

# EAPC Abstracts

## EAPC President's Welcome

Dear Colleagues, Dear Friends,

On behalf of the Board of EAPC, and as President, I am delighted to welcome you to our 16<sup>th</sup> World Congress in Palliative Care. As ever, this Congress is two years in the planning and it has been my honour to work with a dedicated group of colleagues, who have worked tirelessly to bring this programme to fruition.

Berlin is an amazing choice of venue for our Congress for many reasons. Everyone can find something to capture the imagination in this beautiful city. It resonates with history, diversity and vibrancy but most of all, with life. And that, of course, is a key message for palliative care. We who work in this field are as much about life as death, supporting patients and families to live and live well until the end. So, as the people of Berlin, we should embrace life and savour every moment that this Congress and this city will offer us over the next few days.

The 16<sup>th</sup> World Congress focus on global health is a strong message that EAPC is a world player in the development and practice of palliative care. We have a voice which echoes the interface between clinical, research and policy engagement. We represent a critical perspective in national and international understanding of palliative care and showcase our work through this Congress and that of the EAPC Research Network (don't forget Palermo 2020!). Please take time to sit and listen, debate and reflect on the important issues to be discussed here at Congress. Your views are important and help us to shape our EAPC thinking on the way forward. I am also delighted that for the first time, we will have a parallel day on children's palliative care, ably organised by our CEO, Dr. Julie Ling. We expect over 700 delegates will attend this event, a remarkable achievement and one which heralds a new strand in our Congress material which I hope will continue in future years.

There are many people to thank for this event. Our Co-Chairs, Dr. Sébastien Moine and Dr. Anne Letsch, who was also leading the local organising committee, our debt of thanks for the hard work and long hours. Thanks also to the members of the Scientific Committee and Local Organising Committee who have provided the ideas and proposals which shape the 2019 Congress. Your support is, as always, much appreciated. We cannot forget our Conference Partner, Interplan and Elke Jaskiola in particular for organising us and keeping us to task. Of course, my personal thanks to EAPC Head Office, Julie, Eleanor, Cathy and Avril for the logistics, organization and managing all the other EAPC demands at the same time as bringing a world congress together. I would also like to give sincerely thanks to our colleague Claudia Sütfeld our congress administrator who has worked tirelessly to ensure that everything runs smoothly.

Finally, I wish to thank our German friends and colleagues for welcoming us to Berlin and for agreeing to host this Congress.

*Liebe Freunde,*

*die Wahl des Landes und des Tagungsorts für einen EAPC-Kongress ist immer eine Herausforderung. Diesmal allerdings fiel es uns wirklich leicht, denn Sie haben uns überaus herzlich willkommen geheißen. Im Namen des EAPC-Vorstands danken wir der Deutschen Gesellschaft für Palliativmedizin für alles, was sie in den letzten zwei Jahren geleistet hat.*

So, I wish you a wonderful Congress, time to meet old friends and make new ones and opportunities for creativity and relaxation when you can. Welcome to Berlin 2019.



Professor Philip J Larkin  
President, European Association for Palliative Care

believe that the process of being discharged must be done carefully. Little is known about the experiences of relatives and healthcare providers and what they find important during this process.

**Aims:** What are the experiences of relatives and healthcare providers during the process of discharge. In which way can the process being improved.

**Methods:** Interview with 4 relatives of patients who were discharged from hospice and a focus group interview with nurses and a social worker from the hospice to investigate the experiences of family and hospice team. Interview with 3 hospices about the discharge process.

**Results:** Relatives admit that the discharging process is distressing, because legal rules determine the dismissal, not the wishes of the patient. They experience the process within the hospice as going well. Healthcare providers themselves struggle with the other focus, the patient is not dying but their health improved. They experience the communication within the organisation as unsure, not knowing reasons of discharge and not having a step-by-step plan. Some of the other hospices do have a step-by-step plan, some don't.

**Discussion/ conclusion:** Contrary to what was thought, relatives didn't find the process of discharge distressing, as far as the hospice is responsible for the relocation process. We recommend the organisation to make the procedure more transparent with attention paid to the transition of focus for healthcare providers.

**Abstract number:** P01-167

**Abstract type:** Poster

#### Anticipatory Medication in Home Palliative Care: A Systematic Review of Existing Practices, Challenges and Safeguards

*Hernández-Marrero P.<sup>1,2,3</sup>, Martins Pereira S.<sup>1,2,3</sup>, Project EnSupCare: Ensuring Home-Based Palliative Care at the End-of-Life: Supporting Family Carers to Manage Pain Medication*

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**Background:** Family carers provide much of the essential care that enables patients to stay and die at home. Anticipatory prescribing is designed to ensure that there is a supply of medication and apparatus needed for family carers to administer them in the patient's home. Little is known about simultaneously promoting effective methods for ensuring the optimal management of anticipatory medications (AM) and supporting family carers when caring for their loved ones at the end of life at home.

**Aims:** To systematically review the existing literature on AM in home palliative care (HPC) with respect to its clinical, organizational, ethical and legal frameworks, main challenges and safeguards.

**Methods:** Systematic Review following PRISMA 2009. Databases: PubMed, Web of Science, Scopus, ProQuest, CINAHL Complete, MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, MedicLatina, Health Technology Assessments, NHS Economic Evaluation Database and EBSCO databases. Search terms: "anticipatory medication" and "palliative care". Inclusion criteria: studies reporting the use of AM in HPC, in English, German, Spanish and Portuguese, full text, references available. Selected articles were independently reviewed by two researchers. The Hawker et al tool was used for quality assessment.

**Results:** Of the 180 articles retrieved in our searches, 7 were included for analysis. Findings show that nurses have an active role in the prescription and training of family carers in the management of AM in HPC. Some conditions are taken into account for a safe practice of AM. Resourcing concerns, professional expertise and articulation among professionals are perceived as challenges.

**Conclusions:** Anticipatory medication is a major need and has ethical challenges in symptom control at the end of life at home. Research is needed to ensure optimal management of AM in HPC.

**Abstract number:** P01-168

**Abstract type:** Poster

#### Understanding Ethical Challenges and their Impact on Family Caregivers of Patients with Advanced Cancer

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**Background:** Caring for terminally ill and dying patients (PT) can contribute to ethical challenges, but little is known on experiences and impact on family caregivers (FC).

**Aims:** Understanding ethical challenges of FCs of PT with advanced cancer by exploring their experiences and resulting burden, coping strategies and moral distress.

**Methods:** Qualitative semi-structured interviews using open-ended questions with 12 bereaved FC. Data analysis using grounded theory and abductive reasoning.

**Results:** Analyses showed two paths leading to ethical challenges in FC. Challenging situations during the disease trajectory - not necessarily perceived as ethically challenging by FC - either triggered a perceived lack of available choices or a difficult decision-making process. A lack of available choices caused feelings of powerlessness accompanied by anxiety, sadness and confusion. Either then detrimental factors (e.g. no truthful communication with PT) led to paralyzing shock, or resources (e.g. better preparedness) stimulated acceptance of the situation and avoidance of moral distress. In case of difficult decision-making processes, detrimental external factors (e.g. lacking time) caused emotional distress of feeling left alone, helplessness and overwhelm. To overcome experienced obstacles or to make a decision FC used proactive strategies (e.g. social support). Across both paths and independent of FC's burden and strategies, moral distress occurred when FC could not act according to their values (e.g. providing "good" care, respecting PT's will), generating painful emotions. While clinicians' acknowledgment of caregiver role, clarification of ownership of things gone wrong and FC's self-acceptance helped FC to find closure, some identified residual frustration and self-blame.

**Conclusion:** Findings provide a starting point towards understanding paths leading to ethical challenges in FC and can support clinicians to help minimizing associated emotional and moral distress.

**Abstract number:** P01-169

**Abstract type:** Poster

#### Supportive Nursing Care for Informal Caregivers - A Retrospective File Study

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**Background:** In the Netherlands many patients receive end-of-life care (EoLC) at home from nurses working for homecare organisations (HCO). Informal caregivers (IC), such as spouses and children, play a significant role in facilitating patients to stay at home. Nurses also aim to support these IC, but information on how this is done is lacking.

**Aim:** To get insight into supportive care for IC as provided by community nurses.