversations in end-of-life settings. These prototypes were presented in an exhibition, "Room for Death", at the Swedish Museum of Architecture in Stockholm, which included Swedish and English audio- and written text about reflections on settings for death and dying, from June -Sept 2012. Through their role as project consultants, palliative care researchers were asked to contribute with a question directed to the public viewing the exhibition, to explore their reflections.

An A5 paper with the question: "How would you like it to be around you when you are dying?" in Swedish and English

was placed in a central place at the exhibition, for documenting reflections if so desired. The English question was followed with a question about country of residence. This paper was then placed in a small chest, similar to one shown in the exhibition for storing memories.

513 responses to this question were obtained from 48 countries on all continents. Most responses came from Sweden, followed by the US, France, Germany and Italy. Responses have been scanned and transcribed verbatim into a qualitative analysis software program. Analysis is ongoing, and will be continued in collaboration with ethnologists. Preliminary analysis points to many similarities in idealizations of death across countries, including the dominance of themes relating to the sensory environment, the presence of nature, and the importance of the familiar. This will be further elaborated and discussed from the perspective of health-promoting palliative care.

**Abstract number:** P2-295

**Abstract type:** Poster

### Continuous Deep Sedation at the End-of-Life and the Question of Personhood - A Ring Theory Approach to Better Understanding the Personhood of Palliative Care Patients

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The practice of administering continuous deep sedation (CDS) or terminal sedation at the end of life has generated significant controversy, not least for its perceived life abbreviating effects. Although concerns about the potential life-shortening effects of CDS have abated as a result of growing data about its safety together with clearer guidelines and monitoring, the practice remains controversial. Most recently, controversy over CDS has shifted to scrutinizing its wider effects upon a patient's consciousness. Here, the iatrogenic induction of sedation through the application of CDS in a proportional manner ostensibly till death for the treatment of intractable symptoms is said to effectively eliminate a patient's social presence and create a situation largely indistinguishable from 'social death'. Some claim the terminally sedated patient is no longer a person. This paper attempts to confront this assertion through the application of The Ring Theory Model of Personhood.

The Ring Theory Model of Personhood suggests that personhood is constituted by three closely linked, dynamic areas—an inner most ring, the **Innate Ring**, is rooted in Judeo-Christian precepts and views all individuals as reflections of God and imbued with dignity and rights, irrespective of their state of development or degradation; the middle ring, the **Individual Ring**, encompasses the values, beliefs, roles, personality traits, goals and preferences an individual holds and expresses; and finally, the outer most ring we term the **Relational Ring**, consists of an individual's personal ties and connections with others.

Ultimately, this paper

- (1) draws attention to the fundamental conflict dominant conceptions of personhood have created,
- (2) suggests a critical re-theorization of personhood based upon survey data and interactions with patients and caregivers, and
- (3) discusses how the various elements in the Ring Theory Model of Personhood sustain the personhood of terminally sedated patients.

## Organisation of Services

**Abstract number:** P2-296

**Abstract type:** Poster

### Bureaucratic Challenges for the Palliative Care Social Worker

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**Background:** The lack of social measures in Romania during the communist regime is reflected on the entire population. It is a real challenge for a social worker to deal alongside of poverty reflected through reduced access to medical treatments, no proper nutrition, lack of transportation means and lack of health insurance also with complicated procedures in accessing rights stipulated through present legislation.

The purpose of this study is to emphasize the fact that the social system in Romania can be improved, and even if there

are laws to help people in difficulty, there are many gaps and barriers in enforcing those laws.

**Method:** A retrospective study looking 6 months back at Hospice patients for whom the social workers conducted the entire process of obtaining their rights according to law 448/2006.

**Results:** According to our study, out of 326 new patients admitted in hospice services, 187 were after social evaluation qualified as cases eligible for disability certificate. 97% received legal information about their rights in the first week after the admission in our care but 34% died before they had the chance to be reviewed by State Social Service Assessment Department and receive the rights they were entitled to. A number of seven services (Oncology Hospital, City Hall-Social Services Department, General Direction of Social Assistance and Child Protection-State Social Service Assessment Department, Expertise Commission of Disability, Monitoring Service, Legal Service, Financial Legal Rights).

**Conclusions:** Due to bureaucratic and legislative steps that do not take into consideration the short life span of our patients, obtaining the legal rights that come with a disability certificate was extensively delayed. Regardless of the prompt intervention and effort of the social worker, many patients died while their files were processed by one of the many services involved.

**Abstract number:** P2-297

**Abstract type:** Poster

### Abstract withdrawn

**Abstract number:** P2-298

**Abstract type:** Poster

### Founding Multidisciplinary Palliative Care Service in Tertiary Care Hospital - First Initiative in the Country

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**Background:** Tertiary care provides the high level of medical competence and is the best place for improving patient care in the management of the chronic disease and its consequences.

**Service development:** Developing multidisciplinary teamwork in a tertiary care hospital aims to improve quality of life for patients and their relatives.

We have expanded the palliative care services beyond oncology to care for patients with chronic diseases and have implemented international palliative care principles. There are designated in-patient and out-patient palliative care services. We have defined good practices in palliative care and developed methods for implementing the best possible palliative care in hospitals and in home care.

We provide care to improve coping with psychologically difficult environments.

We aim to reducing the expenses and increasing the satisfaction of patients and their families.

Ultimately we aim to meet the requirements of an internationally accredited cancer center which is necessary to established palliative care services.

**Conclusions:** Development of palliative care poses many challenges: it is a multidisciplinary field and there is lot of work still to do to reach perfection.

**Abstract number:** P2-299

**Abstract type:** Poster

### Care Support Volunteering for Palliative Care Patients and Relatives (Volunteer Support Program for Palliative Care)

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**Introduction:** Specific actions focussed to promote collaboration between NGOs and Extremadura Health Service were scheduled in the Frame Programme for Palliative Care in Extremadura, launched in 2002, in order to improve quality of life of patients and relatives.

Moreover, a series of activities devoted to endorse volunteering in such scope were performed by 2005. They gave rise to the Palliative Care Volunteering Organizations Network (currently composed of fourteen non-profit organizations) as well as to the development of a Volunteer Support Program for Palliative Care aimed at coordinating actions to meet the volunteering support demand.

**Goal:** Provide individual care support for terminally ill patients and relatives.

**Methodology:** The Program revolves around the coordination of actions in the ambit of the Volunteer Support Program for Palliative Care, according to the specific needs for volunteer intervention reported by healthcare professionals. This way, the selection of suitable volunteers and, if any, the monitoring of the care support intervention will be fully guaranteed.

**Results:** (from 2006 to 2012)

Performance protocol among Regional Ministry for Health and Social Policy, Extremadura Health Service (EHS) and the various organizations developing the Volunteer Support Program.

Collaboration agreement with EHS for the promotion of the Volunteer Support Program.

240 volunteers joined training in this subject.

Care support provided to 202 patients and performance of more than 748 actions in the ambit of volunteer care support, performed 114 locations of our Autonomous Community.

**Conclusions:** Coordination of volunteering institutions regarding care support for terminally ill patients prevents duplication of efforts and promotes collective experiences and addition of resources, thus favouring a wider coverage of the volunteering intervention demand.

**Abstract number:** P2-300

**Abstract type:** Poster

### What Characterizes Patients with the Need for Long-term Specialized Palliative Care at Home?

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**Background and aim:** In Germany patients do have a right to receive specialized Palliative Care at home. Health-insurances must approve the patients need for specialized Palliative Care on request of a physician. Aim of the present case study was to find out which factors are associated with the need for long-term specialized Palliative Care in a home-care setting.

**Methods:** Cases of patients with the need for long-term specialized Palliative Care at home from the region Schleswig-Flensburg were recorded and analyzed. The specialized Palliative Care Team from Schleswig serves patients in a radius of about 20 kilometers surrounding the town of Schleswig in Germany. The team consisting of specialists in Palliative Medicine and Palliative Care Nurses is on duty 24-hours a day. For our case study long-term specialized Palliative Care was defined as need for specialized Palliative Care for more than three months.

**Results:** Patients with the need for long-term specialized Palliative Care at home had often complex problems and symptoms associated to advanced cancer. Interventions by the Palliative Care Team could e.g. treat psychological crises and recurring spastic ileus situations at home and thus prevent unwanted hospitalization. Patients preferred treatment at home. Many patients stated that they feel save and secure because they do know that a member of the Palliative Care Team is on duty around the clock and will visit them at home whenever needed.

**Conclusion:** For some patients with complex symptoms and advanced disease specialized Palliative Care in a home-care setting is needed and can help to reduce hospitalization in patients with advanced illnesses and complex symptoms. Long-term specialized Palliative Care should be provided for these patients as needed and should be paid for by their health-insurance.

**Abstract number:** P2-301

**Abstract type:** Poster

### Early Referral and a Proactive Approach Can Significantly Increase Referral to the Hospital Specialist Palliative Care Team and Reduce Length of Stay

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**Aim:** To establish whether a proactive approach to seeking referral from a hospital Acute Medicine Unit (AMU) would enable more patients to receive inpatient specialist palliative care support.

**Method:** The base line review of referrals received to the palliative care team from AMU was conducted between November 2009 and January 2010, during which time 23 patients were referred. A pilot study was then implemented from June to August 2011 whereby AMU received a proactive daily visit (Monday- Friday) from a Palliative Care Clinical Nurse Specialist, in addition to the standard method of referral (telephone). These referrals were subject to the same 'triage system', and response time as standard referrals.

**Results:** Referral numbers rose from 23 to 65 patients during the pilot period. Though more patients across all age ranges were referred during the pilot study, larger increases were seen in referral of older people; of patients aged 66-85 years the number rose from 11 to 42.

During the pilot the number of referrals for non-malignant conditions rose. Prior to the pilot, only 1 of 23 patients referred had a non-malignant diagnosis, compared with 10 of the 65 patients referred during the study, and this reached statistical significance ( $p < 0.0001$ , Fisher's exact test).

When comparing the length of stay of patients, those in the pre-pilot group had a mean length of stay of 17.1 days, whereas patients in the pilot group had a mean of 9.2 days.

**Conclusion:** This pilot study shows that a simple intervention can increase referrals to the palliative care team by 280%, including a higher number of patients with non-malignant disease. The average length of stay for these patients was also different, a mean reduction of 8 days for those referred during the study. Similar to the Acute Oncology model, such a proactive intervention to identify patients with palliative care needs early in their hospital admission could improve clinical care as well as reduce length of stay.

**Abstract number:** P2-302

**Abstract type:** Poster

### General Practitioners Use of and Satisfaction with a Community Palliative Care Service

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Community palliative care services have been established in Ireland to provide support to patients with life limiting illness in places of care outside the hospital setting. Delivery of such care requires interaction between the community palliative care service and General Practitioners (GPs), as primary medical carers of the patient. There is limited knowledge of how GPs make use of and their satisfaction with the service provided. This study addressed these questions by examining GP use of and satisfaction with one community palliative care service. Reasons for non referral if applicable were also explored.

A postal questionnaire, modified with permission from an earlier study was used as the research tool. The questionnaire was distributed to the GPs ( $n=314$ ) working in the same geographical area as served by the community palliative care service being studied. Completed questionnaires were returned anonymously by study participants. Data analysis was undertaken using SPSS (Statistical Package for the Social Sciences). Fisher's exact test was used to examine for association between the variables identified. A significance level of  $P < 0.05$  was set for all analyses.

A response rate of 37% was obtained, which was low. Study findings did however reflect generally positive views of the service and its aspects among the respondents. All were aware of the study site service and the majority had referred patients over the preceding two years. Less than 1 in 4 GPs felt their patients with palliative care needs could be managed without the support of the service. Reasons for non referral were unrelated to the service and usually due to patient factors. The majority of GPs described their role as working alongside the service. Areas for improvement were highlighted by over half the respondents, such as increased GP participation in treatment decisions, which should be addressed. 97% of respondents asserted however they would recommend the service to a colleague.

**Abstract number:** P2-303

**Abstract type:** Poster

### Five-years of Palliative Care Unit

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**Background:** In our country palliative care (PC) system is underdeveloped. In February 2007 we have established first palliative care unit (PCU) in our region with 6 beds.

**Aim:** Five years after establishment of PCU we decided to carry out a survey on our work.

**Methods:** We have reviewed charts of all patients (pts) admitted to PCU since February 2007 till end of January 2012. We collected information as age, sex, type of cancer, place of referral, symptoms at admittance, length of hospitalization, prevalence of in-hospital or home death, place of discharge.

**Results:** During first five years of PCU we have admitted 706 pts in 899 hospitalizations. 81% were hospitalized at PCU only once. There were 348 (49.3%) males and 358 (50.7%) females, an average age was 65 (29-95) years. All patients had cancer: 34% pts gastrointestinal, 13% breast, 13%

urinary tract, 9% lung, 9% gynecological, 8% skin, 4% head and neck and 10% other cancers. In 51.8% pts were admitted to PCU from home in 48.2% pts were transferred from other hospital departments. 86.2% of pts had an ECOG performance status 3-4. Most prevalent symptoms at admittance were: pain (52.2%), fatigue (33.2%), cachexia (20.7%), bowel obstruction (18.0%), dyspnea (17.3%). Duration of PCU hospitalization was on average 7.7 days (range: 0-52 days). Only 28.3% of pts were presented to PC team more than 3 months before death. 47% pts died in PCU, in 44% cases pts were discharged to home care. In 53% cases we organized family meeting, social help was needed in 37%. We also provided spiritual care to 32% pts and their families.

**Conclusions:** PCU with 6 beds at our institution provide a palliative care to approximately 200 pts per year. If needed, pts in PCU are offered consultation with social worker and spiritual care provider. In majority of pts we have also carried out family meeting.

**Abstract number:** P2-304

**Abstract type:** Poster

### Identifying Variations in Expenditure on End of Life Care: Lessons for the Future

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**Aims:** To support the recommendations of the End of Life Care (EoLC) Strategy in 2008, additional funding was provided to Primary Care Trusts (PCTs) in England in 2009-2010 (£88 million) and 2010-2011 (£198 million). Variable allocation of these funds by individual PCTs may be associated with inequities in service provision. The aim of this study is to review the allocation of this funding across London, UK, in order to identify variations and issues requiring further exploration.

**Methods:** Data was requested from 31 PCTs in greater London for 2010-2011 to obtain a breakdown of expenditure on EoLC. As this data was not readily available in all cases, requests were sent using the Freedom of Information Act.

**Results:** 29 PCTs responded to the information request. Documented expenditure on EoLC by individual PCTs varied widely. Figures are categorised into expenditure on 1) clinical services and 2) other relevant projects/networks.

Several PCTs included care already funded by the state in their figures, with no detail regarding what proportion was directed at existing versus new services. For example, one PCT demonstrated a range of investment into clinical services, bereavement support, and education, whilst data from another PCT revealed that 16% of investment was provided to local hospices, with the remainder directed to "patients receiving palliative care"; no other services were mentioned.

**Conclusions:** Our results demonstrate variations in funding for EoLC. Data regarding funding allocation should be readily available to key stakeholders. The value of the Freedom of Information Act to facilitate this study was clear, but this route is not readily available to all. Further work is needed to standardise funding streams for EoLC. Maintaining accountability for budget holders is vital, and the challenges of this will be discussed in the context of national work reviewing the funding of palliative care services and development of Clinical Commissioning Groups.

**Abstract number:** P2-305

**Abstract type:** Poster

### Artificial Feeding Decisions - A Model for Palliative Medicine Involvement in Complex Decision Making

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**Background:** Many patients with advanced disease cannot maintain oral nutrition. Artificial feeding carries risks, burdens and benefits. A decision to treat or not treat with artificial feeding requires rigorous assessment, particularly for those near the end of life or lacking mental capacity for whom decisions can be ethically complex. A Feeding Issues Multidisciplinary team (FIMDT) was formed 6 years ago in a 1300 bed teaching hospital. The team meets weekly for 1 hour and includes palliative medicine (chair),

gastroenterology and geriatrics consultants, nutrition nurse specialists (hospital and community), a dietician, a speech and language therapist and an endoscopy nurse. Clinical teams present patients with complex feeding issues, including all patients who may require gastrostomy or home enteral or parenteral nutrition (PN). Palliative care presence promotes patients' advance care planning needs. Previous analysis has shown that introducing the FIMDT reduced 1 month post gastrostomy mortality from 14% to 1%.

**Method:** Retrospective data from electronic referral forms and FIMDT reports (2009 - 2011) was analysed.

**Results:** 392 patients were discussed by the FIMDT. Diagnoses included cancer, complex multiple morbidities, traumatic brain injury, stroke, motor neurone disease, multiple sclerosis and dementia. 191 patients died within one year of discussion whilst only 56 patients were already known to palliative care services when discussed. 119 patients lacked mental capacity. Treatment decisions; 244 patients for gastrostomies, 59 for oral feeding, 57 for enteral feeding tubes, 13 for PN, 7 patients dying-not for intervention, 4 for stents, 4 for venting gastrostomy, 3 for gastrostomy removal, 2 for feeding withdrawal.

**Conclusion:** Half the patients considered for artificial feeding were in the last year of life. Palliative care specialists need to engage with gastroenterologists to achieve the best outcomes for patients. The FIMDT is a model that can achieve this.

**Abstract number:** P2-306

**Abstract type:** Poster

### Economic Impact of Potentially Avoidable Hospital Admissions amongst Patients in the Last Year of Life in the UK

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**Background:** The total cost of UK hospital admissions for adults in the last year of life has been estimated to be in the region of £1.3 billion. It has been suggested that improving and expanding community services may reduce avoidable hospital admissions amongst patients with palliative care needs, thus reducing a proportion of hospital costs. However, the evidence base from the UK is currently limited, and studies to date have only explored the economic impact of avoidable admissions within the context of optimum alternative services being available in the community.

**Aim:** To explore the extent of potentially avoidable hospital admissions amongst patients admitted to hospital in the last year of life, and to cost these accordingly.

**Design & methods:** A retrospective case note review of 483 patients admitted to two UK hospitals in the final year of life. Potentially avoidable admissions were identified and costed, and costs were estimated for care in appropriate alternative locations.

**Results:** In total 7.2% of admissions were classified as potentially avoidable. Taking into account the avoided hospital costs and the cost of providing support in alternative locations, the estimated economic impact was a potential cost saving of £45,287 across both hospitals on a single day. However, reducing the length of stay for all 483 patients by 2 days or 3 days would result in estimated hospital cost savings of £184,865 or £277,297 respectively.

**Conclusions:** The low level of potentially avoidable admissions may reflect a lack of appropriate alternative services available in the two study sites. Greater numbers of admissions may be potentially avoidable but this would require significant expansion of existing services and greater resources directed to community. Resources may be better directed to reducing length of stay for hospital in-patients in the final year of life.

The study was funded by the National Institute for Health Research SDO Programme

**Abstract number:** P2-307

**Abstract type:** Poster

### Hospital Palliative Care Provision: Consultant Views from Outside the Specialty

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**Background:** In the UK much of a Hospital Palliative Care Team's (HPCT) clinical activity depends upon how their skills are utilised by consultant colleagues from other specialities. Referring consultants may be best placed to assess the successes of current models and identify areas of unmet need.

**Aims:** To assess the views of hospital consultants on their own provision of palliative care and on the HPCT and its developing role in a 600 bed district general hospital.

**Method:** Consultants were asked to complete an anonymous questionnaire ascertaining their views in 3 areas-

1. Their own palliative care skills
2. Their opinion on current provision of specialist palliative care
3. Views on the future direction of palliative care services

**Results:**

- 73% response rate. 54% (32 questionnaires) were valid for analysis. 46% medical / 54% surgical specialty split. When rating their overall confidence in providing palliative care -
- 72% - some confidence
- 25% - confident
- 3% - very confident

Consultants felt greatest weaknesses were managing dyspnoea, spiritual and psychological distress. Responders reported high level of satisfaction with the HPCT and with either nurse or doctor patient review. There were varying attitudes to opportunities for joint working. All respondents felt the HPCT had a role in non-malignant conditions but different levels of agreement were held in relation to specific conditions. Consultants admitted experiencing difficulties in determining when patients with non-malignant conditions had reached the end stage of disease.

**Conclusions:** This study provides a broader view of palliative care from a selection of experienced consultants from outside the specialty. It highlights the support for the typical UK model of specialist hospital palliative care and its extension into non-malignant conditions indicating potential future palliative care requirements within an acute hospital setting.

**Abstract number:** P2-308

**Abstract type:** Poster

### Motor Neurone Disease: Providing Specialist Palliative Care Support for Patients and their Carers

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Patients with Motor Neurone Disease (MND) and their families need considerable support, and palliative care services could play an important role in providing this support. Unfortunately, MND patients often do not access palliative care until very late in their illness. Current qualitative research into the reasons is limited and has mainly explored professionals' views.

**Aims:** This project was designed to better understand why MND patients do and do not access early outreach programmes, or specialist palliative care services in general.

**Methods:** This project was designed in three phases:

- 1) initial focus group interview at regional MND Association (MNSA) patient group meeting
- 2) postal questionnaire sent out to all patients known to the regional MNSA
- 3) qualitative, semi-structured interviews with 10 MND patients and/or carers

**Results:** In the focus group patients had highlighted, that need for information might change during the course of the disease or simply with time from diagnosis. Differing needs for patients and carers emerged. Informed by the issues raised we sent out 48 questionnaires, 19 were returned.

Of the patients who replied >50% had been diagnosed for longer than 2 years.

Commenting on the early stages of their disease more than 50% said they had wanted to find out as much as possible, but 40% had initially only wanted limited information. One third of these patients have changed or expect to change their approach over time, while their carers generally tended to wish for more information.

36% had made Advanced Care Planning decisions and most other patients were aiming to.

While the responses to the questionnaire were biased towards information-seeking patients, we were able to include some non-seeking patients and their carers in our interviews to reflect their needs.

**Conclusion:** Early access to Palliative Care should be offered to patients and carers separately and repeatedly to meet individual needs, utilising new models of approach such as social media.

**Abstract number:** P2-309

**Abstract type:** Poster

### Developing Networking: Palliative Day Clinic as an Interface between In- and Outpatient Services

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In 2010 we started project of complementing Palliative Care Day Clinic within PC department (7-bed inpatient unit and 24/7 outpatient service) in a regional hospital. The idea grew out from requirements of patients we watched narrowly in home care setting as well as in PC consultation hour. The goal was to broaden multiprofessional spectrum of End-of-Life home care including rapid managing in case of symptom escalation to enable more patients staying at home.

The present aim was to examine efficacy of the PC Day Clinic, especially regarding number of admission or re-admission to hospital as well as possibility of consolidation networks between in- and outpatient services.

We analysed 320 in- and 365 outpatients we cared since 2010 grouping in those who used Day Clinic or not. We examined number and reasons for admissions from home PC setting to hospital.

**Results:** Within patient group who didn't draw on resources of day clinic we observed no change of clinic admission rate compared with previous years. Contrary to this, in the Day Clinic group number of advanced ill patients who could avoid admission staying at home under good symptom control, became 9% in 2010 and 15% in 2011 more.

**Conclusions:**

- 1) PC Day Clinic proves to be effective structure to optimise and extend home care in advanced ill patients
- 2) We noticed significant reduce of clinic admissions within home PC care patient group who made use of day clinic
- 3) Excess bed capacity accruing from less clinic admissions lead to more effective use of PC inpatient beds
- 4) Better care of home care givers and possibility of giving them time-out during Day Clinic setting helped to prevent burn-out and make family care more stable
- 5) As interface service, PC Day Clinic enables better continuity and flexibility of care for patients, optimise networks and affect mutual understanding and team spirit between in- and outpatient services.

This appears to be significant step to provide a model of all-round palliative care.

**Abstract number:** P2-310

**Abstract type:** Poster

### The Myth of Psychological Empowerment: Impact on Nurses' Commitment and Intent to Leave Primary Palliative Home Care Services

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**Introduction:** Empowerment is an important component of individual, team and organizational effectiveness. Health professionals are key players in providing quality patient care. Empowerment involves a personal sense of control in the workplace as manifested in four beliefs about the person-work relationship: meaning, competence, self-determination, and impact. Affective commitment concerns the attachment to, identification with, and involvement in an organization. Intent to leave involves people's intention of voluntary turnover.

**Aim:** To analyze the relationships between psychological empowerment and two outcome variables (affective commitment and intent to leave) among nurses providing primary palliative home care services.

**Methods:** As part of a larger multicenter survey study, a random sample of 331 nurses providing primary palliative home care services in several regions of Spain was selected. The Psychological Empowerment, the Affective Commitment and the Intent to Leave Questionnaires were used to measure the major study variables. Scales revealed adequate psychometric properties.

**Results:** A series of multiple regression analyses tested the model. As hypothesized, findings indicated that empowerment was significantly and positively associated with affective commitment ( $\beta = .61, p < .001$ ) in the workplace and negatively associated with intent to leave ( $\beta = -.32, p < .01$ ) primary palliative home care services. The

model accounted for 69% of the variance.

**Conclusions:** Current fiscal constraints imposed on healthcare services force many organizations to do more with less. The study found that professionals who have empowering work environments and perceive positive feelings of empowerment have high levels of commitment to the organization and less intention of voluntary turnover.

**Abstract number:** P2-311

**Abstract type:** Poster

### Trust and Organizational Justice: Its Effects on Health Professionals' Perceptions of Psychological Empowerment in the Delivery of Primary Palliative Care

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**Introduction:** It is recognized that an organization's only true sustainable advantage is its people. Health professionals are key players in providing quality patient care. Their perceptions of the work environment influence their well-being and experience of empowerment. Trust is defined as a willingness to be vulnerable to others allowing closer attachments in teams. Procedural justice concerns the fairness of formal decision-making policies in organizations. Empowerment involves a personal sense of control in the workplace as manifested in four beliefs about the person-work relationship: meaning, competence, self-determination, and impact.

**Aim:** To analyze the relationships between two organizational contextual factors (trust and procedural justice) and psychological empowerment among health professionals providing primary palliative care.

**Methods:** As part of a larger multicenter survey study, a random sample of 408 health professionals providing palliative home care services in several regions of Spain was selected. The Trustworthiness, the Procedural Fairness and the Psychological Empowerment Questionnaires were used to measure the major study variables. Scales revealed adequate psychometric properties.

**Results:** A series of multiple regression analyses tested the model. As hypothesized, findings indicated that both trust ( $\beta = .34, p < .001$ ) and procedural justice ( $\beta = .23, p < .001$ ) in the workplace were significantly and positively associated with perceptions of psychological empowerment in health professionals from primary palliative home care services. The model accounted for 58% of the variance.

**Conclusions:** The study suggests a number of implications for practice in organizations. First, facilitating perceptions of trustworthiness in teams is important to empower professionals. Second, managers should show transparency and the fairness of formal decision-making policies in organizations, which are critical to create conditions for empowerment.

**Abstract number:** P2-312

**Abstract type:** Poster

### Enhancing Anticipatory Care Planning through Partnership Working: The STACCATO Approach

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**Aims:** Anticipatory care planning is a central plank of UK health policy and is being advanced in different ways in many localities, despite little research evidence to guide its development. STACCATO (Stow Anticipatory Care Planning Tool), a new, innovative, computer-based assessment tool, is currently being piloted with primary care and social work teams in the Scottish Borders. This in depth evaluation will advance the evidence base on the identification, assessment and planning of care in the last years of life in a multi-professional context

**Study design and methods:** A preliminary process evaluation assessing the efficacy and ease of use of the new tool will be followed by a qualitative study encompassing interviews with patients and carers who have completed a STACCATO assessment and focus groups with staff members responsible for conducting these assessments. Data will also be collected to assess which additional needs have been identified, how these needs have been met and impact on hospital admission rates

**Results:** 104 STACCATO assessments were conducted in the initial pilot period. In most cases (87%), those conducting the assessments judged the tool to be either easy or neither easy nor difficult to use. Two thirds of the assessments identified at least one unmet medical or social need. A tiny

proportion of patients (6%) had an existing anticipatory care plan in place in the event of them being unwell and no-one had a plan in place in the event of their main carer being absent. Key challenges, in particular, inadequate resourcing, large variations in computer literacy amongst nursing staff and elements of incompatibility in health and social care IT systems are in the process of being resolved  
**Conclusion:** STACCATO shows great promise as a comprehensive functional and social assessment tool and leads the way in providing integrated, joined up support for the increasing numbers of people living into older age, many with multiple, complex support needs.

**Abstract number:** P2-313

**Abstract type:** Poster

### Palliation across the Primary and Secondary Sectors. An Innovative Collaborative Project between Hospital, Community and General Practitioner

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The aim was to improve the quality of palliative care for all patients with life-threatening illness who require palliation, to ensure that patients are provided with an offer. The project's target group was patients with COPD, heart failure and cancer.

**Methods:** Qualitative methods are used to identify patients, who need palliative care services. Innovative methods involving employees were used to create a cooperative model. Journal audit were used to evaluate the model after six months.

**Results:** Employees have been involved in the development of initiatives to qualify the palliative care. The nurses have described patients with life-threatening illness, who could be in need of palliative care. Initiatives were tested and adjusted for the benefit of patients in need of palliative care. A cooperation model was developed, which includes symptom screening with the EORTC-QLQ-15-PAL to identify patients, who needed palliative care. A guideline was created to a patient interview, which includes a plan for the future palliative treatment. Electronic correspondence between specialized nurses at the hospital and home care district nurses were established. Journal audit was performed on 79 in-hospital patients and as 18 patients from the community. Results from the journal audit showed that EORTC-QLQ-15-PAL symptom screening is applicable to all patients with life-threatening illness. Nurses' documentation was shown to contain information about the psychosocial conditions. It was found important to document the patient's wishes for the end of life care to avoid unnecessary readmission. The electronic correspondence was shown to contain relevant and sufficient information to ensure continuity in patient treatment and care courses.

**Conclusions:** The results from this project shows, that involving the employees in development of new initiatives improves the quality of palliative care and give attention to offer palliative care to all patients with life-threatening illness.

**Abstract number:** P2-314

**Abstract type:** Poster

### Consultation versus Shared Care Roles in Palliative Care Service Delivery: Deriving an Empirically-based Framework

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**Goal:** There is increasing use of palliative care specialist teams to provide support to primary care and specialist services working in various settings, including the community and hospitals. The way in which these teams operate may vary considerably. Guided by a recently emerging literature on the topic and utilizing a knowledge translation approach, the goal of the project was to develop a conceptual framework to better understand these roles and to propose an approach and instrument to assess these models of palliative care service provision.

**Methods:** An international, 2-day gathering of health care administrators, service providers (specialists and family physicians alongside palliative care physicians and nurses) and health systems researchers was convened in Ottawa, Canada in March 2012. Conversations were audio-taped and notes were taken by research assistants.

**Results:** A conceptual framework to develop a more cohesive understanding of the roles/models and elements of an instrument to assess them began to emerge. Areas of consensus as well as divergence toward the interpretations of the roles existed: There was general agreement on the consultation role, but varying understandings of what the shared care model meant and how to apply it. Some believed that the referring service/physician remains the most responsible for the patient, while others felt that responsibility could be shared or even taken over by the palliative care support team. However, it was recognized that each of these approaches have their limitations and perils.

**Conclusion:** The emerging framework, which needs further refinement, may begin to help teams come to a common understanding of these roles, thereby allowing researchers to better study the impact of applying these different models through the utilization of a standardized instrument. The Ottawa expert symposium was funded through a Meetings, Planning and Dissemination Grant (RPD 237871) from the Canadian Institutes of Health Research.

**Abstract number:** P2-315

**Abstract type:** Poster

### Leading Palliative Care Culture in Hospital - An Experience from Intensive Intership in Hospice

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**Introduction:** In Italy Hospices are organizations that provide Palliative Care (PC) to patients in an advanced stages of a chronic illness. Data show that in hospices in Bologna, patients are addressed by hospital units because of the acute disease-related symptoms. However, patients are transferred to Hospice in an advanced phase with a lack of diagnosis perception.

**Rationale:** The study analyzes the impact of an intensive 3 days residential course on PC and hospice. The course was addressed to physicians and nurses of Internal Medicine Hospital units, referral by oncological life-threatening patients. The research monitored the effects of the course on operators approach towards advanced ill patients.

**Methods:** 8 physicians and 11 nurses from Internal Medicine Unit at the Sant'Orsola-Malpighi University Hospital, attended the course in Hospice with PC theoretical lessons and practical insight. The study compared patients admitted in Hospice from Internal Medicine Unit 3 months ahead and 3 months after the specific PC training of the team unit. The data included:

- number of patients;
  - survival expectancy (- or + than 3 days);
  - diagnosis and prognosis awareness of patients.
- Diagnosis and prognosis awareness has been evaluated also on patients families. Answers were evaluated with Mann-Whitney U test and chi-square test

**Results:** The comparison pre and after PC training highlighted that admittances in Hospice from the Internal Medical Unit show:

- An increasing number of patients (+ 50%)
- More patients with a survival expectancy more than 3 days (+ 88%)
- More diagnosis and prognosis awareness both in patients (p < 0.02) and families (p < 0.07)

**Conclusions:** The increasing of awareness of PC meaning and practice and of Hospice as a care setting from Internal Medicine units operators, generated an higher consideration of Hospice as solution and the transfer of patients in an earlier phase of terminality. These results can be obtained also in a hospice-based short courses.

**Abstract number:** P2-316

**Abstract type:** Poster

### Addressing Social Needs in Brain Tumour Patients and their Caregivers: Experience of an Integrated Neurosurgery/Palliative Care Clinic

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**Background:** Primary brain tumours (PBTs) cause suffering by both unpredictable CNS symptoms and impairment of psycho-social functioning. Disease-specific caregiver burden is also well documented. Therefore, timely palliative care interventions may be beneficial. The aim of this pilot study was to characterise the needs of PBT patients and their caregivers.

**Methods:** In the neurosurgery outpatient clinic of a large teaching hospital, patients with newly diagnosed or recurrent high grade PBTs were referred to the palliative care team (PCT) as indicated by their neurosurgeon. Each patient was seen by the PCT (physician, social worker) on-site immediately after the neurosurgical visit. Duration and content of the consultation were recorded and follow-ups offered as needed.

**Results:** Between May 2011 and August 2012, 30 patients (16 women, 14 men, median age 71 years, range 32-81, 26 Glioblastoma multiforme, 3 Astrocytoma \*3, 1 unconvulsive histology) and their caregivers were seen by the PCT. 8 patients with newly diagnosed disease reported headache and visual symptoms (n=5), cognition (n=4), personality (n=3), and awareness (n=2) changes, while their principal need was detailed discussion of home care options and socio-legal matters. Among 22 patients with advanced or recurrent disease, general weakness and functional disability were the most frequent complaints (n=16), and most often technical support and help with decision making were requested. In 12 cases, families provided care to persons other than the patient. Consultations had a median duration of 60min (range 10-90min). 2 patients felt annoyed by the terms "palliative" and "advanced care directive", but the majority found the intervention helpful.

**Conclusion:** PBT patients and their families present with disease-specific issues. A real-time, on-site palliative care intervention actively addressing these issues is feasible. Next steps will include a prospective evaluation and a randomised controlled trial.

**Abstract number:** P2-317

**Abstract type:** Poster

### Acute Oncology Teams: Improving the Patient Pathway

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**Introduction:** The National Chemotherapy Advisory Group (NCAG) report (2009) recommended the establishment of acute oncology services into all hospitals with an emergency department. St Helens & Knowsley teaching hospitals has been at the forefront of developments and was the focus of a successful Transforming Inpatient Care pilot evaluating carcinoma unknown primary (CUP) in 2008. The acute oncology team has evolved from close working patterns between consultants in medical oncology and palliative care to a fully operational service with two acute oncology (AO) clinical nurse specialists, sessional input from other oncologists, and a weekly multi-disciplinary (MDT) with input from radiology, palliative care and an MDT coordinator.

Patients managed by the AO service fall into one of 3 types:

1. New cancer previously undiagnosed.
2. Chemotherapy/radiotherapy complications.
3. Symptoms related to a known cancer

**Method:** All weekly AO referrals are discussed at AO MDT. All episodes are entered prospectively into an agreed minimum dataset including tumour site, AO type, time to referral, assessment and hospital length of stay (LOS).

**Results:** 552 referrals were made in 12 months. Majority of the referrals came from the chemotherapy alert system and from general wards. There were marked differences in reasons for admission across varying tumour types. 61% breast cancer patients admitted as a complication of chemotherapy compared to 29% for lung cancer. 71% lung cancer patients admitted the reason was due to a new diagnosis or symptom control issue related to the cancer. Patients presenting to hospital as an emergency with a new diagnosis experience the longest admission, however the reduction in LOS achieved from previous pathway has been maintained.

**Conclusion:** The data has shown some fragmentation of patient care despite site specific teams. Future developments will require greater focus and integration with existing teams to improve patient pathways and prevent emergency admissions.

**Abstract number:** P2-318

**Abstract type:** Poster

### The Impact of a Palliative Care Team on the Behaviour of Primary Care Work



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**Introduction:** A Local Unit of Care (LUC) includes a Hospital and several Primary Care Centres working in connection. The Palliative Care Team (PCT) of the LUC works in relation with Primary Care and the Hospital in order to promote a continuous of care. After three years of work we want to know how useful PCT became.

**Objectives:** We aim to determine if Primary Care professionals are involved with the PCT and how that has affected their work.

**Methods:** A questionnaire was constructed to be presented to Primary Care Physicians and Nurses, working in the LUC, which give a total of 247. It was in an anonymous basis and analyzed in a statistical basis.

**Results:** Of the 247 questionnaires sent we got 89 responses. 72 (80.9%) were females, the median of age was 35, 48 were medical doctors and the median of working years was 11. 80 (89.9%) have dealt with terminal ill patients, median 2 new cases/year. Of these 79,8% reported need of expert advice. All the professionals know about the PCT. 67,4% were informed about the Consultation with Primary Care Physicians, 67,4% with the Palliative Medical consultation, 74,2% knew about supportive phone calls and 98,9% knew about the Domiciliary Care Support. They reported that patients that were supervised by the PCT needed less primary care visits and did not use so frequently the Emergency Room Service. 83,1% considered the work of the PCT very important. The major doubts reported were: symptomatic control, support to the family, dealing with the final days and hours, how to communicate and give bad news. All of the professionals reported that they will ask for the collaboration of the PCT.

**Conclusion:** The PCT is the main support in a continuous of care. We made evidence about the importance of an expertise PCT and their implication in providing domiciliary care in terminally ill patients. We emphasized that the Primary Care reported the need of formation in Palliative Care, and the need of supportive domiciliary involvement.

Abstract number: P2-319

Abstract type: Poster

### Organizational Model of Palliative Services in a District

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**Goal:** To develop a continuum palliative care model based on populational studies and palliative care needs of the county.

**Methods:** Demographical and epidemiological data were collected from 2008-2012 by the county healthcare board and palliative care providers from the area, according to a protocol approved by the all study participants. Afterwards a SWOT analysis was done jointly by health authorities and providers for development of a integrated model for palliative care in the county.

**Results and discussions:** Demographic data were process and validate by the Population and Housing Census 2011. The general and specific morbidity and mortality rate for the study years were also take into account to estimate palliative care needs for the district to a figure of 5680 patients annually. A strategic plan for the development of palliative care services in the area was done with the aim to achieve in 10 years a 60% coverage of the needs. The following model was suggested - training for GPs to develop basic palliative care with the aim to cover 27% of the need, increase specialized palliative care services as follows: 36 new inpatient beds, two outpatient clinics that could serve more than 500 patients; four home teams for adults and one for children; a hospital team and one day center; unit private units which can take 10% of the services; hotline for counseling and coordination.

**Conclusions:** This model has the advantage of interconnecting services, and to provide a continuum of quality palliative care. Funded by a San Diego Hospice & The Institute for Palliative Medicine grant Leadership Developing Initiative Programm.

Abstract number: P2-320

Abstract type: Poster

### Understanding Models of Palliative Care Delivery in Sub-Saharan Africa: Learning from Programs in Kenya and Malawi

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**Aims:** The need for palliative care (PC) has never been greater. It is an integral component of healthcare & from

being significantly present in only 5 African countries in 2004, PC is now delivered in nearly 50% of African countries. However still less than 5% of people in need receive it. In order to scale-up PC there needs to be greater knowledge about how models of PC function. A case study evaluation was undertaken to define the models used, contextualise them, & identify challenges, best practices & lessons learnt.

**Methods:** A desk review was undertaken addressing the burden & impact of disease within the countries, the health systems, the development of PC & models of PC delivery identified. 7 sites were visited, (4-Malawi, 3-Kenya). Meetings held with government, PC, community and local health leaders, program staff, & care observed at the sites.

**Results:** 3 models of PC delivery were identified: specialist, district & community level models, providing care in hospitals, health centres & community settings. Core components of each model identified alongside place of care, personnel, referral systems & differences. Models were influenced by the systems in which they were implemented, and expectations about PC's capabilities. Underpinning them were a set of philosophical assumptions shaping the model. The health system structure and beliefs about PC determined, and were determined by, referrals, the patient journey, the 'centredness' of the model & role definition & training.

**Conclusion:** Models of PC delivery grow out of the health systems in which they are placed, & need to be adapted in response to their specific underpinning questions. Models cannot develop in isolation & need to be linked through flexible & dynamic referral systems, thus strengthening the provision of care & ensuring the patient is at the centre of the care being provided. Lessons can therefore be learnt for scaling up PC elsewhere.

**Funded by:** The Diana Princess of Wales Memorial Fund.

Abstract number: P2-321

Abstract type: Poster

### Integrating Palliative Care into HIV/AIDS Care in a Community Health Centre in India

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**Introduction:** India has the second most people living with HIV/AIDS (PLHIV) in the world, yet palliative care rarely is available for PLHIV as existing program serve mainly cancer patients.

**Aim:** To test the feasibility of a replicable model for integrating palliative care into comprehensive HIV/AIDS care in India.

**Methods:** In 2009, our medical college-based palliative care team launched a project to integrate palliative care into HIV/AIDS care at a community health centre in Bangalore. The project has three parts,

- 1. Training-** Two junior doctors and 6 staff nurses from the Community Health Centre were trained over a period of time in essentials of palliative care and thereby enabled to provide palliative care with guidance from our team.
- 2. Service implementation-** Once a week, a palliative care specialist physician from our team participates in round on the HIV/AIDS ward and provides consultation and clinical mentoring in all aspects of palliative care: relief of physical, psycho-social, and spiritual distress and end-of-life care.
- 3. Research-** Data on demographics and symptoms are collected to assess palliative care needs and to make possible ongoing quality improvement.

**Results:** A total of 1951 palliative care consults were done by the palliative care physicians in 3 years and 3 months for 1253 patients. Amongst them, 707 were males and 546 were females. Cachexia, Insomnia and Pain had the highest symptom prevalence.

**Conclusion:** Because of the high burden of physical symptoms alone among PLHIV attending a Community Health Centre in India, palliative care is essential. With training and ongoing guidance, the staff of the Centre are able to provide all aspects of palliative care. This model for integrating palliative care into HIV/AIDS care at the community level can be replicated throughout India. Ongoing assessment of the prevalence and severity of all forms of distress is needed to guide service implementation and quality improvement.

Abstract number: P2-322

Abstract type: Poster

### International Networking to Develop Twinning Partnerships with Hospice Ethiopia

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To build on a project developed by educational and donor support from APCA, Hospice Africa Uganda and fundraising bodies in the USA and the UK. To work towards developing mutually beneficial projects and exchanges via twinning partnerships.

During 2010-12 two groups based within specialist palliative care services (one in the UK, the other in Sweden) initiated twinning programmes with Hospice Ethiopia. The UK group were successful in securing a grant from the International Health Links Funding Scheme which enabled early reciprocal visits. The Swedish group evolved more slowly - healthcare is expected to be seen to by society, hence a reluctance to embrace charity based support. A shift in public view has occurred during recent decades but to ensure credibility the Swedish group registered as a charity prior to launching their fundraising.

Recognising early on that organising support across services would be most effective, the groups were guided by Help the Hospices and the Charter for Recipient's of the Worldwide Palliative Care Alliance advice for launching twinning projects. Memorandums of Understanding were set up and signed in 2012. Both groups focus on educational exchanges, hands on support, promoting models of good practice and developing 5 year workplans. They are now part of a wider consortium set up to strengthen the model.

Palliative care is a human right for patients with both Communicable Diseases (CDs) and Non Communicable Diseases (NCDs). To date, healthcare in low resource countries has focused on CDs. The prevalence of NCDs will grow to that of more affluent countries due to economic progress. Supporting groups and donors have to collaborate to enable and secure development and sustainability of palliative care services in countries where national funding is nonexistent or scarce. International networking and organisation of supporting institutions is essential to empower their actions and secure further progress in this challenging work.

Abstract number: P2-323

Abstract type: Poster

### Palliative Care & Haematology: Is it Solely 'Blood, Toil, Tears & Sweat...?'

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Hematological patients typically have lower rate of specialist palliative care input & uncertainty around identifying transition to supportive care.

**Aims:** To evaluate local palliative care service provision to patients with advanced hematological disease. To quantify documented symptom burden & palliative care interventions in this group.

**Methods:** Case notes of 39 referrals to palliative service with hematological diagnoses over 20 months underwent retrospective review with data extraction pertaining to symptom burden & palliative service utilization. Outcomes included time from referral to death & documentation of place of death.

**Results:** A diverse range of hematological conditions were identified. 79.4% (n=31) died within timeframe examined. Mean time from referral to death was 40 days (1-156). Referrals originated in acute hospital setting in 82% (n=32) of instances.

Symptom burden was substantial (median 5, range 1-9) with fatigue (69.2%, n=27), pain (58.9%, n=23) & confusion (38.4%, n=15) featuring prominently. Identifiable psychosocial distress was documented in just under half of instances. 79.6% (n=31) had ECOG performance status 3 or greater. At referral 43.5% (n=17) continued on chemotherapeutic intervention with over half (56.4%, n=22) receiving transfusion support. Palliative service utilisation encompassed hospital support team input in 87% (n=34) community palliative care in 54.8% (n=22) & hospice inpatient admission in 39% (n=13). One fifth (n=7) engaged with all three dimensions of the service.

Death in hospital predominated at 41.6% (n=13) with 29% (n=9) in hospice. A smaller proportion (19%, n=6) died at home or in residential settings (6.4%, n=2).

**Conclusion:** Significant palliative care needs are identifiable within this patient cohort. Patients are referred late in disease trajectory often receiving active treatment. Greater engagement with palliative care locally than is previously reported in the literature. Collaborative working with hematology using a shared care model may account for this.

Abstract number: P2-324

Abstract type: Poster

### Barriers and Facilitators to the Delivery of Home-based Palliative Care Services in Beirut

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**Aims:** Providers of palliative care (PC) face multiple barriers to the provision of their services in any setting. Barriers are especially pronounced when the concept of PC is new to the healthcare system as is the case in many developing countries. As the first providers of PC in Lebanon, we faced barriers from both healthcare providers (HCP) and the community. This study aims to analyze the barriers as well as the facilitators that affected the delivery of our services.

**Methods:** We conducted a retrospective and introspective analysis of the experiences of our team members who were asked to reflect on reasons they perceive there was resistance to PC services. They were then asked to reflect on factors, incidents or interactions that increased acceptance of our services at both the HCP and community levels.

**Results:** HCPs were concerned about losing their patients and were not convinced that patients could gain additional benefits from our services. Communicating regularly with HCPs, involving them in major decisions, and admitting patients to their services all acted as facilitators. Our effective utilization of novel PC approaches to symptom management allowed us to gain their trust. Having nurses and residents as advocates within the hospital provided a reminder to HCPs of the availability of PC. Caregivers associated PC with giving up, they were unsure about what PC could offer them, and were concerned about losing their connection with their primary physician. Initiating care through the provision of a defined service that was not identified as PC facilitated their acceptance of PC.

**Conclusion:** This critical analysis of the barriers and facilitators allowed us to build on previous experiences and reflect on learned lessons. Our study provides valuable information to others who are struggling to establish PC in a setting where it did not previously exist.

**Abstract number:** P2-325  
**Abstract type:** Poster

## Working Together: How to Organize Integrated Care in Daily Practice for Palliative Patients

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**Background:** The department Palliative Nursing was established in 2002 to enhance the quality of palliative nursing in the Netherlands. One of the activities concerns translation of relevant research results into recommendations for daily practice in palliative care. In this presentation the focus of attention is 'integrated care'. This way of organizing palliative care seems to connect particularly well with the four-dimension based WHO definition of palliative care. However, recommendations for daily practice based on research results on integrated care are scarce.

**Aim:** Development of evidence based recommendations for the organization of integrated care for palliative patients.  
**Methods:** A systematic review of recent literature in PubMed for RCT's concerning interventions on integrated care in palliative practice.

**Results:** Three articles met our inclusion criteria. Three different interventions, all in patients with advanced cancer, were discussed. Integrated care was provided from different perspectives: by a hospital palliative care team, by an outpatient palliative care team, and by a nurse-led telephone-based format. We found differences in frequency and way of contacting the patient, duration of contact, involved disciplines and multidisciplinary teamwork. Self management (i.e. goal setting, patient participation) was an important topic in all three interventions. Physical and psychological problems were also discussed, but in different degrees. All interventions were compared with 'usual care'. Results show differences in effects on symptom control, quality of life and health care costs.

**Conclusion:** This systematic review provides a synthesis of 3 studies on integrated, palliative care. Several recommendations for daily practice can be given. Crucial in achieving better patient outcomes is a multidisciplinary care approach with a strong focus on both self management and symptom management, continued after hospital discharge.

**Abstract number:** P2-326  
**Abstract type:** Poster

## A Collaboration and Consultation Project to Support Palliative Care Patients in the Community

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**Aim:** Innovative solutions were recommended to support palliative care patients in the community setting. Strategies were evaluated within the Edmonton Zone to support the patient and family in the decision to remain at home, or facilitate admission to a palliative care hospice unit. One strategy was to limit transfers to Emergency Departments (EDs) where feasible and when appropriate. Focus was on unexpected events or symptom crises that precipitate calls for palliative consults or Emergency Medical Services (EMS).

**Method:** Preliminary data on utilization of EDs and EMS was attained. Common events and interventions were examined. Partners and stakeholders across rural and urban community settings developed management strategies to decrease transfers to EDs. An integrated identification and registration approach for palliative patients, both cancer and non-cancer, was utilized for the project. An evaluation process was designed to assess impact on patients, families, health care professionals and EDs.

**Results:** We will report on the diverse complexities and challenges encountered in the prevention of unnecessary admissions to EDs, which most often are not optimal choices from patient and family perspectives. Management strategies were comprehensive across cancer and non-cancer populations, symptoms and events, and settings. It was recognized that a cultural shift was required, with opportunities for professional teams to expand their practice and collaborative partnerships. Priorities included ongoing communication with family physicians, appropriate care by the appropriate provider, and optimization of services and resources. We will provide preliminary data on the fiscal and utilization impact of the project.

**Conclusion:** Partnerships between EMS and Palliative Care Teams can optimize care for the palliative patient in the home setting, and decrease utilization of EDs and acute care beds. Identification and registration of palliative care patients facilitate care.

**Abstract number:** P2-327  
**Abstract type:** Poster

## Cost Efficiency of Palliative Care

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**Introduction:** Although the palliative care need coverage in Romania is low, developing palliative care services is a real challenge due to an not stable legal framework, lack of human resources and also financial support.

**Aim:** To evaluate the reimbursed costs of care for patients who died in hospice inpatient unit and to compare these costs with costs of traditional care in an oncology ward from a public hospital.

**Materials and method:** A retrospective study based on patients files. A sample of 77 patients who died in hospice inpatients unit in 2011 was selected. The cost analyses included daily costs per patient reimbursed by Health Insurance House, but also real palliative care daily costs per patient; cost drivers for palliative care provided in hospice inpatient unit were identified. After this analysis, a comparison was realized between reimbursed costs for palliative care in hospice inpatient unit and costs for traditional care provided in oncology ward from a public hospital, generated in a previous research.

**Results:** The main identified driving costs were: diagnosis (p=0,05), presence of metastases (p=0,05), nursing interventions (p=0,05) and average number of daily monitoring/patient (p=0,01). Analyzed costs included: medication, clinical investigations, hospitalization (staff and utilities) and meals. Comparing these costs among palliative care and traditional care the differences were highly significant (p=0,01) for three of categories mentioned above, exception for clinical investigations (p=0,02). The reimbursed cost per day/patient for palliative care was 58% less than traditional care cost. Even the Health Insurance

House would reimburse the real cost of palliative care, the saving would be of 42%.

**Conclusion:** Including palliative care in public hospitals would provide consistent savings, up to 42% even if the real costs of palliative care is reimbursed.

**Abstract number:** P2-328  
**Abstract type:** Poster

## Volunteers in Palliative Care: The Review of the Center for Palliative Care/Medicine

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**Introduction:** Volunteering in hospice and palliative care is an important issue in holistic approach to the patients with life limiting diseases.

In Croatia, volunteering has been the only kind of palliative care service for many years now. The unique thing is that there are health workers volunteers and non-health workers volunteers. Health workers volunteers are physicians, nurses and social workers who perform hospice home visits free of charge, in their free time.

We want to present the work of Center for palliative care and medicine (CPSM), established in 2009. All members are the pioneers in palliative care in Croatia, with prof. Jušić. Center for palliative care/medicine (CPSM) works on international, national and regional level.

The priorities are: to advocate for hospice care for all those who need hospice/palliative care, to promote and support excellence in palliative care, education in hospice/palliative care, hospice home care in local community. Daily activities of volunteers of Centre are home hospice care for patients with life-limiting diseases in local community. The collaboration with local hospitals, churches and primary care physicians has also been established. Volunteering reduced unnecessary hospital admission and help more people to be covered by care at home.

**Conclusion:** Patients with life limiting diseases and their families need support. Many physical, emotional, social, spiritual problems require a holistic approach through multi-professional teams. Volunteers are an important part of multi-professional teams. They "add life today", alleviate the isolation that severe diseases bring, make it easier for families to move forward. Volunteers can make a difference to patients and families at a very difficult time in their lives: they help more people to die in their own home, the place of their choice.

**Abstract number:** P2-329  
**Abstract type:** Poster

## Evaluation of the Implementation of Palliative Care in German Nursing Homes

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**Research aims:** In Aachen, Germany, a palliative care model program has been initiated and managed by the "Servicestelle Hospiz" to implement palliative care in nursing homes. This process is quantitatively evaluated for the first time in Germany. The nursing homes are provided with a specific tailored training program of seminars over a period of 2-4 years.

**Study design and methods:** In November 2010 (T1) a pre-test used as needs assessment analysis was performed using the new and validated Bonn Palliative Care Knowledge Test (BPW)<sup>1</sup> to assess knowledge of palliative care (23 items) and specific self-efficacy (15 items) in nurses. The BPW test was designed especially to the demands of palliative care in nursing homes. After implementation of the training program the questionnaire survey was repeated in November 2011 (T2). Dependent t-tests were calculated. **Results:** In six nursing homes 129(T1) and 131(T2) nurses participated (average professional experience 13.0 years). In the pre-test (T1), the nurses' knowledge was low, with only 52.8% correct answers. In T1, specific self-efficacy reached a mean of 78.5% of correct answers, compared to 94.1% in a control group of experts (n=23)<sup>1</sup>. From T1 to T2, the percentage of participants with experience in palliative care documented increased from 16.4% to 36.6%. The mean value of knowledge increased from 2.40 to 2.44 (not significant, p=.30). The mean value of self-efficacy decreased from 1.68 to 1.65 (not significant, p=.31). Knowledge of nurses not participating in the training program also increased not significantly (p=.13).

**Conclusion:** A tendency of increased knowledge was not significant after one year of implementation of the training program. The tendency of decreased self-efficacy might be caused by overestimation by un-experienced caretakers of their own skills before training. Most likely more time is

needed to reach significant improvement. This will be tested by repetition in November 2012.

**Abstract number:** P2-330  
**Abstract type:** Poster

**Volunteering - An Indicator of Future Success?**

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This session will consider the results of a systematic review of the literature exploring the relationship between volunteering and the sustainability of UK independent hospices from a strategic perspective. Volunteers have played a vital role in the founding and on-going development of UK hospices. Volunteers in both adult and children's hospice services undertake a diverse range of roles, from the governance of the organisation to social, emotional and practical support to patients and families to involvement in income generation and retail. Volunteers play a key role in making strong links with local communities in which hospices are situated.

**Aim:** The purpose of the literature review was to consider volunteering from a strategic perspective and to: Explore current palliative care policy and the implications for hospice volunteering

Consider the role of volunteers in the development of hospices

Explore the current trends in volunteering in UK and their impact on hospices

Conceptualize the relationship between volunteers and hospice sustainability

**Method:** Searching a range of databases, the literature review was carried using key words and inclusion and exclusion criteria. Papers were reviewed and common themes identified and collated and critically analysed.

**Findings:** Findings suggest that the impact of volunteers on hospice capacity and economy is significant. In contrast to this, data also indicated that hospice volunteering models as currently structured may not be sustainable in the future. Given the dependency of UK voluntary hospices on volunteering, this study has identified new insights and evidence, which have the potential to challenge and influence strategic thinking and current attitudes to volunteering.

**Abstract number:** P2-331  
**Abstract type:** Poster

**A Living Community Presence: Bringing Volunteers into the Heart of "Care of the Dying"**

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Volunteering as we knew it, contributed substantially to the development of Hospice-Palliative Care worldwide. OPCARE9 was an EU 7<sup>th</sup> Framework funded Cooperation and Support Action Project involving 9 countries in establishing the evidence base in care of the dying. The Volunteer Workgroup of OPCARE9 systematically reviewed the available literature of the involvement of non-professional personnel in death, dying and bereavement in different countries (paper in press). It became clear that the scientifically accessible literature was mainly published in the English language, thus excluding most volunteering developments published in the native languages of the participating countries. A Thematic Review based on publications from these countries was, therefore, also undertaken (paper in press).

**Goal:** Design, implement and evaluate a curriculum and service, to enable the development of a Core Curriculum for Care of the Dying Volunteering.

**Rationale:** Whilst the evidence from the reviews was limited, it was possible to identify exciting curricular developments in Germany, Italy and the Netherlands. From these, a new approach, focusing on education and training for volunteers to support patients in the last days of life was developed.

**Results:** Strong leadership and management allied to a robust research design were found to be crucial to facilitate the activation of this new service in a clinical context. As a result, a Care of the Dying Volunteer Service (CODV) is currently being implemented into 6 wards of an acute hospital trust in the UK.

**Conclusion:** This presentation reviews the innovative interaction between management, research and education to bring a Living Community Presence into Care of the Dying (during the last hours and days of life) in the hospital context.

**Abstract number:** P2-332  
**Abstract type:** Poster

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**Abstract number:** P2-333  
**Abstract type:** Poster

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**Abstract number:** P2-334  
**Abstract type:** Poster

**Development of Organized Palliative Care in Belgium: Ten Years after the Laws on Patient Rights Palliative Care and Euthanasia**

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In 2002 three laws were published in Belgium, which are central to palliative and end of life care: the law on patient rights, palliative care and euthanasia. We evaluate the palliative care practice in Belgium ten years after these legislations.

Annual registration data indicate that professional palliative care is permanently increasing in home care, hospitals and residential care. About 50% of chronic patients receive professional palliative care in the place where they reside and 30% of the Belgian population die with professional palliative care support. There are three important reasons for this success. First, hospitals, nursing homes and home care have by law multidisciplinary palliative teams, paid by the health insurance. Second, palliative care is increasingly accepted by professionals and the public. It seems to become part of standard treatment. The driving spirit of palliative caregivers plus the satisfaction of patients / families was very stimulating. Third, the evolution to more chronic oncological diseases created more need for symptom relief and palliative care was discovered by non-oncological patients and their caregivers.

The imminent challenge for policy makers and palliative caregivers is how to tackle this continuously growing demand for palliative care in an environment of limited resources. With only 0,5% of the health care budget not more than 30.000 patients can yearly be given a qualified end of life by the specialized palliative caregivers. At least 1% of the health care budget is necessary to manage this growing need for palliative care in the next years.

There is no indication that the law on euthanasia has accelerated or delayed the development of palliative care practice. Palliative caregivers take the duty to guide patients with euthanasia questions in the complexity of the decision making process. Many of these decoded questions turn out to be questions for palliative care. Only 1% of all citizens die in euthanasia.

**Abstract number:** P2-335  
**Abstract type:** Poster

**Lung Cancer and COPD Patients' Experience of Emergency Admission: A Qualitative Critical Incident Study**

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**Introduction:** Emergency admissions (EA) are increasing and are particularly common as death approaches. This has public health and quality of care implications. Despite interventions to reduce EA, few studies have explored patients' experience of EA. COPD patients are thought to receive fewer community services than lung cancer (LC) patients. This study explored the reasons for EA in patients with LC or COPD.

**Method:** Patients with previously diagnosed incurable LC or advanced COPD were invited to participate in semi-structured interviews soon after EA. Each participant was asked to nominate a carer and community and hospital health care professional (HCP) for interview. Interviews were audio-recorded and transcribed. Transcripts were explored and the 'chronology' of the patient and carers' description of the EA process was constructed. Chronologies were compared and organized into categories. Thematic analysis of transcripts is nearing completion, enabling depth understanding of issues surrounding EA from patient, carer and HCP perspectives.

**Results:** 24 LC and 15 COPD patients were interviewed at 3 hospitals in one region; 20 carers and 50 HCPs were also interviewed. 14/24 LC patients died within 3 months of interview; 2/15 COPD patients did so. Most COPD patients were admitted with acute shortness of breath (SOB) via an emergency ambulance call; fewer were admitted by community HCPs. LC patients' experience was more varied and complex, with pain and SOB common, but also admission for clinical investigation and unexpected deterioration apparent. LC patients did not have more community HCP involvement than COPD patients. No EA was considered inappropriate by participants.

**Conclusion:** Exploring patients' experiences of EA enables understanding of the complexity of the process. LC patients, even close to death might not receive enhanced services in comparison to COPD patients. EA in many patients might be appropriate management.

**Funder:** Macmillan Cancer Support

**Abstract number:** P2-336  
**Abstract type:** Poster

**The Representation of Quality of Life among Health Care Professionals in Nigeria and the Implications for Palliative Care Services**

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**Aims:** A study was undertaken to ascertain the main features contributing to the quality of life for health care professionals in Nigeria.

**Methods:** During teaching sessions on palliative care using the Palliative Care Toolkit, developed by Help the Hospices and the Worldwide Palliative Care Alliance for use in Africa, participants in three secondary and tertiary hospitals in Abeokuta, Nigeria were asked, anonymously, for the two main issues that contributed to their own quality of life. 96 participants completed the exercise.

**Results:** The following five thematic areas that were chosen by the participants:

Health - mentioned by 28 participants (29%).

"Good health"/"Growing old with grace"

Family - mentioned by 29 participants (30%).

"Seeing my children make it in life"/"Care of my family",

"Being a fulfilled mother"

Financial issues - mentioned by 33 participants (34%)

This was more commonly cited at the hospital where the salaries are lower (51%).

Religion - mentioned by 41 participants (43%).

"My relationship and peace with God"/"spiritual comfort"

Self esteem - mentioned by 24 participants (25%).

"Happiness", "Peace within"

**Conclusion:** The issues that health care professionals in Nigeria in this study that were seen to be important to their quality of life were primarily of religion, finances, family, health and self-esteem. Religion was the highest rated area and this is in keeping with a country where religion - both Christianity and Islam - are practised widely - the estimated religious attendance at least once a week is 89% of the adult population. Financial issues may be of great concern to them - as patients will be required to pay for all care from consultation to investigations, surgical procedures, beds and medication.

The results give an indication of the areas of concern for the population of Nigeria and the importance of considering these major socio-economic and cultural issues in the palliative care of patients and families.

**Abstract number:** P2-337  
**Abstract type:** Poster

**The Prospects of the Development of Palliative Care in Kazakhstan**

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**Background:** In Kazakhstan, a number of laws and regulations define and approve the main trends of development of palliative care (PC) at the national level. Topics include: professional training of PC specialists; the provision of PC at home; psychological aspects of PC; PC for children; access to opioid medication for the treatment of cancer pain; and providing care for HIV/AIDS patients. National standards for PC are currently being developed and are expected to be adopted in 2012; a PC needs assessment has also been undertaken.

**Aim:** To investigate the prospects of the further development of PC in Kazakhstan.

**Method:** Review and analysis of the information, scientific publications and official reports on the development of PC in Kazakhstan.

**Results:** Currently, PC for the population is provided by hospices in six regions, which is inadequate for such a vast territory with a relatively low density of population. In many polyclinics, the positions of psychologist and social worker have been introduced, but their responsibilities have not been clearly defined. Inconsistencies and a lack of 'balance' in legislation relating to 'drug addiction' confine the rights of both patients and medical workers. As a result, the patient or their relatives may be forced to travel a long distance from their home to obtain opioid medication.

**Conclusion:** According to traditional social and cultural values and beliefs, the majority of patients with a terminal illness prefer to stay at home. Palliative care should therefore be home-based and provided at the level of local polyclinics by mobile nurse teams; provision of care should also involve public organizations via stipulation of government orders for providing care for terminally-ill patients, and through the development of a volunteer movement.

**Abstract number:** P2-338

**Abstract type:** Poster

## Effectiveness and Limitations of the Hospice Multidisciplinary Team

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**Background and aims:** The effective working multidisciplinary team in hospice is the basic principle for complex and multidisciplinary palliative care approach to patient and his family. In Slovakia, there are 11 hospices and hospice care units (5 free standing, 3 operating together with social services and 3 existing within the medical facility). Less than 10 are palliative care units within the hospitals. Despite the fact that every hospice and palliative care unit is somehow setting and operating the multidisciplinary teams, there are several specific limitations to have them properly working. The main aim of this study is to find possible solutions for eliminating those limitations. Specific objectives are to identify personal, technical and financial limitations and to prepare the practical tool - manual to help to achieve maximum efficiency, effectiveness and economy (3Es).

**Methods:** This non empirical study is based on practical experiences of the article authors (manager, psychologist, physician) with setting, managing and supervising the multidisciplinary teams within 40% different hospices in Slovakia. There is real assumption that knowing the Slovak hospice environment the authors are covering 90% of the problems and limitations and are able find usable solutions. **Results and conclusions:** Despite the fact that every hospice and palliative care unit is somehow setting and running the team of professionals, not always we can see good working multidisciplinary teams, but set of individuals - professionals reduced in numbers and not running regular multidisciplinary meetings and therefore not communicating and co-operating towards the patient and his family goodness. They resigned because of too many limitations. The outcome of this study - the manual could help the hospice top management and team leaders to analyse and identify their specific personal, technical and financial limitations and to eliminate them to achieve the maximal level of 3Es.

**Abstract number:** P2-339

**Abstract type:** Poster

## The Plan of Care in Palliative Medicine: An Analysis of Daily Inter-disciplinary Team Meetings

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**Introduction:** Our inter-disciplinary team (IDT) meets daily to discuss admissions to an acute care palliative medicine unit. The IDT consists of physicians, nurses, social workers, nutritionists, chaplains, therapists, and case managers. The primary study objective was to identify the clinical problems and the plan of care discussed by the IDT. We also aimed to identify discharge trends for future research.

**Methods:** This was a retrospective analysis of a quality improvement project. The daily IDT reports daily for 40

consecutive days were derived from 106 consecutive admissions using a preprinted template. No patients were excluded. The IDT report included care processes and outcomes for each person and could capture multiple issues per person. Data included key issues with care plan, actions/interventions/consults, goals of care, and discharge plan. Data was entered into REDCap® Database (Vanderbilt University, Nashville, Tennessee) and analyzed on Excel® (Microsoft Co, Seattle, Washington).

**Results:** Data included 493 IDT reports for 106 patients. 53% were male. Median age (range): 65 (31-101) years. Pain management was the most common (34%) recorded key issue; gastrointestinal 15%; cardiovascular/pulmonary 12%. Pain (81%) was the most prevalent symptom. It was managed by either pharmacotherapy (59%) or interventional techniques (41%). Daily Plan of Care: 1) symptom management (62%) 2) pain control (48%) 3) discharge plan (37%) 4) family conference (10%). 31% had some form of imaging/testing. 24% were on palliative antitumor treatment. Most were discharged either to home (50%) or hospice (32%).

**Conclusions:**

- 1) The daily IDT allowed quantification of daily clinical practices to enhance service delivery
- 2) IDT reports reflected the acuity and complexity of acute care palliative medicine
- 3) IDT provided an individualized plan of care to address medical and psychosocial needs

**Abstract number:** P2-340

**Abstract type:** Poster

## Barriers to and Facilitators for Achieving Best Clinical Practice in Palliative Cancer and Dementia Care

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**Introduction:** It is unclear which factors influence the effectiveness of implementation strategies in palliative cancer and dementia care. This hampers the actual translation of evidence into clinical practice. Particularly in this multidisciplinary field, where improvement in the organisation encounters challenges beyond the usual problems of implementation. The purpose of this study, therefore, was to explore barriers and facilitators for implementing strategies to improve the organisation of palliative cancer and dementia care in Europe.

**Methods:** A qualitative study design, consisting of semi-structured (focus group) interviews was used. The (focus group) interviews were guided by an interview guide. A codebook was established after conducting pilot interviews. Analysis of the data was conducted using the content analysis approach, whereby a framework was used to develop themes.

**Results:** 36 individual and 9 focus group interviews were conducted in five European countries with purposefully selected health care professionals. Although a large variety of barriers and facilitators were noticed, factors influencing personal conditions (such as motivation and experience), structure (such as staffing levels) as well as missing culture of change were considered common barriers across the countries. Extrinsic motivation and incentives, feedback, and face-to-face contact were considered important facilitators across the countries.

**Discussion:** Although palliative care requires a more complex organisation, barriers and facilitators to change the organisation do not seem to differ from those in non-complex organisations. The results of this study will be used to develop tailored strategies to improve the organisation of palliative care during an intervention study of the IMPACT project.

**Abstract number:** P2-341

**Abstract type:** Poster

## Development of Hospice and Palliative Care Culture in Northern Friesland, Germany: Implementing the Wilhelminen Hospice in Niebüll

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**Aim:** The need of inpatient hospice care in Northern Friesland, a rural, large-area region in the northwest of Germany, had been controversially assessed. Nevertheless the local hospice movement fostered the development of a hospice. Since January 2011 the Wilhelminen Hospice is operating and offers place for seven guests' care. This qualitative study was undertaken with following objectives: To evaluate the need of inpatient hospice care; to document the development process with its challenges and potentials; to analyse transfer options in regions with similar frame conditions, to initiate diffusion of hospice culture in the community; to support team building.

**Methods:** The multiperspective action research process includes following steps: Interdisciplinary workshops and conclaves with the team; analysing workshops with the executive committee and the co-operation partners; a palliative care symposium; an open house day for the public and conversations with guests and relatives.

**Results:** The need of inpatient hospice care in Northern Friesland is given. The feedback of guests and relatives is overwhelmingly positive. Main challenges on team level are: clarifying roles and responsibilities, the flow of information inside of the house and with co-operation partners, psychosocial complex caring situations, many deceased guests in short time interval, non-transparent management decisions and lack of appreciating culture in communication. The co-operation partners and the public appraise the hospice as an friendly, open house, "in the centre of community life".

**Conclusion:** The long lasting voluntary hospice tradition in this region, as well as the hospice's location in the centre of Niebüll has an essential impact on its positive public's acceptance and its integration in the local community. Nevertheless establishing a hospice needs high attention for developing organizational and management (hospice)culture as a continuous process.

**Funded by:** The German Cancer Aid.

**Abstract number:** P2-342

**Abstract type:** Poster

## Caring for Patients with Advanced Cancer in the Emergency Department - A Quantitative Survey of Australian Emergency Medicine Providers

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**Aims:** To explore the experiences of healthcare professionals caring for patients with advanced cancer in the emergency department.

**Methods:** An electronic survey was distributed to emergency department (ED) providers throughout Australia. Earlier qualitative work informed the survey development. A response rate of 10% was required to meet the target sample size and descriptive statistics applied. **Results:** 681 responded, including 444 emergency physicians (response rate of 13.5%) and 237 emergency nurses, with over half (51.4%) from major referral centers. Environmental issues were identified as barriers to providing optimal care, particularly overcrowding (83.3%), noise (69.5%) and lack of privacy (77%). The majority believed that ED is not the right place to die (83.8%).

Most reported finding caring for patients with advanced cancer rewarding (64.7%), yet many (73.6%) felt unable to provide optimal care. 64.6% reported that this patient cohort undergoes inappropriate treatment in ED, largely because of inadequate communication or documentation. Accessing after-hours palliative care was difficult (77.5%). Despite this, the majority believed that advanced cancer patients should be referred to palliative care earlier in their illness (69.3%). The majority (67.7%) felt a systematic pathway for care of the dying was needed in ED. Interventions to improve care included direct admission pathways (77.4%) and improved documentation about goals of care.

**Conclusion:** While suggesting patients with advanced cancer should not be presenting to EDs, clinicians find caring for this patient group rewarding. Interventions to improve care in EDs for these patients must address information provision to patients, improved communication between disciplines and consideration of afterhours support to ED by palliative care services.

**Funding:** We acknowledge the funding support of the Victorian Cancer Agency.

**Abstract number:** P2-343

**Abstract type:** Poster

## PALCAP - Palliative Care for People with Disabilities

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**Aim:** The increasing longevity has been one of the most remarkable changes for people with disabilities, although their lifespan still remains considerably lower than that of the general population. Due to the increasing longevity, people with disabilities are likely to die over a prolonged period of time because incurable, chronic illnesses occur more frequently with old age. Therefore there is a growing need for high quality palliative care for people with disabilities, living in residential homes. The study analyses the situation in Switzerland on provision of palliative care for people with disabilities, living in residential homes, and on their participation in palliative care and end-of-life decisions.

**Methods:** A cross-sectional online-survey, conducted from October to December 2012 with 480 directors of residential homes for people with disabilities in Switzerland provides data on following questions: How many residential homes allow residents to die within the residential home? How many residential homes have written policies on palliative care and end-of-life decisions? What is the content of these written palliative and end-of-life care policies and what are the implementation strategies? Which aspects of palliative and end-of-life care are assessed in residential homes for quality assurance purposes? Do people with disabilities take part in end-of-life decisions and does the implementation of written policies on palliative care affect self-determination in end-of-life decisions? Differences are analysed with chi-squared tests and multinomial logistic regression.

**Results:** The results will show, if complexity and degree of implementation of written palliative and end-of-life care policies affect participation in palliative care and end-of-life decisions. The study provides a base to support staff in residential homes to promote self-determination and participation in palliative care and end-of-life decisions for people with disabilities.

## Policy

Abstract number: P2-344

Abstract type: Poster

### Moving towards Pan-Canadian Community-integrated Palliative Care across All Settings

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**Aims:** The Way Forward initiative, a three-year project (2012-2015) funded by the Government of Canada, will engage all settings, sectors, professionals and governments in a dialogue regarding the implementation of community-integrated hospice palliative care. The initiative will address two key objectives. The first is to change the understanding and approaches to aging among key stakeholders as it relates to chronic and life-limiting illness, dying and advance care planning, and secondly, to enable stakeholders to move towards community-integration of hospice palliative care across all health care settings.

**Design, methods and statistics:** A well-constructed agenda is required for transformative change. Strategic directions and priorities for action will be developed, and the relevant partners and stakeholders engaged. A National Framework will serve as a roadmap for action and catalyze the efforts of many stakeholders in Canada. It will balance the overall mix of priorities across different sectors and population groups, and fiscal realities. Priority actions should not depend exclusively on government endorsement for their success. The initiative will also build on the National Framework for Advance Care Planning as a key indicator. The initiative's outcomes will be monitored through a performance measurement and evaluation plan. The evaluation plan will gather data on collaborative relationships, identification of barriers and enablers to implementation, development of knowledge products, tools and dissemination mechanisms, and supporting innovation in the health system.

**Conclusion:** The initiative will facilitate change in how Canadians and community and institutional leaders understand and respond to the issues of aging, chronic and life-limiting illness, and dying. The Framework will support partner and stakeholder commitment to strategies that will overcome structural, functional, jurisdictional, financial, and governance barriers to integration.

Abstract number: P2-345

Abstract type: Poster

### How Can a National Association Contribute to

### Best Practice of Palliative Sedation?

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Although its application is accepted in palliative care as one of the options of last resort, palliative sedation is very often less than optimal practiced. First, there is the question of definition, not just theoretical: a lot of so called palliative sedation is just not palliative sedation but something else, if not bad care. Second, palliative sedation turns out to be not a too easy technique. Good practice requires a well-trained team with skills in communication, a clear view on indication, a realistic expectancy of the sedative process, and a vast experience with the technical effectuation (e.g. intensive observation of the patient). Third, problems might occur in the case of prolonged dying.

In response to these three major problems, the FPCF and its regional networks palliative care started a project wherein several tools were developed. First a good conceptual framework ('Begrippenkader') with clear definitions was elaborated for all end of life decisions including palliative sedation (Broeckaert et al., 2006). Consequently a guideline for palliative sedation (Broeckaert et al., 2012) was published (www.palliative.be). This guideline focuses on the ethical aspects, the decision-making, the communication and the technique of palliative sedation. Third, materials such as a comprehensive folding-chart for caregivers and a folder for the public were designed and distributed via the regional partners, the palliative networks. Finally, a specialized training is currently developed to train caregivers in the guideline.

In sum, great steps are taken and continue to be taken with regard to policy and practice on palliative sedation by means of good medical practice and profound ethical debate. Undoubtedly good practice in palliative sedation and the proper use of it, needs a sustained effort to inform and support both professionals, the patients and their caregivers, and the general public.

Abstract number: P2-346

Abstract type: Poster

### Learning from the Public: Citizens Describe the Need to Improve Access, Provision and Recognition of End-of-Life Care in a Population-based Study from Seven Countries in Europe

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**Context:** Many European countries lack national policies regarding palliative and end-of-life care. This is concerning in light of the urgent need to respond to our ageing populations, and increasing cancer deaths. In order to inform national and international policy, the aim of our research was to determine the public's views and preferences on how they would like to be cared for in the face of serious illness at the end of life.

**Methods:** Implementation of a pan-European population-based survey with adults in: England, Belgium, Germany, Italy, Netherlands, Portugal and Spain. Three stages of analysis were completed on open-ended question data:

- 1) inductive analysis to determine a category-code framework;
- 2) country-level manifest deductive content analysis;
- 3) thematic analysis to identify cross-country prominent themes.

**Findings:** Of the 9,344 respondents, 1,543 (17%) answered the open-ended question. Two prominent themes were revealed:

- 1) a need for improved quality of end-of-life and palliative care and access for patients and families;
- 2) the recognition of the importance of death and dying, the cessation of treatments to extend life unnecessarily, and the need for holistic care to include comfort and support.

**Conclusions:** The public recognise the importance of death and dying. There is concern regarding the prioritisation of

the extension of life over quality of life, patient autonomy, comfort, support and dignity. Within Europe the call for improved quality of end-of-life and palliative care for patients and families persists. An acceptable balance between quality and quantity of life needs to be achieved. In order to fulfil the urgent need for a policy response and advance European research and care, four solutions are outlined: establish government-led national strategies, protect regional research funding, consider within and between country variations, and agree upon EU standards for training, education and service delivery.  
**Funding:** European Commission.

Abstract number: P2-347

Abstract type: Poster

### Abstract withdrawn

Abstract number: P2-348

Abstract type: Poster

### MRSA in Palliative Care Patients: What Are the Risk Factors?

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**Aim:** In this study the aims were twofold.

1. To determine the risk factors for MRSA colonization in palliative care patients.
2. To determine the success rate of the MRSA eradication protocol.

**Methods:** In this prospective study data was collected for all admissions to a 36-bed specialist palliative care unit (SPCU) over an eighteen month period. Data was collected using a two page proforma. This proforma was adapted from one used in a previous study that assessed risk factors for MRSA in nursing home settings. The proforma also collected data relating to MRSA screening and the MRSA eradication protocol. Categorical data were analysed using the Chi-squared test.

**Results:** Data was collected for a total of 609 admissions and readmissions, including data for 467 individual patients. 65 of 580 (10.67%) admission MRSA screens were positive. A second screen was sent in 294 admissions and a further 11 screens were sent during admission for clinical reasons, which yielded a further six and three MRSA positive results, respectively. The following were significantly associated with MRSA colonization: admission from hospital ( $p < 0.01$ ), waterlow score ( $p < 0.01$ ), palliative performance score (PPS) ( $p < 0.01$ ), mental status ( $p < 0.01$ ), MRSA status prior to admission ( $p < 0.01$ ), presence of tracheostomy or PEG tube ( $p < 0.05$ ), and peripheral vascular disease ( $p < 0.05$ ). Of 74 MRSA positive patients, six (8.1%) successfully completed the eradication protocol, while 46 patients (62.2%) died before its completion.

**Conclusion:** This study has identified a number of risk factors for MRSA colonization in palliative care patients. Attempts to eradicate MRSA in the SPCU were largely unsuccessful with only 8.1% successfully completing the protocol. In light of this low eradication rate, focusing MRSA screening on high risk palliative care patients may be prudent.

Abstract number: P2-349

Abstract type: Poster

### Identifying and Improving of Care of Chronic Advanced Patients in Need of Palliative Measures in 3 Health Care District in Catalonia: A Program of Territory Implementation

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**Introduction:** The prevalence of advanced chronic and life limited prognosis patients in Catalonia is 1,2-1,5% approximately; 72.000-90.000 patients/year are candidate of perceiving palliative measures. Approximately 45.000 of those die mainly from evolutionary chronic illnesses. The conceptual innovation about advanced chronic patient (ACP) and palliative care (PC) needs involves all ACP. The NECPAL implementation program (IP) starts by identifying patients, using the NECPAL CCOMS-ICO tool, in need of PC. It initiates actions to improve palliative measures and promoting a case management approach.

**Aims:** To apply actions of implementation of a PC program

for ACP in need of palliative measures in health and social services, within the framework of the Catalan Health Policies for the period 2011-2015.

**Methods:** 3 demonstrative areas participated: Delta del Llobregat, Girona and Osona. Actions: Territory directive strategy to manage the organizational changes to guarantee continuous care resources and case management. Training of clinical leadership. Conditions (2-5% of the population): multiple diseases, numerous admissions, extreme fragility and polypharmacy. Identification of patients with NECPAL CCOMS-ICO tool. Elaboration of transversal clinical trajectories.

**Results:** 1051 professionals have been trained: workshops at primary care (PrC) (N:26) and acute Hospitals(N:30) and Basic Courses (N:6).

**Discussion:** The NECPAL IP is one of the options to improve care towards ACP as a flexible territory strategy, which inserts and adapts itself into regional features.

**Conclusions:** The NECPAL IP promotes actions to better identify and improve care towards ACP in all health and social services. It holds diverse levels of implementation in the three pilot territories, involving all the professionals dealing with such patients. An organization with comprehensive and respectful care towards the patients' will and an adequate case management are immediate consequences of the IP.

**Abstract number:** P2-350  
**Abstract type:** Poster

### Towards a Public Health Model for Palliative Care in Europe

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**Research aims:** Due to the ageing of European society, dying of cancer and chronic disease is expected to increase the coming years and involves a considerable burden for society. Palliative care is an approach aiming at the quality of life of people with a life threatening disease and their families. However, the availability of palliative care services in European countries largely differs as does access to opioids for symptom relief. Whether this is related to population needs rather than population living standards needs further investigation.

**Methods:** A palliative care public health model is drawn combining publicly available data of the EU-27 countries. Aspects of the model are potential needs based on crude death rates in the 65+ population (CDR) and standards for purchasing power (PPS) based on Eurostat data as structure parameters, the Atlas project score for palliative care services availability as a process parameter, and the global opioid consumption (mg/capita) based on data from the International Narcotics Control Board as an outcome parameter. Correlations are tested with spearman's rank test.

**Results:** PPS related negatively to total crude death rate in 65+ population ( $p=0.62$ ;  $P<.01$ ) and positively to the CDR for cancer and chronic disease in the 65+ population ( $p=0.42$ ;  $P<.05$ ). Both PPS ( $p=0.63$ ;  $P<.05$ ) and CDR ( $p=0.47$ ;  $P<.05$ ) correlated positively to the Atlas score for availability of palliative care resources. The Atlas score correlated positively to consumption of morphine ( $p=0.50$ ;  $P<.05$ ) and fentanyl ( $p=0.56$ ;  $P<.05$ ) within a country.

**Conclusion:** Palliative care availability in a country related both to potential population needs and population living standards. Palliative care availability relates to a higher supply of opioids. Future research should concentrate on further refinement of the model including the relation between CDR, PPS and palliative care outcome. This will further improve (inter)national palliative care policy making.

**Abstract number:** P2-351  
**Abstract type:** Poster

### Misbeliefs and Reality about Palliative Care

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**Aims:** Hospice and palliative care exists in Hungary since 1991; I started working in this field among the founding members. Unfortunately, there are still misbeliefs about this subject which slow down progress and cause problems in all levels. The aim is to show common misbeliefs and face them with reality to help the social and professional acceptance of palliative care.

**Results:** The most common misbeliefs are: „hospice care is needed only in the few last days of life”, „hospice is a house where dying patients are put”, „there is no difference between hospice-palliative care and long-term care”, „there is no need to do more than holding the dying person's

hand”, „in Hungary, hospice does not really exist”, „you have to pay for hospice care”, „it is administered only through foundations”, „hospice is equal to old age care”. In reality, the 85 institutional and home hospice care providers, which have been financed through the national health insurance system since 2004, provided palliative care for over 7000 patients last year and have an essential role in education and raising awareness. Besides efficient multi-level professional staff hospice education, palliative care has been integrated into medical residency training. Furthermore, a sub-special training in palliative care will be introduced and the first university department for palliative care has been opened.

**Conclusion:** The breaking down of taboos is an important mission. Cancer, death and dying are still considered as taboo subjects, consequently, caring for dying are also looked at as taboo questions, it seems to be the main it seems to be one causes of misbeliefs - and not only in Hungary.

**Abstract number:** P2-352  
**Abstract type:** Poster

### Need Assessment of Terminal Cancer Patients in Albania

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**Background:** In Albania 75% of the new cancer patients became in terminal phase, within a year. Palliative care (PC) is provided mainly from NGO-s. There is a lack of quantitative and qualitative data on PC issues, to be used for the strategy and action plan implementation. The research aimed to evaluate the prevalence of the terminal cancer patients (TCP) in the country level and to identify the needs of PC from main stakeholders perspective. Specific objectives were a) mapping the TCP in the prefecture level, b) evaluation of the PC services, issues and problems from the perspectives of the patients, relatives and health providers, c) identifying the level of the assistance and support for the TCP from social protection system.

**Methods:** The mixed research methodology was used. The secondary data analyse was used for quantitative part and qualitative was achieved through 58 semi structural interviews with patients, relatives, family doctors, oncologists, representatives of the regional directories, decision and policy makers in central governments, and three focus groups (9 nurses, 10 family physician and 12 patients relatives).

**Results:** PC is provided in 6 from 36 regions in the country level and is only home care based, only 48% of terminal cancer patients benefit palliative care service, 96.1 % of the terminal cancer patients died at home. 83% of drugs for PC are available and reimbursed, but physicians have low knowledge to prescribe them, especially morphine. Patients and their relatives face problems with medicament access, identifying the responsible health providers and non/misinformation on the social beneficiaries.

**Conclusions:** PC service is geography limited and lack the inpatients and emergency home care service during night. Evaluation, treatment and policies for TCP are oriented from medical model. Pain control, quality of medical and social protection services remains main issues for patients and relatives.

**Abstract number:** P2-353  
**Abstract type:** Poster

### The Objectives of the Association of Hospice and Palliative Care of Slovakia as a New Member of EAPC

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The Association of Hospice Care of Slovakia was founded in November 10<sup>th</sup> 2000 and in 2003 was renamed as the Association of Hospice and Palliative Care of Slovakia (AHPC). It is important to say that just this year 2000 got the concept of hospice to legislation for the first time. Currently in Slovakia there are several hospices and palliative units and the AHPC wants to work for them and help them in all areas, such as legislative, legal, media, science and the like.

There is the most pressing issue is the policy of the state in the distribution of funds to various areas of public life. For example, the Ministry of Labour, Social Affairs and Family in general do not participate in the financing of palliative care. It is also very difficult to negotiate with health insurance companies. Equally important is the fact that for example a psychologist and social worker is no longer seen as essential

members of the hospice team in Slovakia and the number of nurses in the conversion of the number of patients is critically low.

In 2012 the AHPC became a collective member of the EAPC and due to that it will be necessary to modify and extend the statutes of AHPC (for example collaborative research which takes place through the EAPC, translation of some documents into Slovak...). In this paper we would like to present the goals and visions of AHPC for the next years in context of our situation in Slovakia and the European and global connection.

**Abstract number:** P2-354  
**Abstract type:** Poster

### A Systematic Review of Palliative Care Research in Ireland: Preliminary Findings

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**Background:** The Palliative Care Funding review (UK, 2011) highlighted that many individuals do not receive appropriate palliative care at the end of their lives. Services do not appear to be set up for the changing demographic and health issues resulting in a huge amount of unmet need primarily based in the older population. There is consequently an urgent need to consider a model for palliative care that is relevant and fit for purpose for the 21<sup>st</sup> century. There is also a need to develop research that is clinically relevant, innovative, and interventional.

**Aim(s):** To examine the type and nature of palliative care research conducted on the island of Ireland over the last decade (2002-2012). This forms part of a wider-scale study to identify research priorities in palliative care for Ireland and Northern Ireland.

**Method(s):** A systematic review was undertaken to identify studies conducted in palliative care across the island of Ireland over 10 years. The search applied strict eligibility criteria and included a search of standard bibliographic databases, websites of key hospice and palliative care sites in Ireland and Northern Ireland, as well as clinical and academic publication lists.

**Results:** 412 publications were originally identified for screening and their abstracts obtained. After a further review the authors undertook a thematic analysis of 248 peer-reviewed articles. These were further examined in terms of study characteristics including research design and outcomes. The thematic analysis revealed the following seven themes: understanding palliative care, treatment and intervention, service delivery, training and education, methodological and ethical issues, measurement and evaluation, and strategy and policy.

**Conclusion(s):** It is anticipated that the short term likely impact of the research priorities identification study will be research undertaken and evidence base development in the prioritised areas of palliative care practice.

**Abstract number:** P2-355  
**Abstract type:** Poster

### Is an Atlas the Way to Monitor and Report on the Status of Palliative Care in a Region?

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**Objective:** The aim of this project was to determine the degree of Palliative Care (PC) development in Latin America (LA) and evaluate the applicability of the EAPC Atlas methodology in other regions of the world.

**Method:** Based on the EAPC Atlas, using the expertise of several of the EAPC Atlas Committee members; and expert advice from the Pan American Health Organization, the Latin American Association for Palliative Care (ALCP) developed a project called Atlas of Palliative Care in Latin America.

Fifty-six PC workers were selected across the region as collaborators. Semi-structured interviews were conducted (in Spanish or Portuguese) covering main aspects in PC development, number of PC services, educational resources and professional activities. Consensus had to be achieved among the collaborators before the data was recorded.

**Results:** Data was collected from 19 countries (RR100%). The number of PC services for LA is 1.2 per million habitants,

while at the national level it varies between 14.6 and 0.23 (Costa Rica and Honduras respectively). Palliative Medicine is recognized as a sub-specialty in 4 countries, with postgraduate educational programs in 10. Eleven percent of medical schools offer PC in the undergraduate level. Eleven countries reported having a national PC association. There is ongoing collaboration in the countries with partners in USA, Spain, UK and Canada.

**Conclusion:** The Atlas of PC in LA describes vast differences among the countries and also similarities but above all, highlighted that the availability of PC in LA is very limited. This project also demonstrates that the Atlas is an adequate resource to monitor and report on the degree of PC development and that the methodology applied for the EAPC Atlas Europe may be adapted and applied in other regions of the world. Further studies are needed to evaluate the use and impact of this information to improve national health policies and patient care.

Abstract number: P2-356

Abstract type: Poster

### Palliative Care for All Programme - Progress and Plans

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**Background:** The HSE/IHF Palliative Care for All report (2008) identified a number of overarching recommendations common to the development of palliative care for all life limiting diseases as well as specific recommendations to support the development of appropriate levels of palliative care for people with COPD, Dementia and Heart Failure. Since 2009 the IHF Palliative Care for All Programme sought to implement and oversee the recommendations of this report.

**Aims:** A review has commenced to determine to what extent the recommendations from this report have been achieved. Particular consideration will be given to the impact of 3 Action Research Projects, to determine their potential for sustainability and translational learning nationally. This review will assist in signposting the next phase of this Programme.

**Methods:** Combination of methods will be used to ensure meaningful engagement with all stakeholders and objective appraisal of literature. As well as documentary review, and conference evaluations there will be qualitative interviews, review of quantitative data and appraisal of recent relevant policy documentation.

**Results:** It is anticipated that when completed the review will outline a positive shift amongst many health care professionals and disease specialists towards the recognition of the relevance and role of appropriate levels of palliative care for people with diseases other than cancer. However, based on early findings it is expected that staff will request further education and guidance to support the implementation of this approach.

**Conclusions:** Despite some significant changes that have taken place in targeted sites, it is expected that this review will recommend that the Programme will benefit from a joint strategic approach to provide a platform for national change that is required. This should extend to addressing the palliative care needs of those with end stage kidney disease, advancing neurological disease and those with multi-morbidities.

Abstract number: P2-357

Abstract type: Poster

### Public Advocacy Activities for the Palliative Care System Creating and the Palliative Care State Policy Shaping in Ukraine

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Since 1990 demographic situation in Ukraine indicates ageing of the population. Today the number of people aged 60 and older is over 22%, and aged 75 years and over is nearly 7%. Cancer and other serious chronic noncommunicable diseases associated with aging, and HIV/AIDS, TB, viral hepatitis etc. lead to an essential increase in the number of people who need palliative care (PC). The number of deaths in Ukraine in 2011 was over 660,000 people, 85% of them died at home, 5% - in hospitals, 10% - other where. The data of NGO 'All-Ukrainian League of Palliative and Hospice Care' (League) Experts shows that since 2005 the number of patients and their families who need PC is about 2 million people annually, and adequate PC in specialized facilities can be provided only from 0, 05% to 10% of them, depending on the region and place of residence: city or countryside.

This situation leads to a great relevance of accessible and qualitative PC System development, which requires an active participation of the whole society. Therefore, NGO's intensified advocacy to the Government and Parliament of Ukraine to shape State Policy on PC System creating and developing, as a strong condition to build a democratic and humane society. League's Working Group has worked out a draft of National Strategy for the Creation and Development of PC System by 2022. It was discussed by the participants of the First National Palliative Care Congress in September 26-27, 2012, and it was given to the Government of Ukraine. League's Experts elaborate a Palliative Care Development State Program by 2020 draft; take part in the drafting law of the Cabinet of Ministers of Ukraine to improve the availability of opioid analgesics for PC patients, directions of Ministry of Health and Ministry of Social Policy of Ukraine, National Standards for PC, clinical protocols and guidelines for PC professionals.

So, public, state and the whole society efforts consolidation is needed to improve PC Policy in Ukraine.

## Psychology & communication

Abstract number: P2-358

Abstract type: Poster

### Tailoring Legacy Building Activities to the Lebanese Setting

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**Aims:** Legacy building activities can relieve existential suffering and create lasting and personally meaningful memories. Palliative care providers can encourage and guide patients and their families to participate in such activities for their emotional and spiritual well-being. Acceptance of this process is strongly dependent on cultural norms and beliefs related to death and dying. This study was conducted by providers of home-based palliative care services in Lebanon. We were interested in providing legacy building activities to our patients as part of the package of palliative care services they receive. We wanted to assess the feasibility of such activities in our setting where there are many taboos pertaining to end of life matters.

**Methods:** We used a qualitative approach which included in-depth interviews with caregivers of patients who had died within the year prior to the initiation of the study and focus groups with health care professionals who work in nursing homes, geriatric units, and oncology units. Data were thematically analyzed.

**Results:** The main themes that emerged were related to family readiness (end of life conversations, time spent with patient, religiosity, privacy issues, truth telling, reminiscence, family coherence); choice of activities (age-appropriate activity, tailoring activity to patient interests, culturally sensitive activities); and the need for a facilitator (rapport with facilitator, skills of facilitator, benefits to facilitator).

**Conclusion:** This process allowed us to gain an understanding of the cultural issues related to legacy building. A legacy building manual was developed and tailored to fit the values, needs and preferences of our community based on the different themes that emerged. Future efforts will focus on piloting of this manual. Others can use this approach to develop contextualized material when considering a new intervention in their setting.

Abstract number: P2-359

Abstract type: Poster

### Managing Uncertainty in Non-malignant Conditions: The Experiences of Young Adults and their Parents

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**Aims:** To understand what helps young adults and parents manage the uncertainties associated with having a life-limiting condition with an unpredictable disease trajectory. To explore how transition impacts on this process.

**Methods:** Semi-structured interviews with young adults (16 - 25 years) (n=27) with renal disease, cystic fibrosis and Duchenne muscular dystrophy and their parents (n=19). Participants recruited from four research sites. Interviews were audio-recorded. Transcripts were subject to thematic analysis.

**Results:** Having and making plans which addressed areas of uncertainty associated with the condition played a crucial role in minimising concerns. Plans related to the following eventualities were very important to families: how to manage or respond to ill-health or worrying symptoms; the

management of medical crises; and/or the management of future deteriorations. Discussing and planning for these situations could also lead to conversations and decision-making about end of life. Of the small minority who had made an end of life plan, all were relieved to have done so and observed it enabled on-going conversations within the family and with the medical team. A number of issues associated with transition could threaten planning including: paediatrics not preparing families about the need to plan for crises or deteriorations; adult health care practitioners failing to identify young adults' desires with respect to parental involvement in decision-making; relationships between the patient and adult team are tentative and still developing; the transfer to adult health care can co-occur with significant deterioration in the on-going. **Conclusions:** Making and having plans around the on-going management of a life-limiting condition are important to young adults and their families. Young adulthood and the transfer from paediatrics can threaten this process.

Abstract number: P2-360

Abstract type: Poster

### Talking Kidneys: Development, Design and Implementation of a Renal Specific Advanced Communication Training Programme

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**Background:** Traditionally renal medicine has been disease-focused; recently there has been a paradigm shift towards a care focus. The renal population is increasingly elderly, frail and co-morbid necessitating a discursive approach, particularly regarding end of life care. Many renal professionals feel unprepared for such discussions, particularly given the often long established relationship with patients.

**Aims:** To develop a renal specific advanced communication training programme to address the needs of renal professionals and their patients.

**Methods:** A multi-professional team was sought to identify issues in end of life communication and to develop a training programme. This team (consulted individually and in a focus group) included: renal and renal palliative care clinicians and nurses, patient and carer representatives, social workers, psychologists, communication skills trainers from a local hospice, and a linguist. Training was designed in response to their concerns, reflecting the specific requirements of renal staff, patients and families.

**Results:** Participants identified the need for: i) better information about the end of life phase, ii) more awareness of the patient perspective, iii) 'hands-on' communication practice in a safe environment, iv) skills to manage challenging discussions, v) follow up to discuss experiences.

A training programme was developed accordingly.

**Conclusions:** The multi-professional approach has enabled the development of a highly-focused advanced communication training programme, drawing on cancer models, but tailored to renal medicine. This training has been rolled out locally to nurses and consultants, and is being formally evaluated to assess staff satisfaction, changes in practice, and impact on patient outcomes, with a view to rolling out nationally. This work highlights the need for renal specific communication training regarding end of life issues. **Funding:** This work is a key component in a project led by NHS Kidney Care.

Abstract number: P2-361

Abstract type: Poster

### Determinants of Hope in Patients Receiving Home Based Palliative Care

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**Background:** Hope is a multidimensional and dynamic construct different from one person to another. As the disease takes its course, the patients' hope shifts from the desire to get better to more spiritual forms towards the end of their life.

**Aim:** To identify factors that maintain hope for patients with advanced cancer

**Method:** Prospective study of patients with advanced cancer cared by our home care team between March 15 to May 15, 2012 after informed consent was signed. Face to face questionnaire containing 27 items with open format or multiple choice answers. Data recorded in Excel, statistical processing using the Epi Info 2002 program,

**Results:** From a sample of 114 patients 100 patients provided their answers. All patients were ECOG 3 and 4. Factors positively correlated with maintaining or increasing hope were: being aware of the diagnosis ( $p=0,003$ ) (this study is done in a culture where there is still a strong push for collusion from the side of family members), establishing the priorities and planning the time that the patient has left ( $p=0,001$ ), planning care with patient and family when multitude problems arise ( $p=0,0013$ ), encouragement from family when problems seem overwhelming ( $p=0,003$ ), length of care over 1 month ( $p=0,005$ ).

**Conclusion: Concrete external factors that maintain hope have been identified in the study.** The early start of the palliative care, would have a beneficial impact in terms of maintaining hope in patients with incurable diseases, since it would facilitate setting the priorities and planning in advance the time left. The honest communication of the diagnosis and the prognosis, done in a professional and empathetic way puts the patient's hopes on a real basis. Also, an efficient communication with the patient's family that underscores the support and encouragement when problems become overwhelming is important.

**Abstract number:** P2-362  
**Abstract type:** Poster

### Existential Behavioural Therapy for Informal Caregivers of Palliative Patients: A Randomised Controlled Trial

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**Objective:** Existential behavioural therapy (EBT) was developed to support informal caregivers of palliative patients in the last stage of life and during bereavement as a manualized group psychotherapy comprising six sessions. We tested the effectiveness of EBT on mental stress and quality of life (QOL).

**Methods:** Informal caregivers were randomly assigned (1:1) to EBT or a usual care group using computer-generated numbers in blocks of ten. Primary outcomes were assessed with the Brief Symptom Inventory (BSI), subscales somatization, anxiety and depression), the Satisfaction with Life Scale (SWLS), the WHOQOL-BREF and a numeric rating scale for QOL (QOL-NRS, range 0-10). Data were collected at baseline, pre-, post-treatment and follow-ups after 3 and 12 months. Treatment effects were assessed with a multivariate analysis of covariance.

**Results:** Out of 160 relatives, 81 were assigned to EBT, 79 to the control group. Participants were 54.5+/-13.2 years old, 69.9% being female. Medium to large effects on anxiety and QOL (SWLS, WHOQOL-BREF, QOL-NRS) were found post treatment ( $p=0.005$ ). After 3 months no overall significant effect was found. In the 12 months' follow-up medium effects on depression and quality of life (QOL-NRS) emerged again ( $p=0.05$ ). No adverse effects of the intervention were observed.

**Conclusion:** EBT seems to be an effective intervention for informal caregivers of palliative patients. It can be applied long term in clinical practice and seems to have positive effects on distress, QOL and affect.

**Abstract number:** P2-363  
**Abstract type:** Poster

### Palliative Care and Self Awareness

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Suffering is multi dimensional. Exploring spiritual and psychological realm is more difficult than the physical one. A magic box lies between the patient and care providers which evolve as self awareness. This needs to be explored by those who want to work in partnership in the best interest of the dying patient and oneself.

A reflective story thus - A 60 plus widower with Cancer stomach, was in anger due to incurable terminal illness. Previously teetotaler now smokes relentlessly. A home care nurse was engaged for his care. Subsequently, he improved considerably requiring less medication and cigarettes. Once, the contented patient expressed his desire for an outing with the nurse. Noticing a ring on her finger he realized that the nurse was engaged. This led to return of turmoil and he died a week later mutely. Here observation is made at the appropriateness of behavior and action of both in the face

of escalating suffering.

In the light of Maslow's hierarchical need, the behavior of the patient was found to be just right. It is beyond doubt that the nurse's presence brought a sea of changes in the life of the patient. Emotions were safely expressed until the loggerhead that arose from the information. This is in conformity with the Gestalt awareness cycle. The nurse on her part could have arranged for the outing involving family members or friends, a stand difficult to have been opposed by him. But it did not happen. The breach in the new relationship led to return of suffering for the patient and stress for the nurse as she was released from duty, fearing the socio cultural implication.

To generate self awareness, we need to put ourselves in the patient's situation, and find out what we can offer emotionally and spiritually. Palliative Care embodies human understanding but with limitations. We need to create a space in ourselves for another person and learn to give and receive unconditioned love for hospice care to sustain.

**Abstract number:** P2-364  
**Abstract type:** Poster

### Simply Willing and Able! What Is the Impact of a Simple Model of Communication Skills?

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**Background:** The End of Life Care Strategy (UK 2008) recommended the roll out of core communications skills to the entire end of life workforce enabling each individual to be able to respond usefully to difficult/unanswerable questions & deal with difficult topics. A 'Simple Skills Secrets' model was developed that could be learnt, remembered & used by staff working in all roles, all settings and at all levels. It enabled safe conversation where neither information nor authority to provide answers to questions existed, encapsulating the essence of communication skills training around active listening, encouraging, summarising, without having to 'fix it' or offer solutions & assist the person to come to a conclusion.

**Method:** A mixed methods evaluation of the impact, included pre & post course testing of confidence & willingness to have conversations with the distressed, & semi-structured telephone interviews with participants 6-8 weeks post course. 149 of 153 staff trained, completed both questionnaires. Using a purposive sampling approach, 14 participants agreed to follow up qualitative interviews.

**Results:** Improvement in both willingness & confidence for all categories was statistically significant; (overall confidence score,  $t(148)=-15.607$ ,  $p<0.05$ ; overall willingness score,  $t(148)=-10.878$ ,  $p<0.05$ ) with the greatest improvement in confidence in communicating with carers (pre-course mean 6.171; post course mean 8.171). There was no statistical significant difference between qualified & unqualified staff. Several themes were obtained from the qualitative data & the value of the model in clinical practice was reported.

**Conclusion:** This model appears to increase the confidence of staff, in dealing with situations which, if handled appropriately can lead to increased patient and carer satisfaction. Empowering staff also appears to increase the willingness to undertake these conversations, which could lead to earlier intervention & minimise distress.

**Abstract number:** P2-365  
**Abstract type:** Poster

### Information in Specialized Palliative Care - What Are the Topics for Palliative Care Teams, when Consulting Patients at Home?

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**Aims:** In terminal illness, information may help patients and informal care givers (ICG) to control critical clinical and psychosocial situations. This is especially relevant for patients at home and their ICGs. Research on their informative needs is mostly based on interviews. We analysed documented information palliative care teams (PCT) give to patients, ICGs and other involved health-care professionals (HCP).

**Method:** During the testing phase of an electronic-patient-record (EPR), patient data was documented by ambulatory specialized PCTs. We analysed free-text entries on information that was provided to patient, ICGs and other HCPs by the PCT using content analysis. The identified data was coded independently and discussed until consensus. Codes were then grouped into categories.

**Results:** 6 PCTs documented data of 46 patients (22 A, 24 A,

mean age: 69.3 ± 12.64, range 36-96). PCTs experienced difficulties in providing information because of cognitive problems or lack of language skills of the patients and ICGs. Communication between the PCT and the patients addressed specific nursing and medical measures (e.g. medication, wounds); resources and care planning (e.g. hospice care); process of disease/coping with end of life; ethical aspects (e.g. limiting treatment). Central topics were similar for ICGs, but coping issues extended beyond the patient's death. ICGs had a general need for information ("a lot of questions") and PCTs valued the information process being late. Additional topics for HCPs were organization of collaborative care (e.g. meetings, case conferences) and keeping them up to date about recent changes.

**Conclusion:** A wide range of topics were addressed. In the care process, PCTs act as a general source of information, not only for topics concerning specialized care. Planning care and resources were important parts, stressing the value of coordination. Because of informative needs of so many involved parties, an EPR proved to be useful.

**Abstract number:** P2-366  
**Abstract type:** Poster

### Strategies to Support the Staff in Difficult Conversations

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**Background:** Earlier research shows that health care professionals find it difficult to talk about severe diseases and death with patients and loved ones.

**Aim:** The aim of the study was to investigate which strategies that can facilitate these conversations

**Method:** The study had a qualitative design using in-depth interviews with staff at palliative and oncology wards at an university hospital.

**Result:** The professionals used different strategies when talking to patients and loved ones. One strategy was to structure the conversation according to 1/ Introduction, 2/ Finding out what the patient and loved ones already knew, 3/ Discuss the actual problem and finally 4/ Planning for the future. Another strategy was to use language symbols for anxiety to decrease these feelings. The last strategy was to give hope to the patient and loved ones. The hope often comprised of a secure care, giving the patient an opportunity to live the remaining life as good as possible until death.

**Conclusion:** A model for how to perform challenging conversations about severe diseases and death with patients and loved ones, act as a support for health professionals and increase feeling of security and decrease feelings of anxiety for patients and loved ones.

**Abstract number:** P2-367  
**Abstract type:** Poster

### Death and Dying in the Czech Republic - Results of a Representative National Survey

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**Aim:** The objective of this survey was to investigate public opinion on death and dying in the Czech Republic.

**Methods:** As part of a larger study conducted with a representative sample of Czech adult population on communication about death and dying, fear of death, and place of death preferences, this paper used CAWI (Computer Assisted Web Interviewing) and CAPI (Computer Assisted Personnel Interviewing) techniques. The sample was weighted for age, gender, education and region. The survey was designed by the palliative home care service Cesta Domu and professional marketing agency STEM/MARK, who also collected the data during their periodical data collection exercise in June 2011.

**Results:** 1095 respondents aged 15 years and older were surveyed (response rate 100%). Most of respondents (77%) think that death and dying are not discussed enough in public. The major explanations provided by respondents are the fear of dying (66%), not discussing this issue in families (59%), lack of interest in the media community (54%), secularization (42%), and lack of personal experiences with a dying relative (40%). When asked what fears do they have regarding death and dying, respondents mostly indicated loss of dignity (51%), pain (46%), loneliness (26%), psychical suffering (24%) and what will happen after death (13%). Respondents indicated a preference to die at home (85%), social care homes (65%), in hospice (58%), hospital (55%) and long-term health care facilities (31%).



**Conclusion:** The results identified barriers to public discussion of death and dying. Place of death preferences are not met with actual place of death as most people in the Czech Republic die in hospitals. The potential contributions of palliative care in addressing major fears about dying indicate policy and public education directions. More public and media discussion about dying and palliative care is needed to raise the awareness of these issues. Study was funded by Cesta Domu and FP7 EURO IMPACT project.

**Abstract number:** P2-368  
**Abstract type:** Poster

**Intervention of a Psychologist in Palliative Care Focused on the Meaning of the Life**

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In this article we would like to define the tasks of psychologists in the hospice and also present results from our researches where we have found a significant positive correlation between the meaning of life and quality of life of dying people (p < 0,05) using the Elizabeth Lucas Logo-test. Reactions of a patient to the fact of disease of illness and hospitalisation are very variable, but they definitely mean a new psychological experience to deal with. A psychologist should therefore be, except diagnostics - which helps with pharmacy-based therapy and interventions - familiar also with the phases that occur in incurably ill patients, but he should also be capable of reaction in these phases to help his patient handle with them. Another part of psychological intervention is also patient's pain, with psychogenic pain requiring special notice of the psychologist to reduce its perception using psychological means and mechanism. Another important aspect is in coping with depression which should be treated psycho pharmacologically - anti depressives with a combination with support psychotherapy.

Psychotherapy is also one of the important tasks of a psychologist in palliative care. One of the psychotherapy methods, the most important in care of the sick is, undisputedly, logo therapy, which puts the most significance into questions of reasons. It is especially important for patients that want to know nothing about religion or belief, but, at the same time, has to face the question of suffering, life after death, etc. To be successful in this logo therapy, patient needs to know that the therapist lives the life he speaks about.

Another method which can be used by psychologist is validation which I consider as a very important and essential for patients with dementia and very old dying patients. The tasks of psychologist should also be focused on the team members and relatives.

**Abstract number:** P2-369  
**Abstract type:** Poster

**Information Dialogue - Method to Recognize when Support is Needed**

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**Aim:** Palliative patients need information about the disease and available support. How can we help the patient and the loved ones to talk about their needs during the remaining illness time?

**Method:** The patient and the loved ones are offered an information dialogue, a meeting with the social worker, a nurse and an assisting nurse soon after arriving at palliative care ward, Sahlgrenska University hospital. The social worker or the nurse leads the meeting after a developed pattern. This includes inviting the patient to talk about the disease, feelings and the future needs for caring and support. The staff gives information about how we can help them during the stay at the ward, about society support, home care, hospice and psychological support.

**Results:** The information dialogue makes it possible for the patient and their loved ones to become acquainted with how we work at the ward and available support. Through this method the staff have an early contact both with the patient and their loved ones. This makes it easier to recognize those who need information and psychological support.

**Conclusion:** The information dialogues reduce anxiety and give a security when you know what caring and support is available. The early contact makes it easier to work and to give support during the whole hospital time and in the bereavement time for the loved ones.

**Abstract number:** P2-370  
**Abstract type:** Poster

**A Picture Paints a Thousand Words...**

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**Background:** Conceptually, each single in-patient room within this purpose built specialist palliative care facility is an extension of the patient's own home and patients are encouraged to 'personalise their space' by displaying photographs, mementos etc. Each room contains a blank white board for patients and family members to use as they so choose. This research was inspired by the rich tapestry of messages and imagery found on these boards.

**Aims:** To describe the varied use of the boards as patients and families choose what and how they wished to reveal of themselves and their shared lived experiences; an opportunity that enabled them to say 'this is who I am'.

**Methods:** This qualitative, descriptive study was undertaken over a nine-month period (September 2011 - June 2012). On receipt of verbal consent by the patient and/or family, ten selected boards were photographed and images reviewed.

**Results:** The display of photographs featured strongly. The themes varied but commonly included family events such as weddings, anniversaries, birthdays and holidays. Some patients included photographs of deceased relatives, work related activities particularly if their career was a source of pride to them, sporting pursuits and family pets. Religious images also featured strongly as did favourite paintings, usually of settings with some particular significance. Many visitors drew poignant or funny images depicting some aspect of the patient's life and grandchildren were particularly adept at displaying their talents.

**Conclusion:** Patients are much more than their disease. The display of photographs, messages and drawings on the board provide a conduit for people to reveal selected aspects of their lived and shared experiences. They enable healthcare professionals to gain a greater understanding of the patient in the unique context of his / her life. The patient is encouraged to say: 'this is who I am' and we are called to listen.

**Abstract number:** P2-371  
**Abstract type:** Poster

**Communicating Bad News**

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**Introduction:** Vital and inseparable part of palliative care is communication. It is undeniable that in our society any conversation about death and dying is awkward and difficult, and even more so when it occurs between a doctor and patient. Communicating bad news to patients is not an optional skill, it is an essential part of professional practice. Communication is strongly influenced of race, culture, ethnicity, religion, and socioeconomic class.

**Aim:** Physicians can use to communicate bad news in a direct and compassionate way that can improve the patient's and family's ability to plan and cope, encourage realistic goals and autonomy, support the patient emotionally, strengthen the physician-patient relationship, and foster collaboration among the patient, family, physicians and other professionals.

**Methods:** Counseling skills through exploration of feelings and identification of key problems with open-ended questions.

**Results:** We live in a culturally diverse country and frequently find that not all our patients and families relate to or accept the idea of individual, autonomous decision making. Often in our practice the family makes the medical decisions when one of the members is sick. These cultural differences also affect the view of truth telling. Very often family ask us not to say the truth. Not that rare it is the responsibility of the children to protect their parents from bad news. Mostly in our country the physician informs the family before the patient. In general there are 50% of patients that they don't know the truth or full truth.

**Conclusion:** Truth telling should be applied in a way that promotes a trust based relationship by taking into consideration the patient's preferences for receiving information and the role of the family as desired by the patient.

**Abstract number:** P2-372  
**Abstract type:** Poster

**Self Management in Cancer Patients Receiving Palliative Chemotherapy: Strengths and Weaknesses in Nursing Support**

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**Background:** Self management is an important issue for cancer patients. It helps to control the consequences of the disease and its treatment, to learn to live with cancer, and thereby to maintain or even increase quality of life. For advanced cancer patients making their own decisions is of psychological importance, it gives a feeling of 'mastering and control'.

The department of Medical Oncology of a University Hospital in The Netherlands showed in explorative research that self management is of great importance for its patients. However, it's not clear to which extent patients receive nursing support on this issue in daily practice.

**Aim:** To determine how and into which extent nurses support self management of cancer patients treated with palliative chemotherapy.

**Method:** A strengths and weaknesses analysis of this topic according to the '3-phase model' (before, during and after treatment), which consists of 'tools' for supporting self management. Selfmanagement is defined as "the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition".

**Results:**

**3-phase model**

Phase	Tools	Strengths	Weaknesses
<b>Before treatment</b>	<i>Collect clinical data</i>	Distress Thermometer, Utrecht Symptom Diary	Not until first visit
	<i>Collect patient experiences</i>	Patient electronic file	Little preparation of patient
<b>During treatment</b>	<i>Sharing information</i>	Face to face and written (ie side effects)	Amount and complexity of information
	<i>Setting goals</i>	Possible by nurse specialist	Not on regular base
<b>Support by the team</b>	<i>Support by the team</i>	Symptommanagement/ coping, team supportive care available	No multidisciplinary plan
	<i>Patient education</i>	USD, anti-emetics, instructions when to call	No education in ie long term consequences, lifestyle
<b>After treatment</b>	<i>Follow up with after-care plan</i>		No after-care (plan) by nurses
	<i>Referrals for follow-up</i>	Rehabilitation program on request	Information/ referrals not on regular base

**Conclusion:** To improve self management support by nurses, four main topics should be covered: revision of information given (timing, amount, complexity); working with an individual integral care plan and individual goal setting; education on lifestyle topics and rehabilitation; and continued integral care after treatment.

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**Abstract number:** P2-373  
**Abstract type:** Poster

**"Don't Blame the Middle Man": The Experiences of Translators Breaking Bad News to Oncology Patients**

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**Background:** Healthcare professionals find breaking bad news difficult and upsetting. Increasing cultural diversity has led to an increasing number of patients whose first language differs to that of the healthcare provider, with more patients requiring a translator to facilitate communication. Hospitals often ask non clinical translators to facilitate breaking bad news. We sort to explore the experiences of translators within a specialist oncology centre.

**Methods:** Qualitative interviews were audiotaped and transcribed verbatim. Thematic analysis was undertaken to identify major themes and subthemes.

**Results:** Five participants were recruited. Major themes included emotional pathways, translation challenges and translator support needs. Sub themes included the significant emotional impact of translating distressing information, feeling guilty for divulging distressing news, being the focus of patients' distress or anger and feeling in conflict with the patient or family. Participants also identified the challenges of accurately conveying information in a culturally congruent format and the need for formal briefing, debriefing and support. However, patients felt a strong sense of advocacy for the patients and found encounters with death and dying emotionally draining. Participants sometimes felt rushed and did not always get sufficient time to convey information. They felt strongly that there should

## Poster sessions

be access to counseling and more time provided to prepare and debrief after such communications.

**Conclusions:** The increasing use of translators in the care of patients with advanced cancer is resulting in more and more lay people being subject to similar emotional pressures faced by clinical staff, yet without the necessary formal training or support mechanisms that are recommended for clinicians. This study highlights the training and support needs of non clinical staff as identifying a unique set of communication challenges faced by translators.

**Abstract number:** P2-374  
**Abstract type:** Poster

### A Patient-centered Approach to Giving Bad News

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**Background:** Giving the bad news might be challenging and requiring special communication skills.

**Methods:** A literature search reveals that much attention has been given to this topic. The typical guidance on managing this patient encounter usually takes a directive approach: give the bad news in person, provide a private setting, utilize feeling reflections, avoid overwhelming the patient with information and ensure the patient is safe to drive home. Many authors suggest that physicians advise patients to create a list of questions and return with a partner or friend who can offer assistance and support. However, one aspect of giving bad news is not observed in the literature. There is no instruction on how to meld the directive tasks of giving bad news with the preferred patient-centered approach.

**Results:** In our internal medicine faculty and residency clinic we use a Patient-Centered Approach to Giving Bad News, were the physician identifies whether the patient's first reaction to the bad news is a "feeling" response or "thinking" response. If the patient displays a feeling response, the physician reflects feelings until the patient's dialogue or non-verbal expression suggests a switch to the thinking mode. Conversely, if the patient's initial response is a thinking response, the physician answers questions and checks for understanding before exploring feelings. An algorithm is used to illustrate this process.

**Conclusion:** The authors think that their approach might contribute to the current understanding of how to give bad news by successfully marrying the informational aspect with the patient-centered approach.

**Abstract number:** P2-375  
**Abstract type:** Poster

### "Do Everything": What it Means for You?

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**Background:** When the patient and/or family want "to do everything" and they request treatments which physicians or institution count as an inappropriate, there is the potential for conflict.

**Objective:** To explore why understanding of the meaning of "Doing everything" is important in palliative care.

**Case study:** A 53 year old African American female presented with a right breast mass of 1 year duration, eventually diagnosed as a metastatic poorly-differentiated adenocarcinoma. Spinal metastases resulted in paraplegia; she had multiple hospital admissions due to cancer-related complications. Due to excruciating pain she was heavily sedated with analgesics at times. The admitting team and her consultants felt that comfort care was the best treatment option. Her sister and brother wanted "To do everything." Many family meetings were held, but they insisted on heroic measures. The bioethics committee meeting was called in to assist in conflict resolution. At the time when the patient was able to express herself, she said "Listen... Listen to the patient who has time to die. I want comfort, respect and to die with dignity."

**Discussion:** Physicians might conclude that "Do everything" means that patient and/or family want cardiopulmonary resuscitation or they request aggressive treatment in terminally ill patient. For some patients everything means comfort care only and for their families to do everything possible to reduce their suffering. Open discussion about patients' and their families values and concerns that lead them to request "everything" usually helps medical caregivers to better understand patients' real preferences and treatment requests.

**Conclusion:** When taking care of seriously ill patients it is extremely important to build strong relationships and good communication with patients and their families. "Doing everything" might have different meanings for patients, their

families and their physicians.

**Abstract number:** P2-376  
**Abstract type:** Poster

### Parents' Experiences with Care and Symptom Management for their Child during the Palliative Phase, and the Impact on Long-term Parental Psychological Functioning

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**Introduction:** Twenty-five per cent of children diagnosed with cancer die. Losing a child puts parents at increased risk for developing psychological problems.

**Objectives:** To explore parents' perception of the quality of care and symptom management and the influence on long-term grief in parents who lost a child to cancer.

**Methods:** Eighty-nine parents of 57 children who died of cancer between 2000 and 2004 participated in this retrospective cross-sectional study by completing a set of questionnaires measuring grief, perception of care (communication, continuity of care and parental involvement), and the severity and level of control of their child's symptoms during the palliative phase. Care was assessed on a 5-point Likert scale (1=disagree;5=agree).

**Results:** Parents highly rated communication (4.6±0.5), continuity of care (4.3±0.6) and parental involvement (4.6±0.7) during the palliative phase. Fatigue (75%), pain (74%), anxiety to be alone (52%) and anger (48%) were the most frequently reported physical and psychological symptoms of the child. Higher ratings of communication ( $\beta=8.93, p=0.03$ ) and continuity of care ( $\beta=11.71, p=0.01$ ) were associated with lower levels of long-term parental grief. The severity of the child's dyspnoea ( $\beta=3.11, p=0.03$ ), anxiety to be alone ( $\beta=4.50, p<0.01$ ), anxiety about the future ( $\beta=4.83, p<0.01$ ), anger ( $\beta=4.99, p<0.01$ ) and uncontrolled pain ( $\beta=6.52, p<0.01$ ) were associated with higher levels of long-term parental grief. Multivariate models combining domains of care and symptoms showed a significant influence of both care and symptom management on long-term parental grief.

**Conclusion:** Palliative care, especially communication, continuity of care, and adequate symptom management in children dying of cancer are predictive for long-term parental grief levels.

**Abstract number:** P2-377  
**Abstract type:** Poster

### Abstract withdrawn

## Research Methodology

**Abstract number:** P2-378  
**Abstract type:** Poster

### Searching for Dignity

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**Objective:** The discussion on outcome indicators in palliative care (PC) includes the question on the evaluation of the construct "dignity". A systematic review on the use of dignity in English language PC literature is planned to learn whether the term is used or defined uniformly. As a first step a search filter with sufficient sensitivity and precision had to be developed.

**Design/methods:** A predefined set of 19 sentinel papers was used to test sensitivity on each step of the search filter development. The search was conducted in EMBASE and MEDLINE. A first intent of basing the filter on MeSH terms was dismissed despite a high sensitivity (90%) due to lack of precision. Combining several text-word terms successively raised the sensitivity score and enabled a more precise search.

**Results:** A search filter combining the text word terms "palliativ", "hospice", "terminal", "euthanasia", "end of life", "end-of-life", "death", "dying" with the truncated term "digni\*" resulted in the highest sensitivity. In the combined search from EMBASE and MEDLINE 95% of the reference articles was found and 2507 publications retrieved. The database was cleared of doublings (964), articles without abstract (601), wrong topic (84). In the analysis of the remaining 858 abstracts another 189 articles were excluded due to lack of relevance. 669 references were considered relevant for

further analysis. 7.4% of the papers were published between 1975 and 1989, 22.6% in the 90<sup>th</sup>, and 70.0% since 2010.

**Conclusion:** Sensitivity and precision of the search filter were considered to be adequate. The increasing number of publications in recent years suggests a rising awareness for dignity and the need of an in-depth analysis of the understanding of dignity in PC literature.

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**Abstract number:** P2-379  
**Abstract type:** Poster

### How Is the Role of the Volunteer with Direct Contact with Patients and Families in Specialist Palliative Care Understood? A Thematic Meta-synthesis of Qualitative Literature

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**Aim:** Volunteers make a major contribution to palliative patient care, and qualitative studies have been undertaken to explore their involvement. With the aim of making connections between existing studies to derive new meanings and advance theories, we undertook a meta-synthesis of these qualitative studies. We sought to uncover how the role of volunteers with direct contact with patients in specialist palliative care is understood by volunteers, patients, their families, and staff.

**Method:** We used systematic review techniques to search for relevant literature that explored the role of the volunteer. We searched electronic citation databases, scanned reference lists of included studies, and undertook handsearches of selected journals to find studies which met our inclusion criteria. We quality appraised included studies. We synthesised study findings using a novel meta-synthesis method, thematic synthesis.

**Findings:** We found 12 relevant studies undertaken in both hospice and home-care settings, with volunteers, volunteer coordinators, patients and families. The synthesis will be completed in 2012. It will derive key and overarching concepts that will provide an understanding in how the volunteer role is understood through relationships with paid staff, patients and families, the implicit boundaries of the role, the tasks involved, and the nature of their contribution.

**Conclusions:** Uncovering how the volunteer role is understood will help inform volunteer managers how to support volunteers in the day-to-day palliative care environment which, in turn, may help to improve outcomes for patients and families. The synthesis will raise the profile of this under researched and often over looked group. The review will demonstrate how thematic synthesis can help synthesise qualitative research systematically, extending methodological techniques to help answer difficult research questions.

**Funded by:** The Dimbleby Marie Curie Cancer Care Research Fund.

**Abstract number:** P2-380  
**Abstract type:** Poster

### How Qualitative Longitudinal Research Can Help to Understand Existential Loss at the End of Life

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**Aims:** To describe how longitudinal qualitative research can highlight the experience of loss in frailty for older adults approaching death.

**Methods:** Qualitative longitudinal study comprising up to three interviews with frail older adults and informal carers over 12 to 18 months. These were compiled as case studies using 'voice centred relational' narrative analysis. The stories of two participants who died during the study are described to illustrate the benefit of the longitudinal approach.

**Results:** Mr M suffered greatly at the end of his life due to pain, unhappiness, social isolation and alienation from the world. Initial interviews offered insight into how self discipline and independence were fundamental to his sense of meaning and purpose. Later interviews showed the deep impact of being unable to live by these core values and led to existential loss, increasing despair and frustration. Dynamic changes in the different dimensions of need occurred during the physical decline.

Mrs O similarly ended her life with a deep sense of unhappiness, alienation in her surroundings and existential loss. Having first lost the power to control her world with her physical self she maintained her sense of autonomy verbally. Once this was lost her sense of existential despair was

profound. Initial interviews involved a repeated and strongly voiced refusal to move to a nursing home and explained her complete disengagement with the world once she was admitted to one even although her opposition was now expressed via resignation. Mrs O's needs across various dimensions also changed over the duration.

**Conclusion:** Longitudinal interviews highlighted dynamic multidimensional changes for both participants while earlier interviews offered the background for understanding later experiences. Deep contextual understanding can be gained that may highlight dimensions of need beyond the physical and show key losses that may lead to a sense of existential death for participants.

**Abstract number:** P2-381

**Abstract type:** Poster

### Epidermiology of Non-HIV Related Kaposi Sarcoma

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**Background:** Kaposi's sarcoma (KS) is the commonest cancer seen at HAU. Most patients have HIV/AIDS thus qualifying this to be epidemic KS. Other than the endemic KS which typically occurs in elderly African men as a slow growing cutaneous and lymphadenopathic tumor Hospice Africa Uganda (HAU) has no patients on long-term immunosuppressive treatments, and no patients who fit the description for classic KS.

**Objective:** This paper explored for subsets of patients who do not fit the epidemiological forms of KS as described in literature after clinical team discussions highlighted departure from the expected patterns for this tumour.

**Method:** Retrospective chart review and data base search revealed 11 HIV negative patients seen between 2003 and 2011 with histologically confirmed KS.

**Results:** Four of the 11 (36%) were elderly (>60years) men with endemic KS. The rest were young adults (age range 28-57 years), nearly half of whom were female. All these developed skin lesions on their limbs over 5 years before presentation to HAU, and these were static or only slowly progressive. 5 of the 7 (71%) never received oncologic chemotherapy and are surviving in good general condition. Two received palliative chemotherapy with remission of their lesions.

**Conclusion:** This study highlights a peculiar presentation of chemo sensitive KS which is not well epidermiologically described. It occurs in immune competent African young adults with no predilection for sex. Larger studied are required to adequately describe this form of KS.

**Abstract number:** P2-382

**Abstract type:** Poster

### Enhancing Oral Representations in Palliative Care Research: Using Timelines with Lung Cancer Patients and their Families and Friends

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**Aims:** To identify benefits of using visual techniques in interviews with patients with advanced lung cancer and those who accompanied them to diagnosis-giving consultations. These interviews were a component of a study seeking to develop an intervention to support patients with lung cancer to share the news of their diagnosis with significant others. Understanding the process of receiving and sharing bad news was key to identifying the place and time for potential interventions to support patients with this process.

**Methods:** In-depth interviews included use of a visual timeline to elicit information from participants. The timeline comprised a horizontal axis on an A3 sheet with news received plotted above the line and news shared below the line. Participants indicated on the timeline when and where they received bad news associated with their diagnosis and with whom they then shared this news and when.

**Results:** The timeline had methodological and empirical benefits. Methodologically, it facilitated participation of respondents as they generated and created their timelines whilst allowing the researcher to clarify the sequence of events. Working with this tool also facilitated the emotional management of these intense interviews by temporarily breaking eye contact between the researcher and interviewee and providing a change of focus. Empirically the timeline was invaluable: it identified receiving (and

subsequent sharing) of bad news as a sequence of events rather than the solitary instance of the 'breaking bad news consultation' frequently referred to in the literature.

**Conclusions:** Visual methods such as a timeline can enhance both the process and outcome of data collection in sensitive interview situations. The changed focus of the interview enabled by the tool helped individuals recall and convey how they received, and then shared, bad news repeatedly over a period of time: a finding crucial to development of a supportive intervention.

**Abstract number:** P2-383

**Abstract type:** Poster

### Are Palliative Care Research Samples Biased? Results from Interviews with Experienced Palliative Care Staff

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**Aim:** There is evidence that palliative care patients wish to be involved in palliative care research but recruitment proves problematic. The purpose of this study was to understand clinicians' and researchers' perspectives about patient recruitment to research studies in palliative care settings.

**Method:** Researchers and clinicians were recruited from various palliative care settings in the UK (n=12). Participants were interviewed individually or in pairs using guided questions during June/July 2012 about recruitment experience to both qualitative and quantitative research and included both competent and incompetent patients. These studies had relatively good recruitment rates. Interviews were recorded, transcribed and content analysis performed.

**Results:** The sample included research practitioners (n=3), clinicians (n=7) and professionals with dual research and clinical roles (n=2). Staff and sometimes relatives, practice 'gatekeeping'; only asking those who fit their ideal participant criteria. These patients were stereotypically deemed nice, co-operative, chatty and younger. Those who tended not to be approached were poorly, emotional, angry or older. Staff saw themselves as protecting vulnerable patients from potential harm from research. However, they recognised that patients wanted to contribute to research and should be asked. They had experience of patients acting autonomously including those who declined a study or withdrew; showing the final decision to enter a research study should be with the patient.

**Conclusions:** There appears to be an unwritten code to only include those fitting the ideal research participant stereotype. Education of staff in palliative care settings is crucial to gain access to all eligible patients. Secondary screening by staff for the ideal participant may create a biased sample. Such gate keeping denies patients the potential satisfaction of having contributed to knowledge development.

**Abstract number:** P2-384

**Abstract type:** Poster

### Nursing Diagnoses in Palliative Home Care

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**Objective:** Describe the nursing diagnoses most often identified by a palliative home care team.

**Study design and methods:** A descriptive study. The participants were a nursing team of palliative home care, composed by four nurses. The data were collected from twenty two patients and their families through structured observation, particularly from an observation grid constructed based on Palliative Care for Dignified Dying - International Classification for Nursing Practice (ICNP<sup>®</sup>) Catalogue. This grid included all nursing diagnosis provided by the International Council of Nurses for this area. The data collection was performed between days 1 and 31 August 2012. To data processing was created a database in Excel, with the possibility of adding other diagnoses observed.

**Results:** The nursing diagnoses often identified in palliative home care team were: "fatigue," "cachexy", "knowledge about the medication regime, lack of", "edema", "skin integrity, compromised", "family process, compromised" and "family coping, compromised". Therefore four of the prevalent nursing diagnoses correspond to physiological needs and the remaining three correspond to needs of security, as defined by Maslow's hierarchy adapted to palliative care. **Conclusions:** Nursing diagnosis activity is relevant to health information systems, specifically to nursing information

systems. The nursing diagnosis gives visibility to nursing care and in this case the activity on palliative home care.

## Non-Cancer

**Abstract number:** P2-385

**Abstract type:** Poster

### Recognition of Atrial Fibrillation in a Hospice Inpatient Unit

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**Objectives:** To review the medical assessment of atrial fibrillation (AF) on admission to a hospice and to examine if AF has any potential relevance in a palliative care inpatient population.

**Setting:** 28-bedded independent charitable hospice in southeast England.

**Subjects:** Retrospective data were collected on 83 consecutive hospice inpatients aged 65 years and over during a six week period in 2011.

**Main outcome measures:** Documentation in the medical admission record of; established AF, relevant drug history, heart rate and rhythm from examination and the proposed management of AF.

**Results:** AF was noted in 17% of patients, with clinical examination suggesting a prevalence of up to 27%. Heart rate was documented in 38% of patients, of these 84% had a normal rate. Heart rhythm was documented in 35% of patients, of these 59% had an irregular pulse. Overall 20% patients were taking rate-limiting medication.

**Conclusion:** AF was common, identified in up to 27% of the hospice inpatient population aged over 65 years. This is several times higher than the 3-9% seen in comparable general or acute hospital admission populations. When documented, the majority of patients (59%), had an irregular pulse, however the clinical significance is not clear. As an examination of pulse was documented in less than 40% of patients, it appears that assessment of heart rate and rhythm on admission could be improved. Since AF represents a potentially treatable condition, studies to examine the symptomatic burden of AF in the hospice setting appear warranted.

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**Abstract type:** Poster

### Use of the Liverpool Care Pathway in End-of-Life Care Following Acute Stroke: The Role of Families

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**Background:** The Liverpool Care Pathway (LCP) is widely recommended to ensure best practice in caring for the dying. It is increasingly used in stroke units to manage end-of-life care following stroke. Cognitive and communication problems are common in severe stroke; families may be proxy information-givers.

**Aim:** We investigated the role of families in decisions concerning end of life care, with specific regard to the LCP. Findings on their role are presented here.

**Method:** Ethics and clinical governance approvals were granted. In four Scottish acute stroke units, casenotes for 100 consecutive stroke deaths were reviewed prospectively and face-to-face semi-structured interviews conducted with healthcare professionals and bereaved relatives. Descriptive statistical analysis of data from the casenote review was performed via SPSS 19. NVivo 9 was used to support thematic analysis of transcribed interview recordings, using constant comparison to develop a modified grounded theory of decision-making. Findings from the casenote review and interviews were triangulated to strengthen trustworthiness of conclusions.

**Results:** Of the 100 consecutive deaths, families were contactable in 96 cases. The LCP was used in 59 of the 100 deaths. Healthcare professionals frequently relied on families for information about patients' wishes. Some relatives felt responsible for making decisions and reported 'signing up' to the LCP. Family opposition to the LCP could trigger staff to use LCP principles e.g. anticipatory

prescribing, without adopting formal LCP paperwork. Families often organised religious care or provided hands-on care. Families sourced information by negotiating meetings with doctors, asking nurses for information, using informal social networks, and searching the internet. **Conclusion:** The LCP is often used in end of life care after stroke. Family views influence whether it is formally adopted. **Funding source:** Chest, Heart & Stroke Scotland

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**Abstract type:** Poster

### End Stage Liver Disease (ESLD) in the Last 12 Months of Life - A Retrospective Case Note Review of End of Life Experience of Patients Known to a Tertiary Unit

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**Background:** Liver disease is a growing global public health problem and 5<sup>th</sup> largest cause of death in the UK, however health policy for this patient group primarily centres on prevention, with little focus on improving care for those with end stage liver disease (ESLD). There is little research into gaps in health care provision or delivery for this group in the last year of life.

**Method:** Retrospective review of purposively selected case notes (30 patients) with ESLD referred to a tertiary London liver unit. Information was extracted using a structured proforma on demographics, ESLD cause, symptoms and service use in the last 12 months of life.

**Results:** Preliminary analysis of 14 patients with a predominant diagnosis of alcoholic liver disease (43% female, 57% male) revealed many physical, behavioural and psychological symptoms, plus numerous medical investigations and complex interventions. There was a high in-patient hospital admission rate, and median length of stay of 10 days. Communication with families about prognosis was evident, although it occurred late.

Discussions with patients about their understanding of their disease and preferences for future care were very limited. Referrals were made to specialist palliative care, but only within the last few days of life. All patients died in hospital.

**Discussion:** Patients with ESLD in the last year of life have repeated lengthy hospital admissions, many medical investigations and interventions. They are often unaware of the severity of their condition. Specialist palliative care is received late when the patient is not always able to communicate their wishes and too sick to transfer. The liver team should address complex unmet needs earlier, adopting a model of shared care with specialist palliative care when the patient deteriorates and becomes more symptomatic. This would meet patient needs more appropriately.

**Funding:** Marie Curie core funding.

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**Abstract type:** Poster

### The Experience and Provision of End of Life Care for People with Advanced Liver Disease who Are Homeless

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**Aim:** To identify which clinical symptoms or behaviours people with advanced alcoholic liver that are homeless and living in UK shelters exhibit, as they are approaching the end of life. To examine which health care services they receive at the end of life.

**Method:** Rapid participatory appraisal using 3 data sources; case note review of 27 residents who died within a 16 month period who had a history of alcohol misuse and possible liver disease, 3 focus groups with hostel staff, field notes of staff interviews and meetings and discussion forum with residents and staff.

**Results:** A combination of physical, psychological and behavioural symptoms occurred as residents deteriorated and approached death. Multiple needs were common as physical and psychological problems were exacerbated by substance misuse. Admissions to secondary care were

frequent and lengthy. Minimal communication and exchange of information occurred between hospital and hostel staff, resulting in poor discharge planning and lack of identification of residents' future health care needs. Hostel staff, often unaware of the severity of a resident's condition, continued to provide care until their deterioration warranted further hospital admission. Residents were reluctant to leave the hostel. Referrals to specialist palliative care were minimal. Unanticipated, sudden deaths had a negative impact on staff and other residents.

**Discussion:** Social care staff need additional training to alert them to changes in residents' condition, to help anticipate deterioration and death and offer earlier support. By obtaining residents permission, better communication and exchange of information between hospital and hostel staff would facilitate discharges and enable staff to discuss future care preferences with residents, important because of the numbers that present with multiple needs. Bereavement support would benefit both staff and residents and encourage discussions on end of life care.

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**Abstract type:** Poster

### Differences in Specialist Palliative Care Service Utilisation between Dementia and Cancer Patients

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**Aims:** To compare specialist palliative care service utilisation between dementia and cancer patients.

**Methods:** A retrospective service evaluation of electronic patient records was undertaken of all patients with a primary diagnosis of dementia referred to a specialist palliative care (SPC) service between 1st June 2010 and 31st May 2011. A random sample of cancer patients referred during the same time interval, matched for age and place of residence, were used for comparison. Service utilisation data was collected from referral to 1<sup>st</sup> March 2012.

**Results:** 50 patients with a primary diagnosis of dementia were referred to SPC over one year. The majority (54%) were nursing or care home residents. Dementia patients spent a shorter time in the service (median 15 days) compared to cancer patients (median 40 days) ( $P < 0.05$ ). The majority of both dementia (66%) and cancer (92%) patients remained in the service until death. Compared to cancer patients, dementia patients had a lower absolute use of a range of hospice services, including home visits, hospice at home and day hospice. However, when adjusted to a rate of service use, i.e. service use/days in service, there was negligible difference between the two groups apart from day hospice use (cancer patient rate: 0.046, dementia patient rate: 0.003). Full statistical analysis will be presented.

**Conclusion:** Dementia patients in this SPC service, spent less time in the service before death and had lower day hospice use but otherwise had comparable service use to matched cancer patients. These results suggest an end of life period can be identified for dementia patients and SPC services involved appropriately. Further research is required into the appropriate timing for referrals and to assess the effectiveness of the SPC involvement.

**Abstract number:** P2-390  
**Abstract type:** Poster

### Living and Dying with Advanced Chronic Liver Disease: A Serial, Multi-perspective Interview Study

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**Background:** Current trends suggest that the number of patients living and dying with advanced chronic liver disease will rise dramatically. However, little is known about how the illness is experienced and managed by patients and their families. Palliative care services traditionally focused on patients with cancer and more recently on other types of organ failure, but those with advanced liver disease are relatively neglected.

**Aims:** To better understand the experiences, goals and needs of patients with advanced chronic liver disease and how these change over time. Specifically, to explore the physical, psychosocial, spiritual and information needs of patients and family carers, and to review their use of health, social and voluntary services and the extent to which these are perceived to meet their needs.

**Methods:** Qualitative, multi-perspective study using serial in-depth interviews. 15 patients with different types of liver disease and their family carers were interviewed up to 3

times over one year. Single interviews were undertaken with case-matched professionals. Data were digitally recorded, fully transcribed, and analysed using grounded theory and NVivo 9.

**Results:** Many unmet physical needs and comorbidities were present. Patients experienced uncertainty, anxiety and confusion about their illness and its likely progression, and wanted strategies to help them self-manage their condition. We found evidence of perceived stigma and social isolation. Medical care was considered good, but interprofessional and doctor-patient communication was problematic. Advance care planning was largely absent.

**Conclusion:** This is the first serial interview study of people with advanced chronic liver disease. There is evidence of many unmet physical and psychosocial needs. Similar to patients with advanced lung disease or heart failure, patients with advanced liver disease receive less support and palliative care than cancer sufferers. Study funded by the ESRC.

**Abstract number:** P2-391  
**Abstract type:** Poster

### The Prevalence and Burden of Physical and Psychological Symptoms in Patients with Heart Failure Attending a South African Public Hospital

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**Background:** Incidence of heart failure is rapidly increasing, and associated with high morbidity and mortality. Evidence of symptom prevalence is scarce. This study aimed to measure patient-reported prevalence and burden of symptoms among patients with NYHA stage 3 or 4 heart failure.

**Methods:** Adult patients diagnosed with NYHA stage 3 or 4 heart failure were recruited from the emergency unit, emergency ward, cardiology ward, general medicine wards and outpatient cardiology clinic of a public hospital in South Africa. Patients were interviewed by researchers using the Memorial Symptom Assessment Scale-Short Form, a well-validated multidimensional instrument which captures presence and distress of 32 symptoms. Disease-specific information was collected from the medical record.

**Results:** A total of 100 patients (response 97%) were included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% reported having no income. Mean Karnofsky Performance Score (KPS) was 50%. Patients reported a mean of 21 symptoms. Symptoms with a high prevalence were 'shortness of breath' (96%), 'feeling drowsy/tired' (93%), 'worrying' (90%) and 'pain' (88%). Symptoms associated with a high level of distress were 'shortness of breath' (90%), 'numbness/tingling in hands or feet' (86%), 'I do not look like myself' (86%) and 'feeling drowsy/tired' (85%). Uni- and multivariate regression analyses, with total number of symptoms as dependent variable, showed no association between presence of symptoms and age, gender, ethnicity, education, income, years since diagnosis or number of hospitalizations in the last 12 months. Increased presence of symptoms was significantly associated with worse KPS ( $b = -1.861$ ,  $p = 0.002$ ).

**Conclusion:** Patients with NYHA stage 3 or 4 heart failure experience a high prevalence of symptoms and report high levels of burden associated with these symptoms. Symptom load is associated with a worse physical performance status of the patient.

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**Abstract type:** Poster

### Palliative Care of COPD Patients in North Glasgow

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**Background/aims:** As a palliative care team we felt we had little information on the increasing number of COPD patients referred to our service and the journeys they take through palliative care. One particularly challenging case highlighted the gap between the expectations of patients with COPD and the reality of their situation. We felt we needed to gather information on COPD patients referred and the trajectory of their care.

**Method:** Retrospective study of all patients with COPD as their primary diagnosis, referred to palliative care from 01.04.11 to 31.03.12. Patients' palliative care notes were reviewed and the Greater Glasgow Clinical database was

sought for information on encounters within secondary care. Data was collected for the period of time until present time or until the patient's death.

**Results:** 30 patients were referred. The majority of patients were referred to outpatient services (86%) with most being referred to Community Clinical Nurse Specialists (CNS) (57%). Most referrals came from secondary care (60%). The reason for referral included symptomatic management of SOB in 93% of cases and anxiety/distress in 40% of cases. 33% of patients were on opioids at referral with this number increasing to 67% at the end of the study period. For benzodiazepines 37% of patients were prescribed these at time of referral, increasing to 80% at end of study period. Only 33% of patients had any record that advanced care planning had been discussed and only 53% had a record of resuscitation status.

The average time from referral to death was 14 weeks (range 1-45 weeks).

**Conclusion:** Palliative care of COPD patients is mainly community based. Surprisingly, most referrals came from secondary care. There was an increase of opioid but more markedly benzodiazepine prescribing. Advanced care planning and DNACPR discussions were not documented in the majority of cases.

**Abstract number:** P2-393

**Abstract type:** Poster

### Palliative Care in an Internal Medicine Department: A Comparison between Non Cancer and Cancer Patients

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**Background:** Several studies published in the last years concluded that non cancer patients (NCP) have similar degrees of suffering and need for symptom control as cancer patients (CP) and could benefit from Palliative Care (PC).

**Aims:** Characterize the needs in PC in an Internal Medicine Department of an Acute Hospital (IMDAH), define the profile of palliative care patients (PCP), comparing non cancer and cancer patients and assess the adequacy of care given.

**Methods:** Prospective and observational study including the patients admitted to an IMDAH in a 9 weeks period. Application of a questionnaire to patients and clinical files review.

**Results:** Of the 670 patients admitted, 15% had PC needs, 54 CP and 48 NCP. The NCP group included patients with Cerebrovascular disease (24), Parkinson dementia (7), Alzheimer dementia (6), Cardiac insufficiency (4), Chronic renal failure (3), Multisystemic atrophy (2), Lateral amyotrophic sclerosis (1) and Lateral primary sclerosis (1). The main admission motive was infection in both groups (45% of CP/80% of NCP). The median number of symptoms/patient of CP was higher when compared to NCP (5 vs 3,  $p < 0,001$ ). NCP had more dyspnea, sleepiness, agitation and insomnia and needed more nursing care than CP ( $\geq 3$  cares - 63% vs 15%). The mortality rate of CP was 42,6% and NCO 18,8% ( $p=0,01$ ).

**Conclusion:** Symptom control and PC philosophy was beneficial to NCP and IMDAH should be aware of the need to provide PC care also to NCP.

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**Abstract type:** Poster

### Estimating the Effect of Palliative Care in an Intensive Care Unit (ICU)

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**Introduction:** Advances in disease prevention, treatment and medical technologies combined population aging resulted in a dramatic increase in the number of adults living with a serious illness.

**Objetives:** Evaluate the Effect of a Group of Palliative Care in an ICU.

**Methods:** Patients were followed by the Palliative Care Service at the hospital through two ways: by request consultation request by the attending physician. Or at triage system, in which all ICU patients were screened by the Palliative Performance Scale (PPS) with cutpoint of 20 points. Patients presenting criteria: chronic, progressive and evolutionary; lifetime supposedly shortened to months or years; unresponsive to disease-modifying treatment; emotional impact related to the possibility of death were approached regarding changing the therapeutic focus to palliative care. They were divided into two groups: Palliative Group (PG) and Control Group (CG) called that somehow (not family acceptance, physician assistant) can not be accompanied by the service despite having indication.

**Results:** We evaluated 131 patients between the period of May until March 2012. 38 patients were in the ICU, 28 PG and 10 CG. Among all patients were only 6 patients with cancer, others were mostly patients with functional failure. There was no difference in age (PG  $78.67 \pm 12.99$  and CG  $69.2 \pm 15.3$  ( $p = 0.11$ )). There was no difference between the groups entering the service was Palliative Care through screening or consultation request ( $p = 0.29$ ). 15 patients of Palliative Group died while 6 of the control group ( $p = 0.55$ ). But there was significant difference between the two groups with regard to time until outcome of ICU: PG  $6.74 \pm 15.3$  and CG  $14.1 \pm 10.57$  ( $p = 0.004$ ) and duration of hospital outcome: PG  $14,17 \pm 24.2$  and CG  $25.1 \pm 28.2$  ( $p = 0.004$ ).

**Conclusion:** The insertion of Palliative Care in the ICU was associated with a shorter stay in the ICU and in hospital, without changing mortality.

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**Abstract type:** Poster

### Symptom Assessment of Terminally-Ill Tuberculosis Patients in the Kemerovo Region

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At the present time, the problem of mortality from tuberculosis is one of the most urgent in Russia, because of social losses among persons of working age. The epidemic threshold is surpassed in the Siberian district. In the Kemerovo region the epidemiological situation on tuberculosis (TB) is complicated. The morbidity, prevalence and mortality rates, and the proportion of patients with MDR/XDR-TB are much higher than data on Russia as a whole.

**Aim:** To assess symptoms that terminally-ill TB patients experience.

**Methods:** 43 terminally-ill patients were included in the study. TB meningitis and/or severe deterioration were exclusion criteria for the study. A pain questionnaire, the Numeric Pain Scale, the HADS depression scale, and Carlston co-morbidity scale were utilized.

**Results:** The average age of the patients was  $42.1 \pm 3.4$  years. Cavitary TB (27 patients - 62.7%) was dominate among the TB types. 14 patients (37.2%) were diagnosed with Miliary TB or Caseous Pneumonia. 19 patients (44.2%) were co-infected with HIV-disease; the median CD4 was 194 cells/mm<sup>3</sup>. All patients of the study received anti-TB therapy and, in addition, 7 patients were on HAART. The main symptoms were identified in terminally-ill TB patients and located in descending order: weakness - 100%, cough - 90.6%, shortness of breath - 67.4%, sleep disturbance - 44.1%, depression - 41.8%, pain - 37.2%, diarrhea - 23.2%, constipation - 18.6%, nausea - 16.2%. 15 patients suffered from pain. 7 patients (16.3%) experienced severe pain, 6 patients (14%) experienced moderate pain, and 2 patients had mild pain. 23 of the patients (53.4%) stated that they did not have relatives who could care for them. The average Carlston index of co-morbidity was of 2.7 points.

**Conclusion:** Patients with terminally-ill TB experienced not only varied physical symptoms, but also psychological and social problems. These patients will benefit from good palliation of troublesome symptoms.

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**Abstract type:** Poster

### Symptom Burden and Palliative Care Needs of People with Advanced Dementia

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**Aims:** People dying with advanced dementia (AdvD) often have poorly managed physical symptoms and suboptimal care. This UK pilot study tests the feasibility of recruitment and study measures in people with AdvD who can be challenging to recruit. This is part of a larger programme grant to inform the development of a complex intervention to improve care.

**Methods:** Pilot longitudinal cohort study of people with AdvD (Functional Assessment Staging Scale 7c and above), assessed at study entry and then monthly for 1 year or until death. Assent for participation was given by a family carer or professional consultee. We assessed physical condition, behaviour, pain, quality of life and symptom management.

**Results:** 26 participants (25 from care homes & 1 in their own home) with AdvD were recruited. Mean age was 85 (73% female & 27% male). Do not resuscitate orders were in place for 83%, and 65% an advance care statement. Pressure sore risk was "very high" in 58%. Participants were moderately agitated (mean Cohen Mansfield Agitation Inventory score 40). None had received a painful clinical intervention in the prior month but 58% had pain during

movement and 12% at rest on the PAINAD scale. Difficulty swallowing and weight loss were the commonest symptoms (58% & 44%), most needed assistance with eating. Analgesia was prescribed in 71%. Mean quality of life score (QUALID) was 25 (usual range 11-55, lower scores=higher quality of life). Mean Symptom Management in End of Life score was 33 (range 20-45, higher scores= greater comfort).

**Conclusion:** It was possible to meet ethics standards and recruit people with AdvD to a pilot study. Data collection using validated instruments was feasible. Participants were frail with high risk of pressure sores, agitation and difficulties swallowing. Comfort scores were lower than in similar populations in Netherlands and USA. This successful pilot will be extended to a full cohort study.

**Abstract number:** P2-397

**Abstract type:** Poster

### Collaboration between Respiratory and Palliative Care Specialists: Developing Interventions for People with Advanced Respiratory Disease

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**Aims:** The aim of this multisite, multidisciplinary research project was to devise, implement and evaluate palliative care responses for people with advanced respiratory disease.

**Methods:** A participatory action research methodology was chosen as its emphasis is on collaboration, action and reflection. This research was located across an acute hospital and hospice care setting. The original participants were the steering group members including clinical nurse specialists and physicians from respiratory and palliative care teams. Other key stakeholders were included as the project developed e.g. physiotherapists, nurses from relevant wards, patients and families. A mixed methods methodology was employed including audits, quantitative surveys, interviews with patients and families, expert focus groups and evaluation techniques.

**Results:** Four of the interventions are highlighted.

- (1) Education; 93% of respiratory staff expressed a desire for palliative care education and 50% of these attended full day workshops on developing end-of-life awareness and communication skills. There was also reciprocal education and training from the respiratory unit with hospice personnel.
- (2) Multi-disciplinary Team Meetings; organised on a monthly basis, they provided a format for brief discussions of patient cases.
- (3) Communication; this involved regular meetings and presentations at local, national and international levels.
- (4) Patient Care Pathway; the collaborative working relationships that developed across the hospital-hospice sites facilitated the development of a patient care pathway tool for people with advanced respiratory disease.

**Conclusions:** As action research takes place within the theory-practice gap, it has facilitated respiratory and palliative care teams to collaborate on bringing about change within real working environments. Furthermore, it has allowed for the generation of a new practice based knowledge of respiratory palliative care to emerge.

**Abstract number:** P2-398

**Abstract type:** Poster

### ALS - Amyotrophic Lateral Sclerosis: Characterizing the Patients Assisted by a Palliative Care Team in a University Hospital in Portugal

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**Introduction:** Amyotrophic Lateral Sclerosis (ALS) is the most frequent motor neurone disease, causing high degree of dependency and overburden for caregivers.

**Aim:** To characterize patients with ALS followed by the palliative care service (PCS) of an university hospital between 6/Nov/2008 and 15/Oct/2012.

**Method:** Retrospective analysis of the clinical process of

patients (pat.) with ALS followed by the PCS.

**Results:** Forty-eight pat. were observed (26 women; 22 men) with a median age of 67 years (43-83). The presentation of the disease was bulbar in 6 pat. (12.5%), mixed in 14 (29.16%) and peripheral in 28 (58.33%). Referenced mostly by Neurology (n=35), 31 pat. were observed in the 1st year of diagnosis, the majority of them as outpatients (n=37). Beyond the dependency and the communication changes, the most frequent problems were: dysphagia (n= 42, 87.5%); sadness/depression (n=39, 81.25%); pain (n=35, 72.91%), insomnia (n=27, 56.28%), constipation (n=29, 60.41%); drooling (n=26, 54.16%) and dyspnea (n=24, 50%). Most pat. were cared for by family members. In the 1<sup>st</sup> observation: 28 pat. had non-invasive ventilation (NIV) and 2 tracheostomy (7 initiated NIV later); 12 had percutaneous gastrostomy (7 inserted that later); 26 pat. took antidepressants. Atropine SL was used in 18 pat. to control the drooling and 4 needed strong opioids for pain management. 11 pat. died in the hospital (22.91%), 6 at home (12.5%) and 5 in other institutions, most due to respiratory failure. Terminal palliative sedation was instituted in 12 pat. (25%) and 13 took morphine for breathlessness at the end of life. The social worker (in PCS since August 2011) acted in 21 situations. The team psychologist followed 9 pat. and 11 caregivers.

**Conclusions:** The results mirror the literature with complex and intense emotional, financial and physical involvement of pat. and caregivers. Beyond the symptomatic control, palliative care represents added value in care organization and in decision-making.

**Abstract number:** P2-399

**Abstract type:** Poster

## Awareness about Palliative Care among Dialysis Nurses

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**Aim:** This research tries to provide more insight on how dialysis ward nurses perceive palliative care and how their personalities and education influence their perceptions and attitudes towards palliative care.

**Methodology:** A combination of qualitative and quantitative research methods is used to analyse the perception and attitudes of dialysis nurses. Their ideas and opinions are captured, and their education levels noted. Then the influence of these as barriers to the implementation and feasibility of palliative care at dialysis wards is analysed.

**Results:** 95% of the respondents agree to an increasing need for palliative care in case of hemodialysis. Broadly, the respondents show a positive attitude towards palliative care; 89% would like more education and training about palliative care to enhance their knowledge. The respondents also have a positive attitude towards Advance Care Planning (ACP), but they disagree about the right moment to introduce or start communication around end-of-life decisions. To date, no systematic or structured approach to ACP in the case of hemodialysis patients is available. Nurses with less than 5 years experience felt clearly less comfortable to talk about end-of-life issues compared to their colleagues with more experience. A lot of barriers impeding the implementation of palliative care are found. The main barrier is the lack of privacy on a dialysis ward. Nurses who received postgraduate palliative care training are 2.2 times more likely to show a positive attitude towards palliative care. Apart from education levels, no further personality characteristics are found that influence their attitude towards palliative care.

**Conclusion:** The need for palliative care for dialysis ward patients is recognized by dialysis nurses, but as this is just the start of the journey and there remains lot of space for improvement.

**Abstract number:** P2-400

**Abstract type:** Poster

## Palliative in Neurodegenerative Conditions: From Research to Clinical Practice

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Palliative care in neurodegenerative disorders (ND) are advocated by several international recommendations. Evidence of clinical practice is sparse and many specialist palliative care services (SPCS) still fear to care for these patients. Since 2007 FARO Foundation started the development and assessment of a new SPCS for people

affected by ND, now fully operative.

**Methods:** Retrospective analysis of the assistances of patients with Amiotrophic Lateral Sclerosis (ALSMND), Multiple Sclerosis (MS), Parkinson's Disease and Parkinsonisms (PD's) are discussed after a manual scan of the medical files of ND patients cared for by the SPCS in the period 2007-2011, focusing relevant PCO and comparison with a random sample of 50 cancer patients.

**Results:** Between 2007-2011 105 patients with a diagnosis of ND have received FARO SPCS. 82 could be included in the analysis: 55 ALSMND, 10 PD's, 17 MS. Mean duration of the assistance was of 177 days. 29 (35%) survived less than 90 days, 20 (25%) between 90 and 120 days and 33 (40%) > 6 months. 52% had at least one period in the pending list. 80% died at home, 12% in the hospice and 8% in the hospital. 32% had a PEG, 28% a non invasive ventilation and 11% an invasive ventilation. 50% used opioids during the assistance (2% where on these drugs before the SPCS). Main reasons for the opioids were breathlessness (62%) and pain (26%). Mean dose 32 mg of oral morphine equivalent. Comparing these patients with the sample of 50 cancer patients it results that the ND group had a significantly longer duration of the assistances, lower dosage and different indication of palliative drugs, higher input of Physiotherapy (PT) and Psychological support (PS) no differences on the place of death.

**Conclusions:** This study confirms that people with ND have a longer EoL trajectory (but 60% died < 6 months), have severe symptoms (50% need opioids in EoL) There is a relevant use of life sustaining treatment, PT and PS.

**Abstract number:** P2-401

**Abstract type:** Poster

## End Dialysis or Dialysis until the End? Case Report and Suggestions for Action

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**Background:** The decision of ending dialysis emerges from the competing interests of prolonging life, maintaining quality of life and alleviating pain. This requires high medical expertise and stable structures of communication and organization. Clinical experience shows uncertainty and different professional positions. This set of problems is exemplified on the basis of the case of a 74-year-old multimorbid patient with no malign pre-existing medical condition and his wish for ending dialysis, and a suggestion for finding a decision as well as possibilities for practical implementation are shown.

**Case report:** Cardiovascular, pulmonal, hepatic (liver cirrhosis) and renal (terminal renal insufficiency with nephrosclerosis requiring dialysis since 2010) patient in serious medical condition with resting dyspnoea and strong low-back pain. Complex medication including antidepressive and analgetic substances (citalopram, mirtazapine, hydromorphone). Patient and nephrologist's request for an expert advice to withdraw from dialysis.

**Considerations:**

1. Discuss goal of care (motivation, quality of life on dialysis)
2. Discuss possible symptoms and their palliation (uremia)
3. Optimization of symptom management (opioid rotation from hydromorphone to buprenorphine)
4. Allow time for consideration and discussion (intrafamily and interdisciplinary conflict)
5. Plan to end dialysis (check list)
6. Reassure that the decision to withdraw dialysis is reversible (patient's decision after improved symptom management to continue dialysis in this case).

**Conclusion:** The decision to end dialysis or not should be taken individually and interdisciplinarily. In this context palliative care can play the role of a mediator (structured decision making, discussing and implementation of alternative palliative treatment).

## Palliative Care in the Elderly

**Abstract number:** P2-402

**Abstract type:** Poster

## Operationalisation of Adult Palliative Care Programme in Jawhar, a Tribal Area in Maharashtra

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With the rising trend in the survival there is increase in the chronic debilitating diseases like Diabetes, CVD, Cancer,

COPD, HIV/AIDS and MDR-TB. Another major concern is about the availability, affordability and accessibility for such patients to health care system. With this intent a palliative care program aiming at providing holistic community based care for such patients was proposed by Tata Memorial Hospital in collaboration with National Rural Health Mission. It aims at involving all cadres of personnel in the hierarchy with special emphasis on the grass root level workers, the latter are expected to provide continuum of care to patients.

**Methodology:**

**Training period:** Training the Medical Officers, Nurses and ASHA workers in the Sub district Hospital (SDH) and Primary Health Centre (PHC) on identification, assessment, management and referral of patients with chronic life limiting conditions.

**Implementation phase:** ASHA workers enrolled the patients based on the checklist of symptoms and diseases provided to them. The Medical Officers (PHC/SDH) with the help of the nurse/social worker assessed the patients and provided symptom management, psychosocial and spiritual support. The ASHA with the nurses provided regular home visits to the enrolled patients on a weekly basis and reported to the MO as and when she felt his intervention was needed.

**Results:** Total Number of patients 125, Rural Hospital 64 Sub district Hospital 61 Among the diseases; COPD 32 CCF 4 Hemiplegia 10 AIDS 4 MDR TB 10 Cancer 10 Leprosy 10 Sickle/Thalassemia 12 cirrhosis 6 arthritis 13 senile debility 14.

**Conclusion:** We learnt that this was just the iceberg of the problem. Additional intervention by way of mobilizing the community by empowering the community based organization, faith based organization and traditional healers in order to generate awareness in the community and ensure continuum of care for patients is a must.

**Abstract number:** P2-403

**Abstract type:** Poster

## Palliative Geriatrics, Hospice and Palliative Care - An Exhaustive Survey of 800 Nursing Homes in Austria

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With increased regularity residents enter nursing homes at a very high age and in bad physical condition (long-morbid and often suffering from dementia). The length of stay decreases and the number of deaths increases. As a consequence knowledge about palliative care is essential for employees to provide ideal care - from the moment of a resident's admission until the end of life.

So far, no data about the current situation in Austrian nursing homes concerning hospice and palliative care were available. Data about the extent to which hospice and palliative care is already implemented in nursing homes, are necessary to support the decision-making process of providers of nursing homes and of policy makers on a national and federal level.

As a consequence an exhaustive survey of all 800 nursing homes was conducted by researchers of the University of Applied Science Upper Austria in 2012. The study was initiated by Hospice Austria and the Federal Association of Nursing Homes in Austria. To collect the data a 14-page questionnaire was developed and sent to all nursing homes as a PDF by email. Main topics inquired were the management of pain and palliative medical care, interdisciplinary cooperation and networking, integration of hospice and palliative care in the daily routine, establishment of palliative care in the mission statement of the nursing home and education. We also collected data about residents, their relatives, nursing staff, volunteer workers and doctors as well as general data concerning the nursing home. The response rate was 36,52%.

The data will be analyzed in a descriptive way on the national level. Comparisons of federal states as well as comparisons of nursing homes that participated in a program to implement hospice and palliative care with homes that did not, were performed using the statistic software SPSS. The results will be available at the end of November 2012 and will be presented on a poster at the EAPC Congress.

**Abstract number:** P2-404

**Abstract type:** Poster

## Palliative Care in the Acute Phase after a Severe Stroke: Experiences of Relatives

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**Aims:** Palliative care has potentially a lot to offer to patients in the acute phase after a severe stroke, but its deliberation and decisions towards palliative care are limited in this phase. This study aims at providing insight into the experiences of relatives of stroke patients with the care provided in the acute phase and the ethical dilemma's with regard to decision-making they (may) have encountered. **Study design & method:** A qualitative study using semi-structured interviews was conducted with relatives of stroke patients with a severe stroke and a poor prognosis in the acute phase. The interviews took place 2-6 month after the stroke, were transcribed verbatim and subjected to qualitative analysis. **Results:** Preliminary results show that communication about prognosis and/or its uncertainty is at times limited, leading to relatives constructing false expectations. Essential care decisions such as the initiation of artificial nutrition are not always discussed with family members or experienced as a choice. [analysis of all data should be completed prior to the EAPC congress].

**Conclusion:** Preliminary results suggest that limited communication of prognosis and (palliative) care options in the acute phase after a severe stroke between health care personnel and relatives of patients may prevent relatives from making choices towards palliative care.

Abstract number: P2-405

Abstract type: Poster

### Are Patients Being Admitted from Nursing Homes to Secondary Care for End of Life Care?

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**Background and aims:** Rhondda Cwm Taf Health Board, South Wales has a greater proportion of patients dying in hospital than nursing homes when compared to the national average. A survey was undertaken of patients admitted from local nursing homes who died within seven days of admission to hospital during that year. Case notes were studied retrospectively for common themes that would allow earlier interventions with the aim of preventing future futile hospital admissions.

**Population and results:** Eighty four patients admitted from nursing homes died within a week of hospital attendance during the twelve month period studied. A sample of twenty sets of case notes were reviewed. The mean age was eighty-seven. Only one patient had a diagnosed malignancy. Sixty percent of those admitted had a diagnosis of dementia. Sixty percent of patients reviewed were bedbound requiring full assistance with personal care and feeding. One was known to the community palliative care team. The majority of the patients (over 75%) were admitted out of normal working hours. Thirty percent of the patients were placed on the End of Life Care Pathway by the time of Consultant review on the Post Take ward round. Half of the patients died within 48 hours of admission.

**Conclusion and suggestions for improvement:** There appears to be a need for increased medical support for nursing homes to provide end of life care. One key component of this could be increased use and documentation of advanced decision and end of life planning. This could involve an extension of existing community Palliative Care Registers. Making such decisions would clearly need an improvement in both the communication between health care professionals, nursing homes and families and the documentation of any decisions made. A number of cases demonstrate that poor communication had significant consequences and directly lead to a number of futile hospital admissions.

Abstract number: P2-406

Abstract type: Poster

### Pain, Analgesia and Cognitive Impairment

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**Background:** Pain is a common symptom, affecting half of

those aged over 65y and up to 2/3 of women over 75y. Dementia and cognitive decline are increasing in prevalence, with an ageing population in the UK. Improving palliative and end of life care for people with dementia, is a national priority (Prime Minister's Challenge on Dementia 2012, NICE guidance 2006, amended 2011, DoH National Dementia Strategy 2009, NSF for long term conditions 2005).

**Aim:** Does cognitive impairment impact on use of analgesia?

**Methods:** Observational study of inpatients across seven Care of the Elderly wards in a large NHS trust. Data was collected on prescription of analgesia (regular and/or as required) and cognitive impairment, through assessment by MMSE (Mini-Mental State Examination).

**Results:** 147 inpatients were assessed and 67% of patients (n=99) had a MMSE completed during the current admission. 12 had a MMSE of < 10, 44 had a score of 10-20 and 43 had a MMSE of >20. The group with no or mild cognitive impairment (MMSE>20) were most likely to have regular analgesia prescribed (n=26, 60%). Those with moderate cognitive impairment (MMSE 10-20) commonly had as required analgesia prescribed (n=23, 52%) and were less likely to have regular pain relief. The group with moderate-severe cognitive impairment (MMSE 0-20) rarely had their as required analgesia administered (not given in 23/25 cases, 85%). Overall, around three quarters of patients with no or mild cognitive impairment received analgesia during this admission, whereas only one third of patients with moderate-severe cognitive impairment were given some analgesia.

**Conclusion:** Education is required to improve confidence and competence in assessing pain, in patients with cognitive impairment. Specifically, awareness needs to be raised of the potential for pain to manifest as distress and consider whether a trial of regular analgesia is appropriate. Further research is needed in this area.

Abstract number: P2-407

Abstract type: Poster

### The Use of Communicative Space as a Means of Knowledge Exchange to Develop Palliative Care Practices in Long Term Care Settings for Older People

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Care settings for older people that provide long-term social and health care occupy an ambiguous and marginalised position in many Western societies. Long term care settings are places where older people are cared for as well as spaces where meaning is experienced and created in the relationships between people and wider social processes. These settings are also an important place of care and support for dying older people. As such these settings are faced with the increasingly need to integrate end of life care into their practice. Habermas's theory of communicative action proposes there is a separation between the life world, that is individual's experiences within the care setting, and the wider system which encompasses the organisation and institutional structures. Kemmis has built upon Habermas's concept of communicative action, through the notion of 'communicative space', whereby change can occur when people come together in a particular place to participate in dialogue in order to address the dialectic of the lifeworld and system world over a particular issue. The opening of such a 'communicative space' is about negotiating together how change can happen. This can be considered an example of knowledge exchange in practice.

This paper will outline the concepts of communicative action and communicative space, their dimensions and relevance to the development of end of life care practices within care homes. We will also illustrate the application of communicative spaces in care homes as examples of knowledge exchange. Three international evidence based examples of communicative space, from Australia, United Kingdom and Canada (palliative care case conferences, reflective debriefing groups and comfort care rounds), will be presented. This paper will demonstrate the challenges and facilitators to the use of communicative space as a means of knowledge translation and the development of sustainable palliative care practices in one general care setting.

Abstract number: P2-408

Abstract type: Poster

### Dementia Friendly Community Pharmacies

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**Aims:** Increasingly, care for people with dementia is acknowledged to be an important issue in palliative care. The translational research project aims at increasing community pharmacists' knowledge and skills regarding dementia-care, building community-based networks of providers, and setting up community-based projects involving people with dementia, their carers and professionals, thereby increasing well-being of people with dementia and their carers and fostering destigmatisation. **Study design:** The project is based on the principles of participatory research, meaning equal collaboration between research and practice, participation of people with dementia, informal carers and pharmacists in all processes and in knowledge generation, and realizing the project in repetitive loops of action, reflection and evaluation. Methods used are focus-groups, workshops, networking activities, and a literature review.

**Results:** Partnership-building, clarifying aims and goals and recruiting interested community pharmacies are the most important steps in the initial phase of the project. People with dementia and their carers expect information on medicines, referral and emotional support from community pharmacists. Community pharmacists are mainly focused on medication management, however, issues like fostering early diagnosis and providing referrals, communication with people with dementia and networking with self help groups and other services are also believed to be highly relevant. **Conclusion:** Community pharmacies are an important health care setting for people with dementia and their carers especially from socially marginalized groups. However, overcoming community pharmacists' biomedical focus on dementia in favor of resource orientation and aiming at well-being and dignity as important outcomes, implementing cognitive services and networking with other providers pose some challenges which should be overcome by working collaboratively towards shared goals.

Abstract number: P2-409

Abstract type: Poster

### Dementia - How Evaluate the Prognosis and Appropriate Care? Six Years Experience of St. Joseph's Hospice and Pain Centre Rajhrad, Czech Republic

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The indicators of poor prognosis at the elderly are very exactly described in the model of frailty. In daily care we can see how difficult the evaluation could be - the evaluation of care offered and needed, very often in close relation to life expectancy. From oncologic palliative care we know the power of multidisciplinary evaluation in the week case conferences. This is the method which we have been using since 2007 also for the non-cancer palliative care patients. The main indicators are evaluate in the VAS classification (1-10) by subjective evaluation of the members of team. The final result we use is called "The palliative adaptation index" - 10-90%. If the PAI is lower then 40% the life expectancy is - in our clinical experience - shorter then 6 months. The PAI started to be evaluated in August 2012 in the prospective trial. The presentation will bring also the final results of the study.

Abstract number: P2-410

Abstract type: Poster

### Facilitation of the Gold Standards Framework in Care Homes Programme: A Mixed Methods Study

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**Background:** The provision of palliative care in care homes for older people is supported in the UK by the use of a range of tools and frameworks, such as the Gold Standards Framework in Care Home (GSFCH) programme. It has been recommended that provision of facilitation should be integral to the introduction of such a programme. To date there is no evidence to support which model of facilitation should be provided.

**Aim:** To develop a typology of facilitation. **Method:** A mixed methods study was undertaken in 38 nursing care homes (NHs) across SE England implementing the GSFCH programme. Different models of facilitation were provided. Participants included all GSFCH facilitators facilitating these NHs. The following quantitative and qualitative data strategies were adopted:  
- Completion of a structured activity log over the two years

## Poster sessions

of the programme. This included detail of phone calls, emails and visits: the time taken and what they did.

Semi-structured interview at the end of the programme.

**Results:** Seventeen facilitators provided facilitation to 33 of the 38 NHs. Five NHs had no facilitator. There was no missing data. The duration of the facilitation provided varied. The NHs received between 2 and 224.13 hours of facilitation throughout the programme. Differences occurred in the format of the facilitation that was provided. Types of facilitation provided included: visits, role modelling, significant event analysis, coding meetings, developing partnerships and after death analysis. There was a significant association between the type of facilitation that had been provided and completion of the programme through to accreditation. Fishers exact test  $p < 0.000$ .

**Conclusion:** Successful facilitation, as evidenced by a NH becoming accredited, was supported by structured ongoing facilitation utilising a range of facilitation activities. Facilitation should be integral to the GSFCH framework programme. The provision of such facilitation requires resourcing and support.

**Abstract number:** P2-411

**Abstract type:** Poster

### End of Life Care Provision for 2,444 Nursing Home Residents: Findings Emerging from a Cluster Randomised Controlled Trial

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**Background:** A 3-year cluster randomised controlled trial was undertaken across 38 nursing homes (NHs) in SE England (June 2008-2011). There were 12 NHs in each randomised arm with one observation arm (14 NHs). This abstract reports the findings emerging from examining the notes of 2,444 residents.

**Aim:** To identify aspects of end of life care from the notes of 2,444 deceased NH residents.

**Method:** Two researchers examined the notes and daily care records of 2,444 deceased residents for length of stay, diagnoses, attendances at out-patients (OPAs) and hospital admissions for the last six months of life. Volunteers from the hospice helped in the collection, collating and inputting data onto a database which was then fully checked.

**Results:** The mean length of stay in the NH was 19 months with a median of 7 months. Thirty-six percent of residents lived in the NH for less than 3.5 months. The mean age of residents dying in the NH was 85 years. Seventy-seven percent of residents were documented as having dementia or cognitive impairment. The recorded diagnosis of dementia increased year-on-year from 30% to 34% to 37% in the third year. The median number of medical diagnoses was four, when classified into systems affected. During their last six months of life in the NH, 22% attended OPAs. Thirty-four percent of residents were admitted to hospital in their last month of life of which 57% were inappropriate with 11 residents remaining as inpatients for their entire last month.

**Conclusion:** Meeting the needs of the increasing number of frail older people dying in NHs is a challenge. These residents are increasingly old with multiple co-morbidities. There is a need to reduce inappropriate hospitalisation at the end of life. Currently in the UK end of life care training is not mandatory in NHs. Recommended staffing levels of NHs is a complex issue, however the reported reduction in skill mix is a cause of concern. It would appear that care provision needs urgent review.

**Abstract number:** P2-412

**Abstract type:** Poster

### Pain among Institutionalized Stroke Patients and its Relation to Psychological and Social Well-being

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**Aims:** Pain is a frequent long-term consequence of stroke. In view of the development of an integrated care and treatment program for institutionalized stroke patients, we aimed to identify the prevalence of substantial pain among them, and its relation to psychological distress (PD) and social vulnerability.

**Methods:** We collected data of 274 chronic stroke patients (mean age 77 years) in 17 Dutch nursing homes through observation lists that were filled out in structured interviews with qualified nurse assistants who knew the residents well. Pain and social engagement were measured with the Resident Assessment Instrument for Long Term Care

Facilities, and PD with the Neuropsychiatric Inventory Questionnaire (NPIQ). We performed multilevel regression analyses to investigate independent relationships.

**Results:** Substantial pain was present in 28% of the residents, mostly located in the affected body side (68%). It was related to a 60% increase in NPIQ-score ( $\beta$  3.18[1.84-4.53]), and to clinically relevant symptoms of delusions (OR 8.45[1.82-39.05]), agitation/aggression (OR 3.82[1.76-8.29]), dysphoria/depression (OR 3.49[1.75-6.98]), and anxiety (OR 2.32[1.08-4.97]). Pain was associated with low social engagement when adjusted for clinical covariates (OR 4.25[1.72-10.53]), but only in residents with no/mild or severe cognitive impairment. This relation disappeared when additionally corrected for NPIQ-score (OR 1.95[0.71-5.39]).

**Conclusion:** Pain is a serious and multidimensional problem among institutionalized stroke patients. It is related to increased PD, that in turn can be a pathway to social vulnerability. Pain management should be a key element in the palliative care provided to this population. Longitudinal research on stroke-specific pain types interacting with other domains of functioning, could open new areas of intervention.

## Palliative Care in Children and Adolescents

**Abstract number:** P2-413

**Abstract type:** Poster

### Talking with Parents about End of Life Preferences when the Prognosis is Uncertain: A Retrospective Audit of Deaths in a UK Neonatal Intensive Care Unit

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**Research aims:** To establish current practice relating to the provision of end of life planning and palliative care in the neonatal intensive care setting, and compare this with national best practice guidance.

**Study design and methods:** A retrospective audit of clinical documentation (by doctors, nurses and allied health professionals) belonging to infants who have died in a single UK neonatal unit over an 18 month period (n=36). Documentation was examined for the recognition of death as a possible outcome (n=36) and further qualitative analysis looked at the discussion of parent / carer preferences for end of life care.

**Results:** Clinicians do identify, through documentation, infants who are at high risk of death. This does not always catalyse conversations with parents about palliative care, either as a transition of care, or as a 'parallel plan' whilst active management is ongoing.

**Conclusions:** Current national best practice prioritises care at home as a probable preference for parents and carers when an infant is unwell. However, the clinical course may not always allow for such plans to be made in a timely manner. Pathways for neonatal patients who may die must acknowledge the need for parallel planning when active management is ongoing.

**Abstract number:** P2-414

**Abstract type:** Poster

### Assessment of Ambulatory Pediatric Palliative Care in Mecklenburg-Western Pomerania

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**Study objectives:** Mecklenburg-Western Pomerania is the least densely populated county in Germany with 1.6 million inhabitants. Currently, there is no established specialized ambulatory palliative care team for children and adolescents (SAPPV). We asked how great the need for such a team is seen by the present suppliers of medical care.

**Study design and methods:** Between May and December 2010, questionnaires were sent to all resident pediatricians and nursing services in the county, asking for the current situation of care for palliatively ill children and adolescents and the needs, demands and expectations regarding specialized care, particularly an SAPPV team. The data were transferred to an SPSS database and analyzed descriptively and statistically.

**Results:** Approximately 30% of physicians and nursing teams surveyed responded. Almost all doctors care for individual children and adolescents with life-limiting oncological, neuro-pediatric and congenital diseases in their practice, however, only a few can perform regular home visits. The vast majority of the doctors desires assistance in specialized

medical palliative care. Particular demands are seen in social and psychological help for dying children. Most nursing services - none of which is specialized in children - care only for individual children and adolescents each year, but many of them employ a trained pediatric nurse. Some teams cooperate with adult specialist palliative care teams. Additive care, coordination and consultation are requested most by doctors and nurses who perform palliative care. All responding physicians and nursing services expressed interest in co-operating with a team SAPPV.

**Conclusion:** The quality of care of pediatric palliative care should urgently be improved in order to ensure relief and dignity of dying children and adolescents and their family environment.

**Abstract number:** P2-415

**Abstract type:** Poster

**Abstract withdrawn**

**Abstract number:** P2-416

**Abstract type:** Poster

### Pediatric Palliative Care - How to Care about the Parents and Siblings after Death

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**Introduction:** Pediatric palliative care (PPC) does not end with the death of the child. Rather, the support of the bereaved families is imperative. The after-care by the supporting PPC-team has proved to be very helpful. The after-care provision by the "Brückenprojekt Dresden" has been developed together with bereaved parents. Its support is twofold: the individual support of the family for one year after the death of the child and the yearly weekends for bereaved parents for an unlimited time.

**Designs, methods and statistics:** In a retrospective study, the after-care of "Brückenprojekt Dresden" during the years 2008-2012 (n=44) was investigated.

**Results:** 77% of the families opted for individual support. Contacts were mainly over the phone (68%), but also personal meetings at families home, in the office or at the funeral (27%) were very significant. Topics for conversations apart from how they felt, were siblings, remembering the child, looking back at the care, return to work, linking with external help providers and counselling. Regarding intensity and frequency a broad spectrum shows the individuality of the families. Participation numbers for weekends for bereaved families showed a big increase (2009-2012: 142%). The parents benefit enormously from meeting other parents. The weekends include joint activities, art therapy, activities for siblings and a ritual in memory of the deceased child.

**Conclusions:** Care for the surviving family members should be part of the work of a PPC-team. Because of the diversity of issues, this after-care has to be arranged through professionals from different areas of expertise and by the whole team. As grieving and inclusion of families in a supportive social environment are very individual, standardised formulas for after-care are not possible. Some fixed components (e.g. active support for one year after the child's death, contact arrangements, birthday card, weekends for bereaved parents) were developed together with bereaved parents.

**Abstract number:** P2-417

**Abstract type:** Poster

### Use of a Social Networking System as a Communication Tool in Home Care

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**Purpose:** Children's home care involves a number of professions, and communication/information sharing are required between them. However, time lag in information transmission and insufficient communication may lead to confusion among staff, and differences in awareness between staff may reduce patient QOL. We used a local social networking system (SNS) for real-time transmission of information and to hold online conferences when required. The problems and advantages are discussed.

**Methods:** The local SNS used is a member-only network service, access to which can be restricted by the community administrator. We used this SNS to record information and to hold conferences. The subjects were terminal childhood



cancer and severely handicapped patients taken care of at home. The medical personnel in the community consisted of a home-visit nursing care service, hospital, home care doctors, medical social workers, and local public health nurses. In some cases, communities included family and schoolteachers.

**Results:** Under stable conditions, we could know the everyday state of the patient from the home-visit nurse and daycare staff. With changes in symptoms, meetings were held online with the home care doctor to decide on treatment, and the staff were notified in a timely manner. In the community including family, the family members were able to express their feelings to the staff.

**Conclusion:** Information can be exchanged through the SNS via mobile phone or computer, reducing the time lag for action according to conditions and sharing of information. Information can be managed for each case. Communities involving family are also effective for family members to express their feelings, and staff were able to correspond from their professional standpoint. This allowed staff to provide grief care before the patients died. By improving the recording of information and additional functions, we expect this to be a tool that will become easier to use in the future.

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**Abstract type:** Poster

### Improving Practice in Children's Pain Management

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**Introduction:** Our knowledge of children's pain has increased in recent years. Despite the availability of evidence, management of pain in children is often suboptimal. The pediatric palliative care team (PPCT) was created within the hematology and oncology unit in 1996. In 2006, its objectives were redefined to include children with non-malignant conditions. Establishing an independent PPCT within a general hospital involves educating other healthcare professionals. We wonder if PPCT's interventions through educational work at patient bedside, lectures, workshops and guidelines allowed changes in management of pain over five years of work.  
**Objective:** Describe and analyse request for pain relief made by paediatricians to PPCT within our institution.  
**Methods:** Descriptive study. We analyzed medical records of patients seen for pain relief (PR) between January, 1<sup>st</sup> and December, 31<sup>st</sup> 2011. Analyzed categories were: age, gender, team requesting, diagnosis according to ACT 2009 guide, illness trajectory, level of intervention (THAG), PASW Statistics 18 was used as statistical software to compile the database. Qualitative data were analyzed as proportions and expressed in percentages.

**Results:** During 2011 our team helped in 162 patient's cases. Patients seen for PR were 35, generating 55 requests and 315 PPCT interventions, showing no decreases in these years. Age ranged from 5 months to 20 years, 51% over 11 years old and 63% were male. According to demanding/requesting team 2 patients were at PICU and 33 at pediatric wards, 26 (47%) requests were made by oncologists, 24 (43%) from non-palliative care conditions with complex PR. PPCT was mainly involved during the treatment stage. Interventions during disease progression, came second and 63% of consultations were shared between PPCT and others teams (level III).

**Discussion:** This study aims at a large gap in medical education about management of children's pain, total pain and use of opioids.

**Abstract number:** P2-419

**Abstract type:** Poster

### Care Delivery to Adolescents with Cancer: The Dialogic Life-death

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**Aim:** This study aims to understand the experience of adolescents with cancer, family and the health team regarding death in the healthcare context, in the light of Edgar Morin's proposed theoretical framework of complexity.  
**Method:** Qualitative research was based on Edgar Morin's ideas about complexity. Study participants were twelve

adolescents (between 12 and 18 years of age), male and female, with different diagnoses (leukemia; non-Hodgkin Lymphoma; bone tumors and central nervous system) and in the several phases of the diagnostic-therapeutic process (diagnosis, therapeutics, relapse, palliative care and survival), attended at the *Hospital das Clínicas*, Brazil; 14 relatives (two fathers, nine mothers and three siblings), besides 25 health team members (eight physicians, five nurses, six nursing auxiliaries, two social workers, two psychologists, one nutritionist and one occupational therapist). The interview was used for data collection. The discussion of data was guided by the dialogic life-death in the context of care to adolescents with cancer.

**Results:** In the context of this study, the adolescents do not clearly express the death that surrounds them. It does emerge in their own and their relatives' reports though, in submission to situations of intense suffering during treatment, as a form of distancing death, as well as in feelings of concern with and fear of relapse, which even adolescents who had already finished treatment expressed. It was observed that the singularity in the way the adolescent experiences time and faces death and the possibility that the family will lose a loved one may not be in accordance with the care the health team offers, considering structural, organizational and affective aspects.

**Conclusion:** It is not enough for the team just to rationally make choices on the use of diagnostic-therapeutic devices, in line with predefined moments in the disease. Instead, a contextualized and sensitive understanding of each situation is needed.

**Abstract number:** P2-420

**Abstract type:** Poster

### 'I Just Want him to Be Comfortable....' - A Conceptual Analysis of Comfort at End of Life in Paediatric Palliative Care

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The death of a child is a unique and individual event. Care pathways may be followed but each event requires a nursing team to respond intuitively to the needs of that child and their family effectively. If comfort is our aim at end of life in paediatric palliative care, how do we as practitioners recognize it? How is it defined? When death is imminent with a child how do we interpret comfort? In addition, do parents have the same concept of comfort at end of life as a multidisciplinary team?

The aim of this analysis is to explore the concept of comfort while caring for a four month old baby at end of life in a paediatric hospice in Ireland. The objectives being to identify aspects of comfort while applying them to a paediatric palliative care setting.

Roger's evolutionary method of conceptual analysis will be used to isolate the significance, use and application of the concept of comfort. The research strategy will include a literature review with inclusion and exclusion criteria and a sampling method.

Antecedents, attributes and consequences of comfort are developed. The results highlighted the complexity of interpretation of comfort for nurses and family. Families and nurses stated the need to ensure effective symptom control, calmness and absence of undue distress at end of life in order to achieve comfort.

Exploration of the concept of comfort at end of life and in paediatric palliative care helps to develop clarity for nursing teams. Communicating with families at this time is challenging and research that develops nursing theory and generates understanding and improves quality of care.

**Abstract number:** P2-421

**Abstract type:** Poster

### Communicating Bad News in Clinical Palliative Care Practice: A Pediatric Nursing Contribution

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**Introduction:** Communication is an essential component in palliative care. Transmitting bad news is an extremely complex activity and demands preparation and sensitivity from health professionals, besides specific knowledge and aptitudes. In view of the incurability of the disease and the transfer from curative to palliative care, it is important to reflect on how bad news is communicated to children, adolescents and their family members.

**Aim:** To understand the experience of mothers and fathers of children and adolescents with cancer in palliative care when bad news is communicated.

**Methods:** A descriptive and exploratory study with qualitative data analysis was undertaken. Empirical material

was collected through a focus group with the parents of children and adolescents with cancer who were informed about the transition to palliative care.

**Results:** The parents report that the moment when the transition to palliative care is communicated is marked by great pain and is often difficult to understand; they report preferring that this news is communicated by a physician who has a bond with the family and patient and emphasize the importance of the psychologist and nursing team's presence at this moment. They mention that understanding the situation takes some time and, based on this understanding, they start to develop coping strategies and their own explanations, always aiming for their child's comfort and happiness.

**Conclusion:** By understanding how the communication process of bad news takes place, this intervention can systematically be incorporated with a view to the production of health care that responds to children, adolescents and parents' real needs. In view of communication of bad news, these study results can contribute to the development of coping strategies for children and adolescents with cancer and their parents, as well as for the health team.

**Abstract number:** P2-422

**Abstract type:** Poster

### Building Capacity in Children's Palliative Care through e-learning: The ICPCN Experience

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**Background:** Education is an essential component of the development of children's palliative care (CPC), yet is not always accessible to those who need it. Challenges to providing training include a lack of recognition of CPC, the limited number of CPC specialists available to teach, a lack of funding or resources, and language barriers. The ICPCN therefore developed an e-learning strategy to make training on CPC available and accessible to those who need it, with a particular emphasis on accessibility in regions where training is limited.

**Method:** A pilot e-learning course was developed and evaluated on pain assessment and management in children, linking in to the WHO guidelines on persisting pain in children. Following the evaluation, which was accessed by 186 people from around the world, changes were made to the course and a program for writing more courses and translating the pilot course into other languages, developed.

**Results:** 186 people accessed the pilot course and since then over 85 people from 30 different countries have accessed the first course on pain in children. A further course on emotional issues has been launched and in the first month 13 participants from 7 countries have accessed it. The courses have been translated into Spanish, Russian, Serbian and French in order to make them more accessible around the world, and the utilization of these different language versions will be explored and discussed.

**Conclusion:** In order to improve the quality of palliative care provision for children, education initiatives need to be available and accessible to those who need it. ICPCN's e-learning programme has enabled people to access training in children's palliative care, and an evaluation of its impact is being planned for 2013.

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**Abstract type:** Poster

### The Development of Paediatric Palliative Care in Norway and National Guidelines

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Until 2009, Paediatric Palliative Care for children with life limiting (LLC) and life treating conditions in Norway had no attention. In three years, this field has now received considerable attention from political leaders and in the Norwegian society; this has led to activity in several areas. The founding of the first organizations working for PPC and advocating for this, has led and contributed to this development. In December 2011, the Committee on Health and Care Services acknowledged the need for improving the response for children in need of PPC and a unanimous Storting decided that Norway should develop national guidelines for children with palliative care needs.

**Methods:** The approach used, was a variety of approaches to raise awareness and promote the need for action, this

included using social media, media, collaborations with political parties and politicians and partnership working with other health professional organizations both internationally and nationally, articles in different journals, conference and giving statements to several public hearings to Storting.

**Results and achievements:** Making guidelines; first conference on PPC in the Nordic region; increased attention, political advocacy and influence. Our plans for the way forward is the recognize and the need to get PPC into the education system and to ensure that the standards for paediatric palliative care in Norway apply the principles of WHO's definition of paediatric palliative care. The Government need to commit to sustained adequate funding to provide holistic, multidisciplinary palliative care in a variety of settings, including home, schools, hospital, respite care settings and to meet this need in the future. This presentation recognizes how advocacy, strategy and collaboration can ensure a multidisciplinary standard for a seamless PPC services to children, it highlights how a small organization can make a difference and impact on development for PPC.

**Abstract number:** P2-424

**Abstract type:** Poster

### "The Pump Was Good because it Meant I Could Be at Home": Patient Controlled Analgesia (PCA) in Paediatric Palliative Care, Experiences of Children and Young People (CYP), Parents and Health Care Professionals (HCP)

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**Aim:** To examine the experiences of CYP, their parents and HCP utilising PCA in the community.

**Background:** Pain management for CYP during palliative phases of an illness trajectory is reported as sub-optimal and of concern to parents and HCP. Studies of PCA demonstrate safety and efficacy in CYP, however little is known about its use in paediatric palliative care populations.

**Methods:** Concurrent with the development of a community PCA service, we undertook a mixed- methods processual evaluation including:

- survey of community nursing services,
- documenting prospective data on each CYP receiving PCA, detailing demographics, illness trajectory, pain and symptom care profiles
- recording acceptability of intervention to CYP and parents
- conducting semi-structured interviews with community and tertiary based HCP on experiences of managing PCA,
- longitudinal systematic participant observation of palliative care service rounds and case discussions.

Concurrent analysis of data was used to inform the development of the PCA service.

**Results:** Analysis of prospective data from the first four cases where PCA was utilised revealed the following:

- CYP who used PCA in the home setting reported satisfactory pain relief and expanded function, although acceptability was diminished because of the presence of equipment,
- Parents welcomed effective and rapidly accessed pain relief and reported a sense of control,
- Access to PCA was dependent on increased cooperation between a number of services providing palliative care, and relied on rapid mobilisation of resources.

**Conclusion:** Delivery of PCA in the community setting was feasible. CYP, parents and health care professionals reported improvements in pain scores and increased functioning. Although collaborative working facilitated delivery, the provision of PCA in the community is a resource intensive service. Further studies are required to determine the efficacy of this pain management strategy.

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**Abstract type:** Poster

### The Impact of Paediatric Respite on Families of Children with Life-threatening Conditions

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**Aims:** There is little evidence to support the provision of respite to children with a life-threatening condition and their families. Very Special Kids provides access to out-of-home

respite at The House, Australia's first purpose built paediatric hospice. This study aimed to evaluate the impact of respite at The House on carers of children with a life-threatening illness.

**Methods:** The study utilised a pre-test and post-test research design with psychometric and open-ended questions. A survey that included the General Health Questionnaire, SF-12 (quality of life measure), Chalder Fatigue Scale and Quality of Marriage Index was completed by carers both pre- and post-respite.

**Results:** The study sample comprised of 58 carers, 23(40%) were fathers, 32(55%) were mothers, 1 (2%) was a step-father and 2(3%) were adoptive parents. Carers had a mean age of 45 years (SD=8.20) with a range between 30 to 78 years. Carers' children had a mean age of 10 years (SD=4.86) with a range between 0-18 years. The most common diagnoses among children were Rett syndrome (8,14%) and cerebral palsy (8,14%). After adjusting for time of completion, analysis of covariance showed that carers' self-reported general distress scores significantly improved from pre-respite (M=13.92, SE=.64) to post-respite (M=10.74, SD=1.02; F(1,37)=15.28, p<.001). Further, carers' fatigue scores significantly improved from pre-respite (M=14.26, SE=.84) to post-respite (M=10.94, SE=1.03; F(1,33)=17.71, p<.001) and carers' mental health quality of life scores significantly improved from pre-respite (M=44.16, SE=1.6) to post-respite (M=49.12, SE=1.6; F(1,32)=8.03, p<.01). Qualitative reports indicated the main reason carers utilised respite was to have a break from intensive care provision.

**Conclusion:** The findings demonstrate statistically significant benefits of out-of-home respite for carers of children with life-threatening conditions and exemplify the need for increased psychosocial support for families.

**Abstract number:** P2-426

**Abstract type:** Poster

### Providing Respite Care for Children with Life-limiting Conditions - The Information Needs of Parents. Findings of Case Study Research in the Republic of Ireland

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**Aims:** This paper presents findings of a study about respite care and the information needs of parents caring for a child with a life-limiting condition.

**Methods:** Utilising multiple, longitudinal, qualitative case study design, families caring for a child with a life-limiting condition were recruited to a study to explore respite care. Multiple in-depth interviews were undertaken with the parents identified by a hospital-based children's palliative care team. All data gathered were analysed using thematic analysis. Each individual case consists of a whole study. Cross-case comparison was also conducted.

**Results:** Nine families were recruited and followed for two years. A total of eighteen in-depth interviews were undertaken with parents caring for a child with a life-limiting condition. The dearth of information available to parents regarding service provision and entitlements was highlighted as an unmet need. Parents were unsure where to get the information and services that they and their child needed. They learnt over time to navigate the system in order to secure the services that they required including respite services. Organisations providing this support and information varied according to child's diagnosis and the parents own preferences. Parents described how the lack of information impacted not only on their child but also had consequences for the whole family. Parents spoke of the need to ensure that other families would have ready access to the information and services they required and thus would not experience disadvantage.

**Conclusion:** Having a child diagnosed with a life-limiting condition impacts on every aspect of family life. In order to ensure that families are able to cope with this they require information from healthcare professionals about the service options available to them. They require information regarding all practical aspects such as the provision of equipment and financial entitlements and grants.

**Abstract number:** P2-427

**Abstract type:** Poster

### 4U Group: Sibling Support in Robin House Children's Hospice

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**Background and aim:** Children's Hospice Association

Scotland (CHAS) provides the sole children's hospice services in Scotland to children, young people with life-limiting conditions and their families. CHAS provides vital care and support through its two hospices Rachel House and Robin House and a home care service.

Sibling support is an important aspect of care and Robin House has developed the '4U Group' following the findings from two studies and the desire to support siblings at a deeper level.

The aim of the group was clearly defined:

- To offer a structured sibling support group, meeting with the same children regularly over a period of six months
- The priority was that the group was for them, encouraging them to feel positive about themselves

**Method:** Before the group began both the siblings and parents were asked questions regarding their expectations. The group met once a month where a predictable and consistent environment provided a secure setting. With peer support being encouraged, a wide variety of activities, tailored to their individual needs, were used to explore a different topic each session. These included imagining time-travelling with Dr Who to explore change, and energetically participating in 'Splat Attack,' a creative way to deal with negative feelings.

**Findings and outcome:** The siblings were enthusiastic about the group and reflected that they had found it helpful. They wanted people to know about what they had achieved. Participants' self esteem and confidence grew and was recognised by both parents and staff. Feedback was overwhelmingly positive, and siblings have continued to refer to it on subsequent stays at the hospice.

The 4U Group recognised the needs of siblings and valued their individuality, introducing them to tools to develop their resilience. It is recommended that this support is extended at Robin House, and is shared with others who are involved in the care of children, adolescents and their families.

**Abstract number:** P2-428

**Abstract type:** Poster

### Hospice House for Children and Adolescents: The French Experiment

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In France, children and adolescents have long been forgotten in palliative care organization. In 2008, a national health program was set up to improve the quality of palliative care and specific pediatric palliative care was defined so as to enable the development of an organizational structure suitable to it. Twenty two specific teams were created throughout the country to spread pediatric palliative care culture wherever it was needed. Meanwhile, a hospice program was created to experiment with the hospice concept that had already been developed in other countries. Toulouse Children's hospital and the French Red Cross worked together to open, in 2010, "Oasis," the first French children's hospice which has the expertise to care for 5 children with life-shortening conditions, and support their families.

We will describe here two years of management of this hospice with its positive aspects and the mistakes that were made. We will analyse some of the technical aspects of this experiment ranging from the architectural point of view to economic considerations.

An information campaign was focused on pediatric palliative care but we realized how difficult it was for parents to accept this concept and we chose to insist on supportive and respite care. We will try to analyze the parents and the children's will regarding end of life care in the French socio-cultural environment. The clinical situations that led to a stay in the hospice house will be described, knowing that home palliative care was concurrently developed. One of the goals of the palliative care program was to avoid useless medical care, especially in the adult setting. However, at the end of their life, easing children's symptoms often requires a high level of technicality. Therefore, the hospice house could not function without a certain amount of professional care givers.

Finally, we will discuss how bereavement support could be organized from the hospice house.

## Advocacy & Media

**Abstract number:** P2-429

**Abstract type:** Poster

**Art as a Link between Palliative Care**

## and Society

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**Aim:** To show the results of an experience to link society, hospital and palliative care by an art project based on photography.

**Material and methods:** This is part of a biggest project funded by The European Union (Euroregió Pirineus Mediterrània) among 3 different art museums at Palma de Mallorca, Toulouse and Lleida. We will offer the methodology and results from Lleida. Health professionals, medical students patients and proxies were asked to participate in the project. They were given a smart phone to make photos at the hospital showing the daily routine for 2 months. Photos could be linked to a small text. Every photo was uploaded to a web page.

**Results:** 13 people were enrolled. And 235 photos were taken. All the photos can be seen at [www.artihospital.org](http://www.artihospital.org). For all the participants the experience was important and positive. It must be pointed that photos by a widow in bereavement were a therapeutic tool for her.

**Conclusions:**

- 1) Modern art can be a good link between society and palliative care.
- 2) Taking photos has a therapeutic roll in patients, proxies and health professionals.

**Abstract number:** P2-430

**Abstract type:** Poster

### Making the Case for Resources and Attention - Advocacy and Communications in Palliative Care

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**Aims:** To build support for the future development of a national hospice and bereavement strategy by raising awareness of what hospice care means and the strategic importance of good end-of-life care for the entire health service.

**Methods:** Taking a multi-layered approach to raising awareness and building consensus. Targeting the **correct audience** who have the power to make change happen - our champions. Bringing **robust evidence** to the table to help them to justify reform and investment.

Demonstrating that our issues **affect a significant number** of people.

Sharing our **experience** and knowledge

**Costing** any proposed solution

Knowing their **policy priorities**

Staying resilient - keep advancing and introducing new angles to our argument

Using a variety of new and existing projects and programmes:

Encouraging patients and families to be **self-advocates** - using a novel project to help people discuss and record future care preferences; organised public events to empower people about their decisions

Supporting healthcare professionals to become effective **advocates for patients** - training in communications and awareness of end of life issues; supporting GPs and primary healthcare workers to deliver palliative care; supporting the development of palliative care beyond cancer

Engaging directly as **advocates within the political system** at all political levels - developing relationships with politicians with an interest in hospice issues

Identifying **advocates in the public service** to promote policy change

Creating **alliances** with like-minded organisations to lobby for policy development

Using media opportunities to sell the message  
**Results:** To date we have identified knowledge gaps and are developing a range of appropriate responses.

**Conclusion:** This a long-term exercise, dependent on correcting misconceptions, filling information gaps, ensuring policy change and promoting a public dialogue on sensitive issues around dying, death and bereavement.

**Abstract number:** P2-431

**Abstract type:** Poster

### Representations of Assisted Dying in the UK Media

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Euthanasia and assisted suicide are both terms which, under

the umbrella term of assisted dying, have caused much debate. Understanding how the media represent assisted dying is crucial because it is often a primary resource where the public can gather information and make sense of social phenomena.

There have been limited studies on the portrayal of assisted dying in the media, with research focusing on narrow themes. The aims of this study were to find out how the reporting of assisted dying differed in the Dutch and British media, to identify the broad themes running through the media's representation of the issue, highlight where assisted dying terminologies had been incorrectly used and verify the hypotheses generated by previous studies.

A recent unpublished Dutch study which conducted a content analysis on euthanasia in the Dutch press was found, using the same search terms as the Dutch study, in the Nexis database, 187 UK articles were located. The process of thematic coding was dynamic in nature and the coding scheme was added to and corrected throughout the analysis making the scheme fluid and effective at capturing arguments and themes.

The results showed the UK media reported assisted dying neutrally which differed from conclusions of previous research. Incorrect use of assisted dying terminologies were found in 33% of tabloid articles. The Dutch press also contained more 'right to die' arguments than the British, whilst the British contained more 'slippery slope' arguments. This reflects the difference of Dutch and British opinions in autonomy in end of life decisions.

The striking danger is that the use of incorrect terminologies and labelling of groups and individuals can lead to confusion amongst the public. This study has the largest assembly of arguments for and against assisted dying that has been documented in current literature and although it has many limitations it is the first of its kind and may hopefully lead to more research in this area.

**Abstract number:** P2-432

**Abstract type:** Poster

### Use of Social Media in Palliative Care - Evaluation of the EAPC Blog after six Months

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The EAPC board of directors has decided to foster the use of social media in palliative care with the aim to expand its outreach, e.g. towards younger professionals and lay persons. It also allows the EAPC to give a rapid response to new developments worldwide. An evaluation of the use of the EAPC blog was performed after six months.

**Methods:** The social media team was installed and set up a blog at [wordpress.com](http://wordpress.com) and linked it to the EAPC Facebook site and Twitter account. New posts were written by the members of the team or were solicited from other key persons either within or outside of the EAPC. In addition, an open invitation to contribute to the blog was placed on the WordPress blog site and was sent out to the EAPC members.  
**Results:** In the six-month period 103 posts in 13 categories have been uploaded to the blog. The blog has received 18,662 clicks. Most (12,404) were from Western European countries (Top three: UK 4,095; Italy 2,204; Germany 972). North America followed with 1,892 and Australia/Asia with 1,743 clicks. Eastern European countries contributed with 1,517 clicks (Romania 363; Poland 163; Russian Federation 105 leading). South America (658 clicks), Africa (322) and Middle East (126) were less frequent visitors. Topics accessed most frequently focused on opioid guidelines, spirituality and EAPC congress activities. Posts with catchy titles (e.g. 'opioids and wisdom') received much more attention than more descriptive titles. Similarly, pictures could channel additional attention, and would also lead visitors to the blog when used as search engines terms (e.g. 'the thinker'). Most frequent link from the blog was the EAPC homepage (850 clicks), followed by the blog homepage (530) and the homepage of the European Palliative Care Research Collaborative (143).

**Conclusion:** Social media are being used increasingly. More contributions from Eastern European authors will be commissioned and translated to increase the blog use in these countries.

**Abstract number:** P2-433

**Abstract type:** Poster

### Swedish Palliative Network - SPN a National Newsletter and Web Site

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**Background:** The amount of information in palliative care is growing and there is a need to filter and handle increasing quantity of professional non-scientific information.

**Methods:** A description of the development of SPN newsletter and web site. A forum for multi professional national exchange was lacking in Sweden and there were no initiatives to start a multi professional palliative care association.

**Results:** At Stockholms Sjukhem, a newsletter was created with the following intentions: free of charge, no commercial advertisement, short articles or communications, relevance for all palliative care team members and monthly issues of, in average, 5-6 pages. New subscribers directly through e-mail or from lists distributed at major palliative care events in Sweden. In ten years subscriptions have increased from 100 to >3000. The single editor has a broad knowledge on palliative care. Also receives information from professionals and makes contact e.g. with those who publish PhD or master exams in palliative care to send in a summary of the study. The software used is a PDF file made from a MS Word document. Newsletters and articles etc can be downloaded from [www.stockholmsjukhem.se/spn](http://www.stockholmsjukhem.se/spn) Surveys on reader satisfaction and specific palliative care questions have been sent to subscribers. The responders are satisfied with the newsletter and many forward it to their own palliative care networks.

**Discussion:** The Newsletter is after 10 years and >100 issues, a well known source for information on palliative care in Sweden. We believe that the relatively short and traditional format and the regular and free submissions as well as the mixture of overall and particular material have been important factors for the success.

Future challenges include sensitivity to the demands of the readers, even those who do not respond to reader surveys, increased interactivity with the subscribers and of course to continuously be a high priority for the readers.

## Spirituality

**Abstract number:** P2-434

**Abstract type:** Poster

### Personal Resources Explaining Patients' Wellbeing: A Structural Model on a Multicentre Study in Spain

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Patients' physical, social, psychological and spiritual needs relieve is essential in the decrease of suffering within palliative care units. From the anthropological model purposed by the SECPAL Spirituality Group, and using a measurement instrument developed to assess the spirituality through three levels: intrapersonal (sense), interpersonal (harmony) and transpersonal (membership).

**Aim:** To study the relationships between this spirituality grade and the emotional wellbeing (absence of anxiety and depression signs) in a sample of patients from Spanish palliative care centers.

**Study design and methods:** Sample consisted of 121 patients (nearly half from palliative care units and the rest from home care palliative (36%) acute care hospitals (16%) and nursing homes (10%). We perform a cross-sectional study with descriptive analyses, correlations and a structural equations path model including measures of psychological wellbeing, resilience and spirituality.

**Results:** Have shown values in indicators of emotional wellbeing similar to other studies (anxiety mean=8.93; SD=2.23; depression mean=6.95; SD=4.04) and, statistically significant and high correlations between spirituality, depression, anxiety and resilience. The data fit the path model properly ( $\chi^2_9=15.85$ ,  $p=.07$ ; CFI=.922; GFI=.939; SRMR=.069; RMSEA=.086), indicating high predictive power of the spirituality grade on depression and anxiety, in a negative way, and a positive relation between spirituality and resilience.

**Conclusions:** Put all these results in relation to previous literature, providing new evidence on the importance of spirituality for patients' emotional wellbeing.

**Abstract number:** P2-435

**Abstract type:** Poster

### Through 'the Gate': Comparison of the Experience of Two Versions of a Course Designed to Raise Spiritual Awareness for Health Professionals

## Poster sessions

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**Background:** The 'Opening the Spiritual Gate' education programme, established in the North West of England, is designed to help the health & social care workforce increase spiritual awareness & improve confidence in assessing & meeting spiritual & religious needs of patients & families. The course includes recognising spiritual distress, needs of different faith groups, communicating where there are no answers, recording & reporting spiritual conversations, resources & support.

**Method:** Pilot evaluation had demonstrated significant change in confidence from the course but the experience of the two methods of delivering the course, face to face & online study, had not been investigated. As part of a master's degree, qualitative analysis of semi structured interviews with participants who had undertaken either type of course was undertaken. The interviews established their reasons for choosing this type of learning, their experience of the course, what they felt had gone well & what had been a challenge, & their overall judgement of the outcome of the course & its impact in practice for them.

**Results:** Several themes relating to differing learning preferences, the technical challenges of online learning, the anonymity & asynchronicity of online discussion compared to the challenges of group discussion, were identified. However themes relating to depth of discussion, diversity of opinion, usefulness of a simple method of communicating in difficult situations etc. were common to both.

**Conclusions:** Both face to face training & facilitated online course can be utilised to help to increase awareness of the spiritual & religious needs of patients & families, dependent upon the learning preferences & work constraints of health professionals. The experiences of those undertaking each course are both different & similar & attract different personalities, those with different learning preferences & those whose work requirements allow one type of attendance over another.

Abstract number: P2-436  
Abstract type: Poster

### Issues of Control and Perceived Disruption of the Self: The Main Reasons for Choosing Assisted Suicide, Despite the Provision of Palliative Care

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**Background:** Palliative care is often seen as a safeguard against assisted suicide. Recent studies demonstrated that palliative care ranked high in terms of provision and quality indicators in countries where assisted suicide or euthanasia are performed.

**Aims of the study:** To explore family members' accounts of patient's reasons for choice of assisted suicide choice and their perceptions of the interactions with health care professionals and palliative care during decision making.

**Methods:** Qualitative study using semi-structured interviews and thematic analysis with eleven relatives of eight deceased patients, cared for by a palliative care team, who undertook assisted suicide between January 2007 and May 2009 in Southern Switzerland.

**Results:** Interviewees suggested that pain and symptom burden were not regarded as reasons to seek assisted suicide, rather existential distress and fear of loss of control were the key determinants. In some cases the general decision to use assisted suicide was made more than 10 years earlier. According to relatives, a need for control over their situation and death circumstances was reported as common. Relative's proxy accounts reported a number of misunderstandings about the nature and purpose of palliative care: fears that morphine would interfere with decision capacity, palliative care seen as useless because it did not influence the illness and other issues. Patients did not regard receipt of palliative care services as influential in preventing their decision to proceed with assisted suicide.

**Conclusions:** Assisted suicide was preferred by these patients despite provision of palliative care. Existential concerns regarding fears and control played a greater role.

Abstract number: P2-437  
Abstract type: Poster

### Spirituality and the Arts - Discovering what Really Matters

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The creative arts help us access aspects of our experience that may elude recognition and articulation. This can reinforce resilience and enhance understanding of ourselves, other people and our world. A body of evidence shows that the arts and humanities can help patients to manage pain and the side effects of some treatments, and to come to terms with what can be major and distressing episodes in their lives (1). The arts have for many years been used for therapeutic support and intervention in end-of-life care, but are somewhat under-represented in the field (2). The arts and humanities encourage us to value ways of knowing, particularly experiential and presentational knowing that in healthcare contexts can be marginalized by the clinical sciences' focus on propositional and practical knowing. Arts-based enquiries explore how individuals and communities construct meaning by representing and reflecting upon experiences that challenge prior understandings of the world and our place in it. Arts-based enquiry is thus a natural ally of spiritual growth and care. Creative arts methods are also increasingly being used in research enquiries in which spirituality is an integral, albeit at times more an implicit than explicit, part. This paper outlines possibilities opened up by arts-based enquiries in the particular setting of a large London hospice. Following an orientation to the setting, the paper falls into three sections:

1. Concrete examples given to make connections between spiritual pain and the use of the arts
2. A dynamic arts programme is introduced to show how linking the arts with the general public's experiences of spirituality can change attitudes towards death
3. Results of an evaluation using a range of qualitative tools are shared highlighting some key themes which illustrate how the arts can support and enhance people's spiritual experiences and beliefs

<sup>1</sup>Starikof R. (2004) London Arts Council England  
<sup>2</sup>Hartley N. (2008) London: JKP

Abstract number: P2-438  
Abstract type: Poster

### Confirmatory Structure of Two Measures of Spirituality in Spanish Palliative Care Units

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**Aim:** To present and discuss empirical evidence about the competitive structures regarding two different spirituality measures applied to palliative care practice in Spain.

**Design & method:** Data from 121 participants from a cross-sectional study are used to assess reliability, criterion and factorial validity of two spirituality measures: GES (8 items) and FACIT-Spa (12 items). Competitive confirmatory structures for GES consisted of a three factors structure (*intra, inter and transpersonal*) vs. a second order factor analysis with the same three first order factors plus a second order factor named *spirituality*. FACIT competitive models are those reported in mostly English speaker literature comparing two against three factors based on *meaning/peace and faith* constructs.

**Results:** Both measures provide adequate reliability in terms of internal consistency (GES  $\alpha = .72$ ; FACIT-Spa  $\alpha = .80$ ). Results from the competitive confirmatory factor analyses are reported and discussed in terms of their better fitting options. With respect to factorial validity the best-fitting model for GES was the second order one, with a good model fit ( $\chi^2/df = 29.12$ ,  $p < .05$ ; CFI = .926; GFI = .942; RMSEA = .083). Regarding FACIT, a better comparative fit (established with a lower amount of model AIC of -26.93 compare with -23.78) was obtained for the 3-factor structure (NNFI = .957; CFI = .967; IFI = .968; RMSEA = .070).

**Discussion:** Current results pointed to an adequate reliability of both measures, clarifying their dimensionalities, with a clearest structure for the GES. It should be borne in mind that this measure was developed to solve a gap in the spirituality measurement literature: to attend spirituality in palliative care taking into account a main trait of Mediterranean culture: the interpersonal resources.

Abstract number: P2-439  
Abstract type: Poster

### Soul Searching: Developing a Tool for Spiritual Assessment

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**Background:** The recognition of the importance of spirituality has been highlighted in recommendations for palliative care. The UK 2004 National Institute of Clinical Excellence guidance: 'Improving Supportive and Palliative Care for Adults with Cancer' suggests spiritual assessment should be an integral part of care, being regularly completed and being the responsibility of the whole team. This study was conducted in a tertiary cancer centre in the United Kingdom with over 7000 new patients treated each year. Currently there is no formal assessment of spiritual care needs carried out during the nurse assessment. Identified as one of the key obstacles, was lack in staff's confidence in assessing spiritual needs. Following this a formal spiritual assessment method was piloted.

**Objective:** To develop and pilot a formal spiritual assessment tool and referral criteria, in order that spiritual needs can be confidently addressed by all health care professionals, leading to a better quality of care for patients.

**Method:** A baseline literature search reviewed a range of assessment methods and referral criteria. A chosen tool was then adapted and piloted by members of the hospital Specialist Palliative Care Team and hospice nurses. **Results:** All nurses involved in the pilot (n=8) stated the tool helped in structuring the spiritual history and 3 nurses stated they would use this tool again, without any further improvement to it. The remaining 5 nurses felt they were adequately experienced but said it would be useful for less experienced nurses. Confidence in using the tool was reported as high.

**Conclusions:** Having a formal assessment method was new to the cancer centre. The introduction of a structured spiritual history tool was helpful to staff and was confidently utilised, without being too time-consuming to complete. This is a small pilot study with scope for future work. The aim is to introduce an assessment tool that all staff can use during patient assessment.

Abstract number: P2-440  
Abstract type: Poster

### Frequency of Spiritual Concerns in a Palliative Care Setting in a Developing Country: Are there Cross-cultural Differences?

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**Aims:** To study the frequency of spiritual concerns in a palliative care setting in a developing country and compare these with those reported from Western developed countries.

**Study design and methods:** A qualitative study design was used to acquire information on frequency of spiritual concerns in Hindu cancer patients undergoing palliative care in a hospice. An ethics committee approved the study and written informed consent was taken from all participants. Interviews based on semi-structured format discussing spiritual concerns were conducted and recorded on a digital voice recorder. The audios were transcribed in English, reviewed and coded. Interviews were continued till theme saturation was reached.

**Results:** Ten patients (7 female, 3 male) were interviewed. Number of spiritual concerns ranged from 6-22, (mean 11.6) per person. The commonest spiritual concerns were benefits of Pooja (religious activities), faith in God (100%); concept of rebirth, reconciliation of own condition, perspective of future (80%); belief in Karma, and "Why me?" (70%). Spiritual concerns, commonly reported in western literature, related to loneliness, need for seeking forgiveness, need to be remembered later, and religious struggle, were reported by none of the subjects. Concerns about angry God, gratitude, guilt/shame, loss of control and reconciliation with others were reported by 10% only.

**Conclusion:** This study confirms that specific spiritual concerns are common in traditional developing countries. It identifies strong cross-cultural differences in the key areas of spiritual concern, when compared with western palliative care patients. These findings emphasize the importance of spiritual care in the development of palliative care but cautions the direct transferability of western models of spirituality within this setting.

Abstract number: P2-441  
Abstract type: Poster

### The Impact of Faith and Hope During the Palliative Phase on Long-term Psychological Functioning in Parents who Lost a Child to Cancer

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**Background:** The aims of this study were to investigate  
1) faith and hope for parents of a child dying of cancer,  
2) the impact on long-term traumatic grief and depression,  
and  
3) factors that helped parents to cope during the palliative phase.

**Patients and methods:** Eighty-nine parents of 57 children who died of cancer between 2000 and 2004 participated in a retrospective cross-sectional single centre study and completed a set of questionnaires measuring grief and depression, and exploring faith, hope, and factors that helped parents cope.

**Results:** For 19 parents (21%), their faith was very important. The majority of parents had hope for: a meaningful time with their child (n=68,76%); a pain-free death (n=58,65%); and a cure (n=30,34%). Most parents indicated that their child (n=70,79%) helped them to cope during the palliative phase. Approximately 14% (n=12) of parents could be categorised as having traumatic grief and about one quarter of parents (n=22, 25%) showed symptoms of clinical depression. Nine parents (10%) showed symptoms of both traumatic grief as well as clinical depression. Parents' faith and hope for cure during the palliative phase were not associated with long-term traumatic grief (OR=0.86,p=0.49;OR=1.08,p=0.70) or depression (OR=0.96,p=0.78;OR=1.13,p=0.42).

**Conclusion:** Faith was important only for a minority of parents. The majority of parents had hope. Faith did not protect parents from traumatic grief and depression, while hope for cure did not put parents at increased risk for traumatic grief and depression. For most parents, their child was an important source of coping.



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