



CATÓLICA

INSTITUTO DE CIÊNCIAS DA SAÚDE

LISBOA · PORTO · VISEU

RELATÓRIO DO ESTÁGIO DE CUIDADOS PALIATIVOS NO SOUTH ADELAIDE PALLIATIVE
SERVICES, AUSTRÁLIA MERIDIONAL, 2014

Relatório de Estágio apresentado à Universidade Católica Portuguesa para obtenção
do grau de mestre em
Cuidados Paliativos

Por

José António Pais Silva

Lisboa, 2015



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Sob a orientação de Ms Catherine Swetenham e Prof Dr David Currow

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Summary

A practical component was felt to be essential to make theory and practice meet in Palliative Care, at all levels, even after directed postgraduate studies. As such, I opted to undergo a 9 week Palliative Care internship in a reference institution – South Adelaide Palliative Services (SAPS), from July to September 2014 in Adelaide, South Australia. This institution offers hospice, outpatient, hospital consultancy and home care services. Additionally, it is famous for conducting good quality research in Palliative Care. An internship was thus carried out with the aim of improving symptom control options, psychosocial understanding and management principles, namely communication of bad news and service structure observation. Furthermore, a research project concerning the symptomatic control of dyspnoea was also carried out. All components of care were visited and in all of them fruitful discussions with in-matter specialists were held. Schedule flexibility was possible to allow for objective completion and, at a certain point, to satisfy a personal inclination for a certain area. This practice had multiple implications in my professional life as a medical Oncology registrar: It allowed me to feel much more comfortable in dealing with partially refractory symptoms and to gain perspective on the typical course of disease in some pathologies. Additionally, communication skills were greatly improved by being able to see some conversations that would challenge the *status quo* of practicing medicine in Portugal and adapting them to our culture. The research project resulted in a paper being submitted, and is now awaiting reviewer's comments. All in all, the proposed objectives were met and fulfilled, with the necessary limitations, and the experience was considered very fruitful on all levels.

Key Words: Palliative Care Internship, Symptom Control, Psychosocial issue management, Dyspnoea

Resumo

Mesmo após o término da pós-graduação em Cuidados Paliativos, ainda me pareceu necessário aprofundar a componente prática para conciliar a teoria e a prática. Como tal optei por efetuar um estágio de 9 semanas numa instituição de referência em Cuidados Paliativos – a *South Adelaide Palliative Services* (SAPS), de Julho a Setembro de 2014, em Adelaide, na Austrália. Esta instituição oferece serviços em ambiente de *hospice*, consulta externa, consultoria hospitalar e cuidados domiciliários. Também é famosa por conduzir investigação de boa qualidade nesta área. Como tal efetuei este estágio tendo por objetivos a melhoria do controlo de sintomas, uma melhor compreensão e gestão dos problemas psicossociais associados, nomeadamente a comunicação de más notícias e a observação da estruturação de um serviço coordenado a este nível. Além disso, desenvolvi um projeto de investigação referente ao controlo sintomático da dispneia. Todas as valências do serviço descritas foram frequentadas e em todas elas ocorreu uma discussão frutífera com os profissionais envolvidos. O horário desenvolvido foi propositadamente flexível de acordo com a necessidade de cumprir os vários objetivos propostos e com a inclinação pessoal, entretanto desenvolvida. Este estágio teve implicações múltiplas na minha vida profissional como interno de Oncologia Médica: Permitiu sentir-me mais à vontade na gestão do doente com sintomatologia parcialmente refratária e obter perspetiva da história natural de algumas patologias. Notei um ganho considerável no aperfeiçoamento das técnicas de comunicação pela oportunidade de observar algumas discussões entre profissionais de saúde e doentes que desafiariam a forma como encaramos estes tópicos em Portugal e que tenho aproveitado, com as necessárias adaptações. O trabalho de investigação resultou num artigo submetido, presentemente aguardando os comentários dos revisores. No cômputo geral, considerei como cumpridos todos os objetivos propostos como alcançados, com as necessárias limitações. A experiência foi considerada muito proveitosa, a todos os níveis.

Palavras-Chave: Estágio em Cuidados Paliativos, Controlo de sintomas, Gestão de problemas psicossociais, Dispneia

With thanks to:

Kate Swetenham, David Currow, Brian Le

Luís Capelas

Diana Ferreira

Ana Sofia Carvalho

My family

Everyone at SAPS

And, of course, the ever enduring and courageous patients

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1- Introduction

“Practice makes perfect” would be a correct way to sum up the reason why I felt an internship would be more suitable to fulfil my needs and ambitions of acquiring more knowledge in the field of Palliative Care. Indeed, tempting as a research project would have been, it seemed that, after the post-graduation studies in Palliative Care, there were still a lot of loose ends to make theory and practice meet. However, as a Medical Oncology registrar, appropriate care of my patients requires a good practical knowledge of how to best use the information gathered during the post-graduate studies.

Palliative care, according to the World Health Organization can be defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”(1).

Often in my short medical career I have witnessed a certain embarrassment of the medical profession when discussing or treating patients with incurable diseases. Nonetheless, at present and predictably in the future most deaths occur as a result of chronic incurable diseases, rather than sudden acute ones (2,3). As such, there is an inappropriateness of the model of care that can lead to mismanaging these patients. Furthermore, it seemed that the technical background formation in Palliative Care in Portugal is still rather scarce, if we take into account a much broader view of the definition of Palliative Care, extending far beyond symptom control (important as it is), as foretold in the above definition. On the other hand, a significant proportion of the actions one takes are based on imitation rather than constant innovation.

Bearing this in mind, I discussed my intentions of trying to develop practical skills in this field, if possible in a place where the system and culture were already fully implemented. With this I hoped to get a sense of the full potential that lies in systematically applying good quality Palliative Care to patients.

As a consequence of this discussion I contacted some members of the South Adelaide Palliative Care Services (SAPS) namely the head of the clinical department (Ms Kate

Swetenham) and the head of the research department (Prof Dr David Currow) that approved of my proposal to conduct an internship amongst them. This report thus serves the purpose of describing and characterizing the work developed therein.

SAPS has a long standing reputation of dedication to Palliative Care and is therefore internationally regarded as a reference centre, not only but also, by the European Society of Medical Oncology (ESMO), to provide education, both for nursing and medical staff, in this field. Part of this international recognition also stems from the significant scientific output conducted therein covering basic, translational and clinical qualitative and quantitative research.

As such the internship took place in South Adelaide Palliative Services in South Australia, Australia, for a period of 9 weeks from 10/07/2014 to 11/09/2014. The internship comprised a working schedule from 8:30 am to 5:00 pm from Monday to Friday, during the designated weeks.

The general goals of the internship were further subdivided into several fields in order to systematize the internship and acquire a dimension of “measurability” of the gains attained. Different goals often resulted from performing different tasks. However, a *Gestalt* effect was unsurprisingly present and, as such, different explicit or otherwise objectives were fulfilled while performing the same activity. The different goals were divided as follows:

I- Symptom control

Obtaining more detailed and proficient clinical knowledge of pharmacologic and non-pharmacologic methods of symptom control as well as learning how to implement this knowledge on an everyday basis. As a doctor this is the function that is most commonly allocated to me and of which I am often supposed to have the last and most informed word on, in my workplace. I wished to develop this skill in several settings namely a Palliative Care tertiary level ward, outpatient clinic, consulting and home care. To this end, I proposed to shadow several nursing and medical members of staff as they watched the patients and embark on clinical discussions regarding therapeutical options for the specified case at hand.

II- Psychosocial issues

As the medical degree in Portugal does not include a comprehensive course on learning how to deal with these issues, most of what I learned was in the Palliative Care post-graduate studies. Whereas perhaps some of the techniques used were intuitive others were not and require observation and practice to achieve a satisfactory level. Thus it was of major importance to learn how to deal with several difficult issues namely but not limited to communication of bad news, dealing with end-of-life issues, amongst others. To achieve this goal I proposed to participate in interdisciplinary meetings focusing on managing psychosocial issues as well as following the several professionals involved in a clinic specialized in this approach (social worker, registered nurse, psycho-oncology specialized nurse), apart from all the other activities performed where this element was naturally also present.

III- System functioning and structural development

Given the fact that we are in the early stages of development of a programme to implement Palliative Care services on a nation-wide scale, with ample room for improvement I set out to take advantage of the inside knowledge collected. With this, I hoped to gain insight into the structural articulation of the system, that is, a more in-depth knowledge of how the several components of care coordinate themselves to attain a provision of good quality Palliative Care for patients and families alike. Perhaps one day this knowledge could be used to improve Palliative Care in Portugal. It made sense to achieve this goal precisely by working as best as I could within the system, that is to perform the activities previously described in the other objectives.

IV- Research

Research in Palliative Care can be viewed as a good example of the glass half full or glass half empty paradigm. If, on one hand, there are known difficulties in performing clinical research in this area, on the other hand,, there is much to research to be done and, in my point of view, an ethical obligation to do so. The option would be, in the words of my co-tutor Prof Dr David Currow “to experiment on patients themselves”. Also, I would

envison my role as a health professional in any area to be able to conduct both clinical work and research alike. SAPS is indeed one of the main hotspots of research worldwide, as far as Palliative Care is concerned. Clinical research in SAPS is being developed in multiple areas. Nonetheless, their main focus has been on the topic of dyspnoea and its symptomatic control. As such, I proposed to use some of the designated time of my internship to help conduct some research in this area.

This report is structured in the following manner: firstly, a description of the actual department is made, with reference to its physical spaces, geographical location and area of influence, human resources and their organization as well as the activities developed therein. Secondly, a description of the work performed during the internship is made with a brief descriptive analysis of the casuistic observed. This item includes a more detailed version of the objectives proposed as well as the strategies implemented and competences acquired to achieve them. A critical analysis is then made, per objective and on the whole, where the attendance of the objectives is not only verified but also put into perspective. Lastly, I will describe the future implications of this internship in my professional life, followed by concluding remarks containing a global evaluation.

Throughout this report, the Vancouver style of referencing was applied.

2- Description of the place of internship

A) SAPS put into perspective

SAPS is responsible for all of the southern Adelaide metropolitan area. Adelaide is the capital city of the state of South Australia. SAPS was formed after the remodelling of several Palliative Care departments with the purpose of including a bigger population, ever more in need of this kind of attention. SAPS developed with the inclusion of both hospital based care, coupled to Flinders Medical Centre (FMC) as well as home based care in coordination with nurse services that regularly visit the patients and administer medication (Royal District Nurse Service) as well as other providers of specific aspects of care (Domiciliary care, Meals on wheels, etc...). SAPS is part of the Southern Adelaide Local Health Network (SALHN) which comprises, in terms of hospitals, FMC, Repatriation General Hospital (RGH) and Noarlunga Health Services (NHS). Both the headquarters and the hospice facility pertaining to SAPS are located at the RGH. SAPS covers a population of 350,000, and receives over 1400 referrals each year (71% of which are oncologic diagnosis) and has up to 500 active patients and families on their books at any given time (4).

B) SAPS human resources

I- Head of department:

Ms. Kate Swetenham

II- Medical team:

The medical team consists of five Palliative Medicine consultants. This team is led by Dr Michael Briffa who is employed fulltime, however all other consultants work a part time roster. Their names were as follows: Dr Peter Allcroft, , Dr Susan Haynes, Dr Tim To, Dr Toula Christos.

The medical team also includes a part-time senior consultant psychiatrist: Dr Karin Myhill

III- Nursing team:

The nursing staff were divided into those that worked predominantly at the hospice (inpatient nurses) and those that were community based (community nurses). The community nurses cover either home visiting or support to the other hospitals within SALHN through a consultation liaison model. Within the nursing team there were also different levels of specialization ranging from enrolled and level 1 registered nurses, found in the inpatient unit to, Level 3 specialist nurses and Nurse Practitioners, found in the community team. The nurse specialization is quite different from that known to us in Portugal. Some practical differences that should be taken into account are for instance the fact that Nurse Practitioners can prescribe medication, order pathology tests and radiology in their field of expertise. The Nurse Practitioner title is protected under the Nursing regulation body in Australia and requires annual credentialing and demonstration of working within the defined scope of practice. The palliative care Nurse Practitioner is able to prescribe opioids as this fits within their defined scope of practice. Another striking feature is the very solid background theoretical knowledge they possess as well as a commitment to providing education and engaging in research as well.

Hospice based: The Hospice is a 15 bed inpatient unit which receives referrals from the community palliative care team as well as general practitioners, hospital specialist services and even patients and family members themselves.

The Hospice is the only 24 hour 7 day palliative care facility for SALHN. The community nurses all work a 5 day week whereas the inpatient nurses are rostered over 7 days.

There is a level 3 palliative care specialist nurse Ms Jane Cotton who is in charge of the Hospice. She is supported by 2 senior clinical nurses, Ms Sharenne Codrington and Ms Kate Vialls. Together they oversee and coordinate the inpatient nursing team which is made up of enrolled nurses, level 1 registered nurses and level 2 registered nurses.

Level 2 registered nurses in the inpatient unit are required to hold a post graduate qualification in palliative care as well as have demonstrated clinical experience.

Community oriented:

The community team is made up of the following specialist level 3 and level 4 registered nurses;

Triage of new referrals to the service – RN3 Joanne Wells (PhD)

Community Home Visits

Area 1 – RN3 Miranda Gibbs

Area 2 – RN3 Robyn Jezewski

Area 3 – RN3 Shawn Johnson

Area 4 – RN3 Patrick Cox

Nurse Practitioner – RN4 Karen Glaetzer (Master of NP)

Nurse Practitioner - RN4 Heather Broadbent (Master of NP)

Hospital Liaison

Flinders Medical Centre – RN3 Liz Reilly and RN3 Sarah Flynn

Noarlunga Hospital and Repatriation General Hospital – RN3 Dianne Anthony.

IV- **Research team:**

The research team consists of one part time Palliative Medicine Consultant as the head of department, as well as several research nurses.

Medical team: Prof Dr David Currow, Dr Peter Allcroft

Research nurses: Ms Aine Green, Ms Urska Cosic, Ms Vera Margitanovic

V- **Other members of staff:**

Pharmacist: Paul Tait

Complementary care nurse: Ms Margaret Thomson

Social workers: Ms Sarah Lawton community team and Ms Jenny Richards for the inpatient team.

Volunteers: The service has 120 volunteers on the program. The volunteer program employs a manager Ms Anne Friedman

Secretary: The service employs administration officers to support the clinicians.

Ms Ros Strapps manages the front reception desk and receives all referrals to the service that come from the community.

Ms Christine Waterson supports the inpatient unit with clerical services.

Ms Denise Alder provides support to the service Director (Ms Kate Swetenham) and is in charge of medical typing for outpatient clinics run by palliative medicine consultants.

Ms Ros Ramsay supports the bereavement service by providing administrative support in maintaining their data base, sending out bereavement information and preparing the memorial services.

C) SAPS' structure and activities

The work developed in SAPS is distributed along the following activities

I- Hospice "Daw House"

This facility has been shaped to meet the needs of what is expected of a true hospice, following the principles behind its roots. Thus, despite being an in-hospital facility it presents quite distinctive features in comparison to a standard ward, the main purpose of which is to make it seem more like a home and less like hospital. Several points contribute to make this shift in paradigm real. Firstly, the building design itself. The hospice is built in a U shape, with the rooms on the periphery. There are 7 individual rooms and 4 double rooms with a total of 15 beds. All the rooms have an opening to an outside garden, which is built in such a way as to allow the passage of a bed.

The central space is occupied by a living room with some kitchen facilities. The living room has a number of entertaining facilities such as a TV, a piano or several board games and puzzles that can be played on a common living room table. The kitchen has cooking

items which can serve the purpose of cooking or baking meals as well as keeping some required items close by.

The “clinical” environment is kept away from the first glance. Nonetheless, a closer look finds evidence of an open space with computers, a nursing room, a medication room and other support facilities.

Although this building is located in a hospital (RGH) it stands isolated from the other buildings reinforcing its role as something with clinical care but not quite a hospital.

Apart from the structural facilities *per se*, several points of methodology followed reinforce the hospice’s focus on Palliative Care. All patients (or substitute decision makers - SDM) are informed about this and its consequences. This includes the conscious decision of not having reanimation equipment in the Hospice. Like all Palliative Care patients, the actions that are or are not suitable depend more on the patient than on the label of “Palliative Care patient”. Thus being, if an acute event occurs and a previous discussion with the patient and family supports further intervention, the hospital Medical Emergency Team is called in to assist in dealing with the situation at hand. Another example of information often discussed with patients and/or SDMs is the non-obligation of using an antibiotic to fight an infection. This, of course, does not exclude its use, when deemed adequate.

The medical in-ward team, consists of a 6th year medical student, a resident and a registrar who see the patients on a daily basis. A consultant does rounds with them 3 days a week and is available daily for any major situation needing immediate action. The medical team is physically present until 17:00h and on call thereafter. The rotation for medical on call duty is made on a weekly basis. The medical team also includes a psychiatrist 3 days per week, who is available to discuss patients, direct management of any psychiatric issues within an end of life care context or participate in case discussion meetings to direct appropriate care.

Nursing staff are present round the clock 7 days per week, in shifts. Their presence and actions is the substance that holds the hospice together and allows fluidity and accuracy in the passage of information regarding inpatients.

All work developed within the realm of Palliative Care is multidisciplinary in essence with complementarity of knowledge, competences and approaches. Therefore, other professionals bring their expertise into action. Thusly, the aid of a physiotherapist, a nutritionist, a social worker, a spiritual therapist and pharmacist can be sought, when needed. Early identification of grief reactions can be addressed by the bereavement counsellor who has a social work background. Complementary care services are also available for the patients committed into the hospice. This last service is provided by a nurse specialized in this field of knowledge aiming often at general well-being but also, on occasions, called in to assist in symptom management as well. This service is often more directed at family care givers rather than patients themselves.

An art therapist is also available on site. She works with patients and families who express themselves in alternative ways, with the help of art, rather than conversation. This is particularly important when dealing with families with children. She is also in charge of a project that involves casting the hands of patients and family in plaster, a project called “legacy passage therapy”.

Another ongoing project available includes the availability of volunteer dogs that visit the patients. This proves to be a remarkable means of communication and entertainment especially amongst the least outspoken patients managing to find routes of communication where human-to-human interaction seems to have been insufficient. A resource that is available to inpatients and outpatients alike is the help of a team of volunteers trained to develop several specific tasks, often of a catharsis or ludic nature such as assisting in writing a personal biography of the patient to his/her descendants.

Daily routine starts at 8:30 am with a conjoined nursing staff and medical team meeting. Next, the medical observation of patients begins with a strong focus on the main points of distress for the patients, physical symptoms or otherwise. In the afternoon, the patients are discussed, often in set meetings with establishment of a working plan for each patient.

Patients are asked to rate their symptoms every day as part of the palliative care outcomes collaborative (PCOC) which is a quality improvement process to ensure care delivered is patient focused and directed by need as stated by the patient (Attachment 1).

The Phase system is used to categorize patients in all settings, but is reviewed daily within Daw House for all inpatients. Phase 1 relates to stable condition, phase 2 is an unstable condition, phase 3 the patient is deteriorating and this is expected within the course of the illness and phase 4 relates to a patient in the terminal stage of their illness. Inadequately controlled symptoms are usually the trigger which will lead to a change in the phase score. If a phase 2 score is given a multidisciplinary discussion is triggered where the patient is reviewed and reassessed.

Assessing this structure is sometimes not immediate as it is often in high-demand. As a consequence, there is a priority list on which potential candidates are placed. The occupancy rate was around 88% in 2013 (4).

II- Outpatient clinic

This activity is held in several distinctive ways:

First appointments: First appointments are held preferably at an early stage of disease. Indeed, clinically speaking there is no reason to be unprepared for death in certain chronic illnesses. Chronic illnesses form the backbone of the burden in disease in the 21st century developed world. Most of the patients are relatively asymptomatic and autonomous, at this stage. This appointment is therefore aimed at getting to know the patient from several points of view. This in turn, assists in predicting which kind of needs will need to be fulfilled most likely in this case and to immediately start acting on them. To that end, the patient is sequentially interview by a number of health related professionals. First, the Palliative Care Nurse practitioner holds an appointment aimed at devising strategies to deal with the physical symptoms, if they are present. This includes medication, planning procedures or just early referral to a member of the medical team. The patient and family then move on to see the social worker. This health professional holds a very active role here making sure that all the necessary social tools to assist with the foreseen functional decline are taken care of. In addition, the patient and family are informed of all the benefits they are entitled to. This included information to consider planning a living will or more day-to-day subjects such as taking care of

disabled parking space spots or subsidised taxi-vouchers to meet medical appointments. A social distress evaluation was also performed where the social worker applied the “distress thermometer” (Attachment 2). This tool enables the patient to be more explicit about the level of distress he/she is feeling as well as being able to pinpoint the exact reason(s) for that level of distress.

Next, both patient and family are separated into different interviews. Families are then interviewed by the Caregiver Network Facilitator to ascertain their level of distress as well as their adjustment mechanisms. Another point of the interview is to try to help families face the difficulties and find strategies to help them in doing so as well as assessing the need for respite. This meeting is also helpful to try to probe for some sensitive issues that are often not addressed or fully discussed while patients and families are in the same room.

The patient in turn is reviewed by the psycho oncology nurse where a mental health screen is undertaken using the Kessler K10 tool (Attachment 3) and they are assessed for coping and adjustment to their illness. Issues such as where they wish to be cared for when they are dying and ultimately where they want to die are discussed in this session.

This introductory clinic process takes around 90 minutes per patient and as such families are advised to come with enough time to spare.

Standard medical appointments: In the medical appointment acutely decompensated patients can be observed. Otherwise this is a place to regularly check up on patients. This appointment is held in the presence of a palliative care nurse that solves a lot of problems as they arise, on the spot. The approach is systematised in physical, psychological, social and spiritual issues, although often with a bigger emphasis on the physical component. All of the patients complete the Edmonton Symptom Assessment Scale (ESAS) before the appointment which guides the clinician along the first steps of the appointment. All new patients to a medical clinic are allocated 1 hour for the initial appointment. All subsequent visits are considered to be review appointments and as such are allocated 30 minutes.

Specialized medical appointments: There are also specialized appointments available for certain pathologies, usually directed at illnesses not pertaining to the field of Oncology as is the case with neurodegenerative diseases. In this context a motor neuron medical appointment is available.

III- Hospital consultation

Palliative Care is a much solicited specialty to provide advice on patients. Perhaps because there is still considerable difficulty in dealing with the change of paradigm from cure to incurable disease, a Palliative Care expert is often called in to help manage this process. Another reason is that the dialogue between medical specialties is quite more fruitful in Australia and, as such, different specialties are called in to give advice on how to manage a particular aspect of a clinical situation. As such, consultation with different hospital departments and patients, whether in RGH, FMC or NHS is frequent from ICU to Neurology, Nephrology, Internal Medicine, Pneumology and, of course, Oncology and Haematology. This observation often focuses on the communication of bad news or helping out with partially refractory symptom control. The most complex cases can be referred to Palliative Care through this option or even admitted into Hospice, if deemed necessary.

IV- Home visits

A significant proportion of the patients express their wish to remain at home for as long as possible in the course of their illness, including until the time of death which is accomplished in 28% of patients (4). Bearing this fact in mind it is no wonder that so much effort has been put into a community approach. Here, supportive care is delivered to patients no longer fit enough to attend appointments or with acute symptom decompensation. As in other aspects of SAPS functioning, the medical staff are usually called in as a second line option or for high complexity cases. Most of the follow-up is therefore performed by nursing staff. Given the geographical dispersion of the territory covered by SAPS careful planning was of the essence to allow the optimization of visits. A medical and nursing visit along 60 km of journey one way to the edge to their territorial

influence could render this team otherwise useless for the whole morning, if proper planning was not made.

In this context and as a way to optimize human resources an ongoing project at SAPS is the telehealth project where there is an attempt to conduct more regular check-ups on patients via a video web conference.

Whereas some cases can present with significant complexity even in the home environment, an effort is being developed to identify an essential set of medicines regularly used in the end-of-life context as a means to make the bridge between what is prescribed and what pharmacies have readily available on their shelves. As such there is a considerable preference towards prescribing metoclopramide, butilscolamine, haloperidol, clonazepam and morphine, in this setting, for the required symptoms (5).

V- On call duty

From 5:00 pm to 8:30 am there is a member of the nursing team that is on call for any major problem arising with patients, not currently committed into the hospice or other hospital departments. Patients and families are asked to call only if they think the problem is not manageable until morning and to delay more day-to-day questions for their respective attributed nurses to take care of, on day time schedule. Often this assists patients with the decision to resort to a hospital emergency department or to deter their visit if the problem is only symptom control and they have the necessary medication at home. There is also a doctor on call for that support, which the nurse can use for more complex cases, as well as to support anything that might be urgently needed in the hospice during night time. Also, any admittance to the hospice during the night time or weekend has to go through the approval of the on-call medical doctor.

VI- Research directed activity

SAPS is closely connected with the Palliative Care Clinical Collaborative Studies (PaCCCS) group and follows the premise of “why don’t we experiment on our palliative care patients and conduct good clinical research instead?” drawing attention to the

deleterious effects that the taboos surrounding research in Palliative Care can have. This is a very active department and, at any given time, there are at several simultaneously ongoing clinical studies, many of which are conducted as multicentre studies across Australia. The emphasis of research falls on the symptomatic control of dyspnoea. It is one of the most accomplished and productive departments in Palliative Care research, worldwide.

The nurses contact the patients for follow-up and for direct inclusion into the trials. All phases of a clinical trial can be observed in PaCCCS from recruitment to data handling, to publication.

Work is also done in collaboration with other sites to address some basic science issues. Also there are several ongoing qualitative studies as well. All in all, the quality of the research conducted is high and covering a lot of facets of what it is and what it actually means to provide “Palliative Care”.

VII- Clinical meetings

Psychosocial meetings:

This meeting includes the participation of an element of each professional group as well as the psychiatrist and the medical doctors conducting ward rounds on that day. Although all in-hospice patients are briefly discussed here, the focus falls on those in which psychosocial or spiritual problems seem to be either more relevant or complex. These meetings are held weekly.

Multidisciplinary meetings:

This meeting includes both medical and nursing staff alike. In it, the most problematic cases are discussed whether in hospice, out-patients or committed into other hospital facilities. The goals of discussion are multiple. If, on one hand, ideas were gathered from different professionals towards solving a particularly complex problem on the other hand it also enables all professionals working at SAPS to be advised of more complex cases beforehand. This proactive approach is also regarded as a means to promote some

of the psychosocial relevant actions and initiate the gathering of social resources in due time. All terminal cases and deaths are also discussed. This meeting is held weekly.

VIII- Scientific meetings

Informal sessions (Weekly team education session)

The themes approached during these sessions are of a practical nature such as information sessions on how to complete the new advanced care directives forms, the referral processes to other community agencies, or the sharing of results from the latest research study.

Hospital Grand Rounds:

These meetings are aimed at a broader audience including all doctors, nurses, students and all those willing to participate. They include the presentation of a topic in particular, for instance, revision of cases of a given pathology in that hospital. Alternatively the theme could be purely theoretical. It was not specifically aimed at Palliative Care although the topics were often indirectly related. This session was held every fortnight.

Medical Journal Club:

This meeting was held weekly amongst the medical staff, with or without the presence of the pharmacist and the nurse practitioners. The meeting encompassed a review over Palliative Care specific topics or the presentation of several original papers. There is ample participation from all members making it more like a constructive conversation and less like a presentation, at times.

Nursing Journal Club:

This meeting is held every fortnight amongst nurses. The same principles followed by the medical journal club apply here albeit at more nursing oriented themes. Again, the participation of the pharmacist is common.

Clinical trial update meeting:

The prime motive of this meeting is to remind the nursing and medical staff of ongoing clinical trials in the area of Palliative Care, currently ongoing or recruiting at the centre. In this meeting, several ongoing clinical trials are reviewed and a brief update is made. Furthermore, all new publications in which SAPS is included are mentioned as well clinical trial closures. This meeting is accompanied by morning tea provided by the research team to promote clinicians' and nurses' attendance. This meeting is held fortnightly.

3- Internship description

A) Objectives and competences proposed

The objectives and competences to be acquired proposed were developed in agreement to what could be obtained from an internship at SAPS. However, being a practical internship and not an investigational work, an effort was made to keep them purposely broad. The goal was precisely to come in contact with a wide variety of settings and valid approaches to be made to Palliative Care patients and families and not to focus on one particular aspect of care.

I- Per activity developed

The following activities were made available for us to accompany at SAPS, on a regular and scheduled basis, as defined in our internship project proposal (table 1).

Table 1 - Time distribution per activity developed

	Hours per week	Total amount of hours
Outpatient clinic	8	72
Palliative Care consultancy	8	72
Hospice	4	36
Home visits	4	36
Multidisciplinary and psychosocial meetings	4	36
Research	12	108
Report development	-----	100

II- Per competence to be acquired

Again, the competences sought after seek to cover a wide range of topics bearing in mind my future work as an oncologist, particularly in a health system with an, as of yet, underdeveloped Palliative Care network . Thus, the competences to be acquired were described as follows.

Contact with challenging situations in terms of symptom control and their approach particularly in the areas of pain control, dyspnoea and gastro-intestinal disturbances, amongst others: minimum 40 patients, regardless of the setting. Symptom control is understood by many as a core element in Palliative Care and is indeed considered a central aspect in this area (6,7).

Contact with situations in which bad news were communicated and improvement of the techniques used: minimum of 10 patients in clinical context or multidisciplinary meeting. Several studies highlighting the importance of structuring this sort of conversation have been published in recent years, making this item a mandatory reference in some health professions' pre-graduate *curricula* already (8,9).

Contact with situations of psychological, social and spiritual suffering and improvement of its approach: minimum of 10 patients in clinical context or multidisciplinary meeting. The prevalence of this kind of suffering is high amongst Palliative Care patients and thus there is a need to acquire training in dealing with these matters. Plus, the concept of "total symptom" closely knits this objective with symptom management as a definitive must to provide good quality care and relief of suffering (10–14).

Contact with an integrated Palliative Care system with recovery of ideas for future projects, as comparison and idea gathering are important to gain insight of where to go next (15–20).

Production of a study on the symptomatic control of dyspnoea. Palliative Care has been defined as an area of importance that, nonetheless, frequently acts on absence of evidence based data. This paucity of data stems mainly from ethical issues concerning research on the dying patient. However, research in this field is not incompatible with sound ethical judgement and as such should be undertaken undergone (21–27).

B) Descriptive and critical analysis of the activities developed

I- In Hospice

i- Population characterization

During the internship period I had the chance to follow 29 patients committed to the Hospice. As can be seen in Table 2, the gender distribution was quite balanced with thirteen patients (45%) belonging to the male gender and 16 (55%) to the female gender.

The mean age found was 71 years (Q25,Q75: 54,5-79,5%). When comparing to the mean life expectancy in Australia (28) this could be thought of as a relatively young age. Perhaps the existence of a Gerontology ward could be partially accounted for in that difference. Also of note, often younger patients are known to present more of a challenge in Palliative Care, particularly when one includes psychosocial issues as well as a bigger physiologic reserve that will enable terminal situations to last longer than in their older age counterparts. In addition, it is less common for younger patients to have already in place social support as is the case with some older people already living in assisted residences.

At a functional level, there was a significant compromise of function as assessed by the mean Australian Karnovsky Performance Scale (aKPS) status with an average value of 36,6 as can be observed in Table 2 and, more explicitly in Figure 1. The aKPS has been adapted from the standard Karnovsky Performance Scale to better suit the Australian Population (29).

This scale corresponds to the Australian adaptation of the well-known Karnovsky Performance Scale. Outcome analysis was performed only on the patients that had separated from the hospice at the end of the internship (n=16). Under this premise, 14 (87,5%) out of those 16 patients died in Hospice. Only 2 patients (12,5%) were discharged home. Although this corresponds to a high death rate, which is not the sole purpose of a hospice, the fact that the internship occurred in the peak of winter, where the health services are more pressed, may have contributed to this fact. In addition,

often some priority will be given to patients approaching the terminal phase which will positively influence the hospice death rate.

Table 2 – In hospice patient characterization

Summary table of in hospice patients	
Gender (n=29)	N (%)
M	13 (45%)
F	16 (55%)
Age (n=29)	
Median	71
Q25	54,5
Q75	79,5
aKPS (n=29)	
Mean	36,6
Standard deviation	18,6
Number of days in hospice (n=16)	
Median	14
Q25	5,25
Q75	20,5
Hospice discharge (n=16)	N (%)
Death	14 (87,5%)
Home	2 (12,5%)

The median number of days in hospice was 14 days (Q25,Q75 5,25;20,5), generally a bit longer than a regular medical ward which may be related to the more explicit inclusion of social criteria as a reason for committing patients as well as a lesser focus on acute patients.

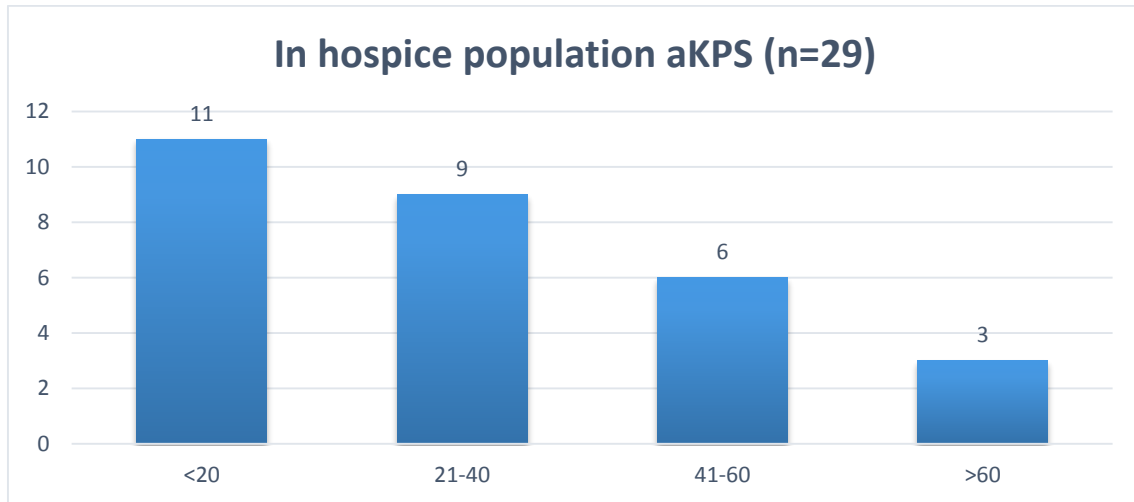


Figure 1 – Australian Karnovsky Performance Scale distribution in in-hospice patients

ii- Main diagnosis characterization

Oncologic diagnosis were still the predominant group of diseases involved. The reasons for that are multiple. These cases can be quite complex from the symptom management point of view. In addition, generally speaking the functional decline and life expectancy are usually more predictive in oncologic situations than otherwise which enables Palliative Care to be more systematically considered. Also, historically speaking, Palliative Care stemmed from caring for Oncologic patients and then expanded into other areas. Thus, it is possible that Oncologists may be more prone to consider Palliative Care than other medical specialties. The group of diagnosis encountered can be seen in Table 3. Here it is worth picking out the relatively high incidence of Melanomas found (10,3%), perhaps not so surprising when one considers the Australian context. Melanoma is thus found alongside the “usual suspects” in terms of prevalence and gravity.

Amongst the in-hospice patients I would like to highlight 2 cases that I found particularly interesting.

The first case belonged to a man, 40 years of age, phototype I, with Melanoma. This patient was diagnosed late as the main complaint was vague neuro-psychiatric manifestations upon which a CT scan was performed for diagnosis of brain metastasis, but not until late in disease. The fact that the original manifestations were neuro-

psychiatric, with no attributable disease to be “blamed for” made the psychosocial management of this patient, already difficult, even harder.

Table 3 – Main diagnosis in committed patients

Main diagnosis	N=29	%
Oncologic	27	93,1
Prostate Adenocarcinoma	4	13,8
Breast Cancer	3	10,3
Melanoma	3	10,3
Non Small Cell Lung Cancer	3	10,3
Pancreas Adenocarcinoma	2	6,9
Oesophageal Adenocarcinoma	2	6,9
Glioblastoma	2	6,9
Ovarian Adenocarcinoma	2	6,9
Endometrial Adenocarcinoma	1	3,4
Cervix Carcinoma	1	3,4
Head and Neck Carcinoma	1	3,4
Mesothelioma	1	3,4
Small Cell Lung Cancer	1	3,4
Multiple Myeloma	1	3,4
Neurological diseases	1	3,4
Lateral Amyotrophic Sclerosis	1	3,4
Genito-urinary diseases	1	3,4
Diabetic Nephropathy with end-stage renal disease	1	3,4

Another case that called my attention was that of a 67 year old man with non small cell lung cancer. This case was particularly interesting by the various settings in which Palliative Care was provided for this patient, with SAPS. My first contact with this patient was at the Oncology ward, in the first observation by a Palliative Care consultant. The patient was committed into this ward and had not responded to chemotherapy treatments. The patient presented with difficult to manage thoracic pain which was eventually controlled and the patient discharged home. Later on, I was able to observe

this patient in the outpatient clinic. The patient presented with a good performance status with complaints of a lumbar pain. Due to an acute exacerbation of the pain pattern and opioid induced constipation a home visit was required which I was able to attend to. At this time, the patient presented with a performance status deterioration, increased pain and some ideas seemed a bit difficult to grasp. As these clinical issues further deteriorated management was no longer possible at home and the patient was committed into the hospice. There he was started on methadone. While performing a thorough evaluation of the patient a persecution based delirium was noticed and conservatively managed. The patient eventually died at the hospice.

iii- Main reason for commitment into the ward

As the focus of Palliative Care resides more on symptom management, the reasons for committing a patient into the hospice are necessarily different from those normally present at regular acute medical ward, (Table 4).

Table 4 – Hospice admission reason

Hospice admission reason	N=40	%
End-of-life	10	25
Pain	10	25
Delirium	6	15
Anxiety	2	5
Psychosocial issues	2	5
Nosocomial Pneumonia	2	5
Dyspnoea	1	2,5
Stridor	1	2,5
Melena	1	2,5
Dysphagia	1	2,5
Focal neurologic signs	1	2,5
Epistaxis	1	2,5
Vertebral Bone Fracture	1	2,5
Nausea	1	2,5

For this purpose I considered more than one possible reason for admittance into the hospice per patient. This includes both symptom control as well as psychosocial management. Admitting a patient over a given symptom does not however always translate into trying to resolve that symptom at all costs. A good example of that is delirium which, at the end of life is only reversible in around 40% of patients (30) and, as such, a conservative management approach is often taken. This is in sharp contrast with symptoms such as pain or dyspnoea where the symptom management is often more aggressive.

iv- Critical analysis

In my rotation, as previously stated, I accompanied the rest of the medical staff every Tuesday for 4 weeks. I must admit that, coming from a very hospital-based medicine practice, I initially feared that this would be too short. Nonetheless, one of the most positive aspects to gain from this experience was precisely the coordination between several aspects of care, namely those that avoid having to resort to committing patients to a ward. Plus, it enabled me to already know patients committed into the hospice from other settings which further contributed to get to think of the patient as a whole, rather than the very narrow point of view of the person as an in-ward patient, detached from most of the things that make this patient unique. Although I was not able to directly ask for blood tests or other complementary exams as well prescribing medication, I was able to thoroughly discuss treatment options before they were made which was just as enriching.

In terms of fulfilling the objectives per competence to be acquired this activity allowed me to come in contact with the most difficult cases of symptom management: those that had to actually be committed to control. On the other hand, as many patients are committed as their general performance status starts to decay the other competences also found room to develop. Indeed functional decline often works like a Pandora box in that once this is overtly self-evident a lot of the other psychosocial issues also come into play. As such, work into dealing with psychological, social and spiritual suffering was very much a key note as well in this setting. To the extent that this was systematically evaluated and acted on rather than just reacting “on demand”. Although most patients

were already informed of their general prognosis, there is room here for the communication of bad news as well as often patients will wonder if they will still return to a performance status that enables them to do some activities, if they will ever leave the hospice again, etc... These issues are then addressed in a structured way.

In addition, some of the clinical meetings mentioned before take place in a building right by the hospice and as such attending these meetings was facilitated by being at the hospice.

II- Outpatient clinic

i- Population characterization

During my internship I was able to follow 33 patients in outpatient setting be it in first Palliative Care appointments, follow-up medical appointments and specific Motor Neuron Disease appointments. In a very brief manner, the patient gender distribution was balanced. Age-wise the distribution was very similar to that described for patients committed into the hospice with a mean age of 71 (Q25,Q75: 60,5; 82 years), as explained in Table 5. From the functional status perspective the values are not presented as they were quite uneven, although with a higher Karnovsky Performance Score than the in hospice patients.

Table 5 – Outpatient characterization

Gender	N
M	16
F	17
Total	33
Age	
Median	71
Q25	62,5
Q75	81

ii- Main diagnosis characterization

In as far as main diagnosis are concerned, again, as expected, a predominance of oncological diagnosis was found. At this stage, I would like to point out the relative importance of non-small cell lung cancer, representing almost 20% of the diagnosis, in consonance with what would be expected when analysing the morbimortality of oncologic diseases (31). However, a closer look, reveals some diagnosis that were not found in hospice. This included diffuse systemic sclerosis, COPD (Chronic Obstructive Pulmonary Disease) and Lateral Amyotrophic Sclerosis. Table 6 lists the diagnosis encountered.

Table 6 – Outpatient main diagnosis

Main diagnosis	N=33	%
Non Small Cell Lung Cancer	6	18,2
Lateral Amyotrophic Sclerosis	4	12,1
Gastric Adenocarcinoma	2	6,1
Neuroendocrine Tumour	2	6,1
Oesophageal Adenocarcinoma	2	6,1
Colorectal Adenocarcinoma	2	6,1
Head and Neck Carcinoma	2	6,1
Mesothelioma	1	3,0
Lymphomatose Granulomatosis	1	3,0
Breast Cancer	1	3,0
Diffuse Systemic Sclerosis	1	3,0
Cervix Cancer	1	3,0
Prostate Adenocarcinoma	1	3,0
COPD	1	3,0
Interstitial Nephritis	1	3,0
Gastro Intestinal Stromal Tumour	1	3,0
Myelodysplasic Syndrome	1	3,0
Ovarian Adenocarcinoma	1	3,0
Mantle Cell Lymphoma	1	3,0
Pancoast Tumour	1	3,0

In this setting I would like to point out a few cases that impressed me the most. The first, a patient with GIST (Gastro Intestinal Stromal Tumour) who presented after several surgeries with a complex pain management case. I remember being struck by both his level of knowledge of the disease as well as the therapeutic scheme involved. Of note, his level of deeper understanding of where his illness was progressing to was impressive. All of this made all discussions that much easier. In the field of benign pathologies I would point out the case of a diffuse systemic sclerosis patient that impressed me with her remarkable attitude of cooperation with clinical trials both at the level of disease specific drugs as well as in the Palliative Care setting.

iii- Main reason for observation

I followed the same methodology to establish the main reason for observation in the outpatient setting, that is, one patient could have more than one reason per appointment. As can be observed in Table 7 pain control still remains the main reason for the appointment. Although several experts in pain control were available these were usually left for more severe cases that required specialized interventions such as peripheral nerve blockade, intrathecal analgesia or another technique of sorts. In the more pharmacological approach all the consultants and, indeed nurses as well, seemed to master pain management approach in a very solid way.

Also to be observed in Table 7 is the number of Palliative Care appointments made in asymptomatic patients, which constitutes the second reason for observation. This is a valid approach if one considers the predictability behind some of these diseases in which it makes perfect sense to consider Palliative Care appointments from a very early stage onwards. For some of these patients Palliative Care will indeed be required in the short run. It thus makes perfect sense that by the time that occurs the patient is already familiarized with the Palliative Care team and speciality. This in turn helps to dispel fears that this specialty is restricted to patients in the terminal stage of disease. It also shows how some of the patients were stable enough with their medication to live their lives with an optimized, even if not perfect, functional status.

Table 7 – Main reason for the appointment

Main reason for the appointment	N=49	%
Pain	9	18,4
General Follow-up	8	16,3
Asthenia	7	14,3
Nausea	6	12,2
Dyspnoea	4	8,2
Depression	2	4,1
Malignant Obstruction	2	4,1
Xerostomia	1	2,0
Night Sweats	1	2,0
Cough	1	2,0
Anorexia	1	2,0
Dysphagia	1	2,0
Sialorrhoea	1	2,0
Ataxia	1	2,0
Frontal-temporal Dementia	1	2,0
Rectal Fistula	1	2,0
Constipation	1	2,0
Diarrhoea	1	2,0

Asthenia was also a frequent reason for the appointment although at this level the therapeutical options available are indeed scarce. Thus, when this symptom proved to be significant the role of the Palliative consultant was more psychosocial referring to techniques to adjust to asthenia, rather than pharmacologic options to reverse it. From my observation it was also evident that Palliative consultants at SAPS did not think amphetamine approved derivatives to be very useful in this setting, although often a limited approach with corticoid was sometimes attempted.

iv- Critical analysis

As for the first appointments they impressed me by how early detection of problems was possible before they became critical. Social issues could then be adequately

addressed perhaps before that patient needed to be admitted into an acute hospital and thus the amount of what we call “social cases” was quite lower. This strategy proved fruitful both for patients and for the system as a whole in terms of saving time and resources. These appointments are purposely held afar from the hospice or any other hospital as a way to show patients that starting their Palliative Care follow-up is not synonymous with rapid decay and ensuing death. I assisted these appointments for 4 mornings.

The follow-up appointments were a privileged time of discussion with consultants on treatment options and how to best manage patients where the medical control is not so tight (often these patients would be observed only monthly). I frequented these appointments one morning per week of internship.

As for the motor neuron disease appointments there are also gains to be had. It is a disease with which I was not so familiar with. Plus, as an oncologist registrar it is not something I have much contact with. In that way, this was a good way to see how Palliative Care could be applied to non-oncologic diseases in a systematic fashion. I watched this appointment for 3 afternoons during the internship.

Although the cultural dimension is not explicitly mentioned in the objectives of competences to acquire it hardly goes unnoticed. Indeed, perhaps the most striking feature of outpatient appointments was the cultural difference. Most patients were well informed of their disease, treatment options and their consequences as well a general acceptance of the progress of their disease. This enabled truly informed discussions to occur rather than tellings in the hands of the medical staff. Patient wishes and preferences could thus truly be acknowledged, as they were informed ones. In addition I found a level of acceptance of death unusual to my experience as medical doctor in Portugal. This had multiple benefits not the least of which was that the Palliative Care experience was not at all considered depressing but rather a space for discussion and improvement of the quality of life in remaining time. Perhaps the outpatient clinic was the place in which these features were more evident.

As for the rest of the objectives defined, the outpatient clinic was a good way to systematize symptom control management. Psychosocial issues, which did not seem so

evident in the hospice were still held in account with a thorough evaluation right from the first appointment, as previously described.

III- Palliative Care consultancy

i- Population characterization

I followed a Palliative Care consultant, registrar or nurse in consultation service throughout FMC or NHS. Again the population observed was gender balanced and the median age was 72 (Q25,Q75: 59; 86 years) as present in Table 8

Table 8 – Consultation service patient characterization

Gender	N
M	12
F	13
Total	25
Age	
Median	72
Q25	59
Q75	86

ii- Main diagnosis characterization

In this case, oncologic diagnosis while still the predominant group of diagnosis referred to Palliative Care consultation, are not so preponderant. In fact, there is a bigger share of patients with circulatory diseases such as stroke or heart failure. Also, advanced dementia was a reason for consultation. In these specified cases a discussion with the main caregiver was made to plan for treatment objectives and limitations. In both cases a conclusion was reached that the treatment goals should be aimed at comfort only. This did not include nasogastric intubation and feeding or establishing an intravenous access for hydration, for instance unless there was a good reason for doing so. Table 9 shows the list of diagnosis observed.

Table 9 – Main diagnosis of the patients seen while in consultation service

Main diagnosis	N=25	%
Oncologic	N=16	64
Non Small Cell Lung Cancer	3	12
Pancreatic Adenocarcinoma	2	8
Vulvae Carcinoma	1	4
Glioblastoma	1	4
Multiple Myeloma	1	4
Tonsil Carcinoma	1	4
Bladder Carcinoma	1	4
Acute Lymphoblastic Leukaemia	1	4
Prostate Adenocarcinoma	1	4
Hepatocellular Carcinoma	1	4
Breast Cancer	1	4
Colorectal Adenocarcinoma	1	4
Unknown Origin Carcinoma	1	4
Circulatory System	N=4	16
Ischemic Stroke	2	8
Sub Dural Haematoma	1	4
Restrictive Miocardiopathy	1	4
Mental and Behavioural Diseases		
Alzheimer's Disease	2	8
Genito-Urinary Diseases		
Chronic Renal Disease	1	4
Respiratory System		
Advanced Pulmonary Fibrosis	1	4
Digestive System		
Intestinal bowel perforation without surgical indication	1	4

iii- Main reason for observation

The reasons for requiring Palliative Care consultation are listed in Table 10. Situations like difficult symptom management stand out. Usually a first attempt would already

have been made to solve these symptoms. Such symptoms included delirium, pain and dyspnoea in patients with advanced disease.

Table 10 – Main reason for requesting Palliative Care consultancy

Main reason for Palliative Care request	N=35	%
Delirium	5	14,3
Pain	4	11,4
Dyspnoea	4	11,4
Initial Referral	4	11,4
End-of-life	2	5,7
Oedema	2	5,7
Recurrent Pneumonias	2	5,7
Asthenia	2	5,7
Nausea	2	5,7
Refractory Vomiting	2	5,7
Constipation	1	2,9
Dysphagia	1	2,9
Diarrhoea	1	2,9
Intestinal Occlusion	1	2,9
Jaundice	1	2,9
Depression	1	2,9

iv- Critical analysis

Although not always explicit, another reason for requiring Palliative Care consultation was not only to have the initial discussion of therapeutic limitation but also end-of-life discussions with caregivers and other family members. In this setting I realized that Palliative Care team members are viewed not only as symptom control experts but also as communication experts. A view shared across the medical spectrum but not always explicitly written down on referral forms. As such, I think that being able to follow this activity was quite productive as a tool to fulfil the proposed objectives namely symptom control improvement, bad news communication and psychosocial symptom development.

As for the objective of learning the structure and functioning of an integrated Palliative Care system, despite not referring it after each category, this was fulfilled by observing the integration of every aspect of care such that optimizing this objective requires observing the system at work from as many angles as possible. The consultation service was, therefore an important part of this as it enabled me to see how different medical specialties in the hospital system interact and how they rely on Palliative Care.

I attended the consultation service a day per week.

IV- Home visits

I followed 5 patients in the home setting. A brief description of these patients is found in Table 11. As can be seen all but one patient had oncologic diseases and the reasons for home visits were not unlike those that were observed in the afore mentioned settings. Some of these patients were visited on multiple occasions.

Table 11 – Characterization of the patients followed in home visits

Gender	Age	Main diagnosis	Palliative Care Request
F	64	Non Small Cell Lung Cancer	Pain, constipation
F	69	Non Small Cell Lung Cancer	Asthenia, nausea
M	62	Vulva Melanoma	End-of-life care
M	54	Breast Cancer	Pain
M	63	Intrathecal Benign Tumour	Pain, agitation

I think it is worth mentioning the difference between practicing in this setting and practicing in the hospital setting with which I am more familiar. I felt privileged to be able to assist people in their homes and watch from this perspective how a family in their intimacy deals with the dying process. All these patients had quite low Functional Performance Scores although not all of them were terminal as was the case of patient with a benign intrathecal slowly growing tumour which, nonetheless, rendered him unfit for daily activities. This patient presented with a very difficult to manage chronic pain

condition. However this was not considered a reason for resorting to a hospital facility. And indeed, with the necessary support, it shouldn't be.

Also of note mentioning is the high degree of symptom management achieved in this setting which further contributed to the trust that people deposited in the Palliative Care teams and which was fundamental in avoiding that people resort to an Emergency Room service for symptom control.

A recent pooled analysis of patients and carers' expectations in community Palliative Care service provision has placed both trust in the competence of Palliative Care teams and their easy access at the heart of what makes someone opt for this kind of follow-up (oral communication at the 2015 Spring Oncology meeting, Évora, Portugal, not yet published). SAPS seemed to be able to provide both.

I attended this activity in the spaces left between the other activities. As previously explained, given the geographical distances involved this was an activity worth planning in advance as one trip could mean that other activities would be hard to fulfil during that day.

V- Multidisciplinary and psychosocial meetings

I attended the multidisciplinary meeting on a weekly basis. As for the psychosocial meetings I attended them on a weekly basis on the weeks where I was in hospice. This was a great way to acquire knowledge from every perspective from the community nurses to the psychiatrist. It was also a good way to observe the several components of SAPS work together as strategies and tips ebbed and flowed in the discussion.

VI- Research activity

As previously mentioned this was an important objective in this internship making it truly a research and clinical internship, as can be seen in the number of hours allocated to the research project which was quite relevant. This activity was developed under the guidance of Prof Dr David Currow.

The main focus of research was the symptomatic relief of dyspnoea. Indeed this is a common symptom in late disease, in several pathologies (32) and our strategies to deal with dyspnoea are, at the moment unsatisfactory. Plus there hasn't been as many progresses here as in other areas of symptom control such as pain management.

One of the therapeutical agents of choice is opioid therapy, namely with Morphine (33–36). However, even if the clinical effectiveness of Morphine therapy has been studied in the relief of chronic refractory breathlessness (37), patient preference has not. Patient preference may be important to reveal undisclosed or difficult to measure benefits or downsides of opioid therapy (38). With this purpose in mind I helped to conduct a pooled analysis of the only three double blind, cross-over, randomized clinical trials (RCTs) available that measured morphine preference in the context of dyspnoea relief (34–36). This work covered patients with chronic refractory dyspnoea on account of COPD or heart failure.

To conclude this analysis, background peripheral work was also conducted on some basic notions of statistics, functional scales of patients with dyspnoea, chronic therapeutic patient preference and qualitative dyspnoea analysis, amongst others.

Out of this work, some interesting conclusions were reached that put into question the validity of measuring dyspnoea simply as an intensity scale or the importance of measuring net patient value of adding a therapy with side effects vs maintaining a known side effect.

This work was done in close collaboration with my colleague in the internship Dr Diana Ferreira. Also other authors, namely those responsible for the RCTs previously conducted, the university statistician Dr Stephen Quinn and, of course, Prof Dr David Currow were of paramount importance in being able to design and conduct this analysis.

I had the opportunity to present the findings of this work, together with Dr Diana Ferreira, in a medical Journal Club meeting at SAPS.

This work has been submitted to “The Journal of Pain and Symptom Management”. At the present time I await reviewer comments (Attachment 4).

VII- Brief overview of the Royal Melbourne Hospital Palliative Care Department

During the last week of internship I had the opportunity to visit the Palliative Care department associated with the Royal Melbourne Hospital. This visit was not only suggested but also facilitated by my co-tutor Prof Dr David Currow and its purpose was to gain a wider view of Palliative Care in the Australian setting, rather than just focusing on one example. Melbourne is located in a different state (Victoria), circa 800 km away from Adelaide.

This was a very fruitful experience as there were a lot of differences between the services and the population served. Contrary to the expectation that things would be more or less similar across the board in Australia. The differences begin even before one enters the department. Melbourne is quite a more multicultural state. A hint of that is perceived just by the mere observation of the hustle and bustle that covers the streets as well as activities and the general way of thinking. Other elements are strikingly different as well such as the climate or the sheer size of Melbourne. Indeed, unlike Adelaide, Melbourne is a huge metropolis that definitely has a big city feeling to it, for good or worse.

It is in this context that the Royal Melbourne Hospital Palliative Care department is set. The Palliative Care department here is more hospital based. There is a ward as well but it is integrated in a hospital complex of quite big dimensions and as such it seems to follow more of a traditional sense of hospital care and hospital integrated routines. This ward contains 12 Palliative Care designated beds. There is also a hospital consultancy service, outpatient clinic and home visits available. During this week under the tutorship of the head of department Dr Brian Le, I was able to go through each of these components of care, even if only briefly. I will describe, but not quantify this experience as the little time involved was not significant to amount to a quantitative experience worth measuring and describing in statistical terms. The conclusions reached are naturally limited in this context.

Melbourne is a much bigger city. Getting around can be made more difficult by traffic, in comparison with Adelaide. This has repercussions on the home visit planning, as well as visits to nursing homes. Plus as previously said, the scope of this department is more

hospital based. As such, while there is indeed a liaison service with the community, its expression is rather modest.

The clinical staff was less numerous which also made the task more difficult. Furthermore, unlike Adelaide with its majority of Anglo-Saxon descendants, Melbourne is very multicultural with a large Italian, Greek and Asian influence. This also made it more difficult for the clinical staff to adapt to different ways of viewing and dealing with the process of dying, especially in the case of Mediterranean cultures such as patients and families of Greek and Italian origin which seemed more prone to hiding information from patients (and depositing it on families) thus making it more difficult to have serious and informed end-of-life discussions.

Amongst the patients observed, on a community level I would point out a case of an elderly man in a nursing home, progressively more asthenic with both dementia and anaemia. After a discussion with the family a therapeutic plan was established to try a single transfusion and evaluate its effect on the asthenia. If such an intervention succeeded in improving the asthenia eventually it could be repeated or the source of the anaemia further investigated. Otherwise the transfusion would not be repeated. This case provided an evidence of, despite not focusing on the community follow-up, that this service still strived to at least coordinate the care of its patients with the available community carers.

At the hospital level I would stand out the case of a patient of Greek origin in her end of life. This patient presented as a particularly difficult case as the family (children) not only insisted on not telling the patient of her disease but were also very outspoken about not accepting her death with numerous references to law suits and a very aggressive tone towards the clinical staff with accusations of inefficiency and even negligence. This however provided an opportunity to observe how the communication with this family was carefully planned and held. The patient died on my last day of practice with the family insisting on a paracentesis in the last hours of life as they focused on this technical gesture as a way to possibly save their relative. As I left Melbourne this patient had not come to terms with the departure of their relative and, as such, this family was discussed in a clinical meeting with appropriate referencing to bereavement services, if they so accepted.

Also noteworthy is the apparent lack of ongoing research, to the best of my knowledge. However, the service provides important medical formation for interns, residents and registrars. These attributes relate to how Palliative Care services are organized and distributed across Australia, divided in 3 categories: 1st, 2nd and 3rd resource levels of Palliative Care services(39(40). The lack of focus on research and the underdevelopment of the community setting characterize this department as a specialist Palliative Care level resource 2. A head-to-head comparison is thus not directly possible as SAPS is considered a specialist Palliative Care level resource 3 department containing all the functions ascribed to a Palliative Care service. However a short comparison of the available functions at each site is presented on Table 12.

Table 12 – Comparison of the services provided by SAPS vs the Royal Melbourne Hospital Palliative Care Service

Service	SAPS	Royal Melbourne Hospital
Home visits	Yes	No
Hospital Consultation	Yes	Yes
Inpatient Unit	Yes	Yes
Research Unit	Yes	No
Affiliated with a university	Yes	No

The fact that the focus was more hospital based and with less available staff contributed to acting more when facing a problem rather than being able to act in its prevention.

Nonetheless, I could observe how, even so, the background level of formation was excellent. Here I had the opportunity to assist how medical residents prepare for their medical practical exams and how Palliative Care is considered an important or even essential component of that post-graduate formation.

4- Professional practice implications

As my medical background could not be legally recognized to be able to practice independently in Australia the internship was purely observational. This means that I was not able to perform any invasive technique or sign any prescription or exam request. However, I considered none of the above as elements that hindered my learning since not many invasive techniques are performed in Palliative Care patients and that I could discuss all patients with the attending health professional who would then write the prescription or exam request. Curiously, as communicating with the patients is still considered purely observational there was ample room to perform this which, as previously explained, was of great importance.

As a practicing clinician working in Oncology in a Portuguese large cancer centre the professional implications are manifold.

These implications were centred on what I had previously defined as objectives. Therefore, good practical work on symptom control was of essence and perhaps the kick-off to the other levels proposed. Symptom control was considered the essence I think perhaps because traditionally it is often regarded as the main role of the medical staff (6,7,41,42). Thus, perhaps this is where I felt I would be more called in to help (which does happen nowadays). Since this is the case I felt it was mandatory to master symptom control measures for at least the most common symptoms. At SAPS I found that all health professionals from doctors to nurses had a profound knowledge of symptom control pharmacologic and non-pharmacologic options.

As for the psychosocial objectives, indeed, despite the cultural differences involved I feel that my communications skills have been greatly enhanced by being able to observe SAPS' professionals at work. This is true on every aspect but perhaps even more so when the communication of bad news is taken into account. As we were rightfully taught at the postgraduate studies there is a need to dispel the myths surrounding the point that good communication skills are innate and spontaneous. Indeed, perhaps precisely because that myth exists, extra work is needed to practice and improve communication skills (43,44). At present, my work as an Oncology resident is precisely the management of patients in a large Oncology ward. This often includes normal treatment

complications. However it is safe to say that a significant proportion of those whose oncologic disease is not of successful curative intent will be sooner or later committed into the ward that I work in. Thus, good symptom control and good communication skills are skills that I have to resort to on a daily basis. Indeed watching bad news communication in SAPS has enabled me to use these techniques, with the necessary adaptations. And it has been rewarding to see that it can be done with very encouraging results. This has been perhaps one of the greatest teachings. That communicating bad news can actually prove to be a very useful element to form a bond between patient and health professional(45) and that there are quite a lot of patients out there that would like to know more about their situation (46).

One major criticism that could be made could be that all the learnings at SAPS would be easily applied there but not in my working environment where the necessary structure and functions are not fully implemented. This is partially true. However, as a health professional dealing with palliative patients on a daily basis I think that improving the system we work in should also be a major goal. Applying the knowledge gained to an individual patient is, of course, the main, or at least the most immediate, objective to be attained. Nonetheless, I feel there is a need to improve the system as a whole so that all the patients we cannot or will not have the chance to see may benefit from improvements in their care. Contributions obtained from systems where things work differently or that have already been more solidly implemented may be of use in this setting (19,20).

Although observing the various facets of SAPS at work was the stepping stone to provide a general view of the system as whole, perhaps there was one feature that impressed me the most, in this context. This was the case of the first appointments conducted at an outpatient clinic away from the hospital. The fact that patients could be approached while still relatively functional and asymptomatic and thoroughly assessed seemed very attractive. It represented considerable investment, not the least of which in human resources (4 health professionals for one appointment). However the gains were obvious as the complications could be foreseen and there was a real chance to act on what the patient needed the most instead of just reacting to the (mostly expectable) complications due to happen in the course of disease.

Thus came the idea, admittedly adapted from here, and also admittedly not as perfected, to conduct a screening of sorts of every committed patient for physical, psychological, cultural, social and spiritual issues so as to direct the goals of care from there onwards, again with focus on anticipating problems before they are critical. For this purpose we developed a screening tool to be applied to every patient in ward. We all know that investment in infrastructure and human resource is presently scarce, at best, in public institutions. Bearing that in mind, this project focused more on a systematic approach that could lead to optimization of Palliative Care for the patients ahead of time, than in great schemes of what could be done if resources were plentiful.

Thus from this experience I gathered the knowledge to participate in a task force in my home institution to try to implement a Palliative Care structured and systematic assessment. This project has been submitted to the European Society of Medical Oncology (ESMO) for certification. As of present, we await the reviewers' comments. (Attachment 5)

Finally, but definitely not the least, the research project we conducted provided valuable gains to be used in my practice. Research in itself is important not only to move the level of scientific certainty forward in treating Palliative Care patients but also because it often feeds a loop where the clinical performance itself is elevated. Plus, being a new area, with much empirism still involved it is of the utmost importance that this empirism is quickly substituted by solid evidence based medicine (22,23). The research project focused on dyspnoea – perhaps one of the most distressing and difficult to control symptoms but it also provided insight into several other subtleties. Not the least of which, it taught me to look at the concept of dyspnoea as a total symptom (37). That is, just as we describe and treat the concept of total pain as a symptom derived not only from a physical experience but also and importantly modulated by other psychological, social, cultural and spiritual factors, there is also perhaps a need to expand this idea into other symptoms. I believe that dyspnoea is one such symptom.

In addition, with this research project I hope to have laid the first stone to a future cooperation between my home institute and PaCCCS. I feel that a large cancer centre such as the one I work in could greatly benefit from this collaboration. They certainly have the knowledge. My home institute certainly has a lot of patients who would benefit

with better care than what they receive. Every day there is a reminder of how much we need the knowledge that for now we can only say we would like to achieve in future studies. Thus, having been able to see how to perform good quality Palliative Care research I do envision a role for further research in my professional future life.

From the personal point of view, and this is also important in terms of professional practice implications, these objectives come together as a whole. That is, most of the time and effort was naturally put into developing clinical skills that can be directed at the patients I see. However the loose ends on both sides of the picture are a better understanding and management of these patients, which can be achieved by research, and improving their quality of care which can be done by trying to find solutions and resources to improve the way we treat Palliative Care patients as a whole.

5- Concluding remarks

To conclude, I find that this practice was very fruitful in every aspect. The chance to come in contact with a fully functional Palliative Care developed system was just as relevant as understanding the paramount importance of all the members of staff and their motivation to continuously improve SAPS. It was also important to see how Palliative Care permeated all the different care settings be it at home, in the outpatient clinic, in a regular hospital ward or in hospice.

From another point of view, the perspective gained from observing yet another Palliative Care service at work in Melbourne made the experience all the richer. Indeed this was a very useful week to realize how to assemble a Palliative Care service based in a hospital setting which, even if not optimum, is still our reality in every day practice.

The clinical component of the internship was directed by Ms. Kate Swetenham and the research component was directed by Prof Dr David Currow who were both tireless in making sure I got the most solid and comprehensive perspective possible.

Perhaps most important of all, 9 months past after this internship, with several working environments since then, from internal medicine to intensive care and oncology ward, I feel that some of the teachings I learned there have accompanied me and have been useful for patients. In addition, hopefully this internship has laid the ground for future work and collaboration in this area.

To sum up, I consider this internship a very good quality one, without question. I would definitely recommend one such experience to those interested in improving their practical knowledge and skills in Palliative Care, in all aspects.

6- Bibliography

1. WHO. World Health Organization [Internet]. Definition of Palliative Care. 2002 [cited 2015 May 2]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
2. Who. The Solid Facts. 2004;1–35.
3. United Nations General Assembly. Report by Secretary-General on the prevention and control of non-communicable diseases (A/66/83). 2011.
4. SAPS annual Report 2012-2013. 2013.
5. Tait P, Morris B, To T. Core palliative medicines : meeting the needs of non-complex community patients Representatives of SA Ambulance Service. Aust Fam Physician. 2014;43(1):29–32.
6. Kelley AS, Meier DE. Palliative Care — A Shifting Paradigm. N Engl J Med. 2010;363(8):781–2.
7. Pastrana T, Jünger S, Ostgathe C, Elsner F, Radbruch L. A matter of definition - key elements identified in a discourse analysis of definitions of palliative care. Palliat Med. 2008;22(3):222–32.
8. Alelwani SM, Ahmed Y a. Medical training for communication of bad news: A literature review. J Educ Health Promot. 2014;3(June):51.
9. Baile WF, Buckman R, Lenzi R, Glober G, Beale E a, Kudelka a P. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–11.
10. Kallenberg K, Brakenhielm C. Pain and suffering as existential questions in palliative care. Eur J Palliat Care. 1994;1(1):54–6.

11. Gao W, Bennett MI, Stark D, Murray S, Higginson IJ. Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. *Eur J Cancer*. Elsevier Ltd; 2010;46(11):2036–44.
12. Sudore RL, Villars P, Carey EC. Sitting with you in your suffering: lessons about intractable pain at the end of life. *J Palliat Med*. 2010;13(6):779–82.
13. George R. Suffering and healing--our core business. *Palliat Med*. 2009;23(5):385–7.
14. Kissane DW. The Relief of Existential Suffering<alt-title>Relief of Existential Suffering</alt-title>. *Arch Intern Med*. 2012;172(19):1.
15. Marques AL, Gonçalves E, Salazar H, Neto IG, Capelas ML, Tavares M, et al. O desenvolvimento dos cuidados paliativos em portugal. *Patient Care*. 2009;Outubro:32–8.
16. Smith S, Brick A, O’Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014;28(2):130–50.
17. McNamara B, Rosenwax LK, Holman CDJ. A Method for Defining and Estimating the Palliative Care Population. *J Pain Symptom Manage*. 2006;32(1):5–12.
18. Franks PJ, Salisbury C, Bosanquet N, Wilkinson EK, Lorentzon M, Kite S, et al. The level of need for palliative care: a systematic review of the literature. *Palliat Med*. 2000;14(2):93–104.
19. Herrera E, Rocafort J, De Lima L, Bruera E, García-Peña F, Fernández-Vara G. Regional Palliative Care Program in Extremadura: An Effective Public Health Care Model in a Sparsely Populated Region. *J Pain Symptom Manage*. 2007;33(5):591–8.
20. Bruera E, Sweeney C. Palliative care models: international perspective. *J Palliat Med*. 2002;5(2):319–27.

21. Jubb a M. Palliative care research: trading ethics for an evidence base. *J Med Ethics*. 2002;28(6):342–6.
22. McLaren G, Preston C, Grant B. Evidence based palliative care. *BMJ Br Med J*. 1999;319(7224):1573.
23. Rubiales ÁS, Del Valle ML, Argüello MT, Flores L a. Del empirismo a la medicina paliativa basada en la evidencia. *Med Paliativa*. 2003;10(3):157–61.
24. Rubiales AS, Flores L a., Del Valle ML, Gómez L, Hernansanz S, Gutiérrez C. Investigación cualitativa en medicina paliativa. *Med Paliativa*. 2004;11(4):231–8.
25. Kaasa S, Caraceni a. Palliative Cancer Care Research. *Palliat Med*. 2010;24(3):259–60.
26. De Conno F. The growth and development of research in palliative care: a personal odyssey and reminiscence of people, places and ideas. *Palliat Med*. 2010;24(4):362–72.
27. White C, Hardy J. What do palliative care patients and their relatives think about research in palliative care?-a systematic review. *Support Care Cancer*. 2010;18(8):905–11.
28. Australian Bureau of Statistics. Australian Life Expectancy [Internet]. [cited 2015 May 3]. Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4125.0main+features3110Feb 2014>
29. Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliat Care*. 2005;4:7.
30. Breitbart W AY. Agitation and delirium at the end of life: “We couldn’t manage him”. *JAMA*. 2008;300(24):2898–910.


31. Australian Institute of Health and Welfare. Lung Cancer Epidemiology in Australia [Internet]. [cited 2015 May 3]. Available from: <http://www.aihw.gov.au/acim-books/>
32. Reuben B. Dyspnea in Terminally. :234–6.
33. Jennings a-L, Davies a N, Higgins JPT, Gibbs JSR, Broadley KE. A systematic review of the use of opioids in the management of dyspnoea. *Thorax*. 2002;57(11):939–44.
34. Johnson MJ, McDonagh T a, Harkness a, McKay SE, Dargie HJ. Morphine for the relief of breathlessness in patients with chronic heart failure--a pilot study. *Eur J Hear Fail J Work Gr Hear Fail Eur Soc Cardiol*. 2002;4(6):753–6.
35. Abernethy AP, Currow DC, Frith P, Fazekas BS, McHugh A, Bui C. Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. *BMJ*. 2003;327(7414):523–8.
36. Oxberry SG, Torgerson DJ, Bland JM, Clark AL, Cleland JGF, Johnson MJ. Short-term opioids for breathlessness in stable chronic heart failure: A randomized controlled trial. *Eur J Heart Fail*. 2011;13(9):1006–12.
37. Johnson MJ, Bland JM, Oxberry SG, Abernethy AP, Currow DC. Opioids for chronic refractory breathlessness: Patient predictors of beneficial response. *Eur Respir J*. 2013;42(3):758–66.
38. Sloat S, Boland J, Snowden J a., Ezaydi Y, Foster A, Gethin A, et al. Side effects of analgesia may significantly reduce quality of life in symptomatic multiple myeloma: a cross-sectional prevalence study. *Support Care Cancer*. 2014;23(3):671–8.
39. Palliative Care Australia. Palliative Care Service Development : A population based approach. 2005.
40. Palliative Care Australia. Service Provision in Australia : A planning guide. 2003;

41. Kearney M. Palliative medicine - just another specialty? *Palliat Med.* 1992;6(1):39–46.
42. Desbiens N a., Mueller-Rizner N, Connors AF, Wenger NS, Lynn J. The symptom burden of seriously ill hospitalized patients. *J Pain Symptom Manage.* 1999;17(4):248–55.
43. Orgel E, McCarter R JS. A failing medical educational model: a self-assessment by physicians at all levels of training of ability and comfort to deliver bad news. *J Palliat Med.* 2010;13(6):677–83.
44. Costantini A, Baile WF, Lenzi R, Costantini M, Ziparo V, Marchetti P GL. Overcoming cultural barriers to giving bad news: feasibility of training to promote truth-telling to cancer patients. *J Cancer Educ.* 2009;24(3):180–5.
45. Whitney SN, McCullough LB, Frugé E, McGuire AL, Volk RJ. Beyond breaking bad news: The roles of hope and hopefulness. *Cancer.* 2008;113(2):442–5.
46. Fallowfield L J V. Communicating sad, bad, and difficult news in medicine. *Lancet.* 2004;24(363):312–9.

7- Attachments

1- Attachment 1

PCOC assessment form

[Insert Service Name Here]				(Please complete or affix Label here)											
				UPI: Surname First name: DOB:											
PCOC Assessment															
Instructions: [Insert here]															
Year 20		Date													
		Time													
Clinician Rated Score	Phase (1-5)														
	RUG ADL (total 4-16)														
	Bed Mobility														
	Toileting														
	Transfers														
	Eating														
	Total RUG:														
	Problem Severity Score (0-3)														
	Pain														
	Other Symptoms														
Psychological/Spiritual															
Family / Carer															
Australia-modified Karnofsky (10-100)															
Patient Rated Score	Symptom Assessment Scale (0-10)														
	Difficulty sleeping														
	Appetite problems														
	Nausea														
	Bowel problems														
	Breathing problems														
	Fatigue														
	Pain														
	Patient = pt Proxy = pr														
Reason for Phase End (1-7)															
Staff Initials:															

PCOC ASSESSMENT

JULY 2014

2- Attachment 2

Distress Thermometer

DT Treatment Review

Patient's name Date

1. Please circle the number below (0-10) that best describes in general how much distress you feel you have been experiencing over the past week, including today.
2. If any items below have been a cause of this distress for you over the past week, including today, please tick the box next to it. Please leave it blank if it does not apply to you.
3. Then rank (1st, 2nd, 3rd, 4th) your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern) and put this number beside the item in the RANKING column.

<div style="text-align: center;"> <p>THERMOMETER</p> </div>	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 10%; text-align: center;">RANKING</th> <th style="text-align: left;">Physical Problems</th> </tr> </thead> <tbody> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> My appearance</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Bathing or dressing</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Breathing difficulties</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Passing urine</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Constipation</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Diarrhoea</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Eating or appetite</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Fatigue, exhaustion or extreme tiredness</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Feeling swollen</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> High temperature or fever</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Getting around (e.g. walking)</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Indigestion</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Sore or dry mouth</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Nausea or vomiting</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Pain</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Dry, itchy or sore skin</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Sleep problems and/or nightmares</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Tingling in hands and/or feet</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Changes in how things taste</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Hot flushes</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Memory or concentration</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Speech problems</td></tr> <tr><td style="text-align: center;"> </td><td><input type="checkbox"/> Wound care after surgery</td></tr> </tbody> </table> <p>Other concerns (e.g. other medical conditions, etc.):</p>	RANKING	Physical Problems		<input type="checkbox"/> My appearance		<input type="checkbox"/> Bathing or dressing		<input type="checkbox"/> Breathing difficulties		<input type="checkbox"/> Passing urine		<input type="checkbox"/> Constipation		<input type="checkbox"/> Diarrhoea		<input type="checkbox"/> Eating or appetite		<input type="checkbox"/> Fatigue, exhaustion or extreme tiredness		<input type="checkbox"/> Feeling swollen		<input type="checkbox"/> High temperature or fever		<input type="checkbox"/> Getting around (e.g. walking)		<input type="checkbox"/> Indigestion		<input type="checkbox"/> Sore or dry mouth		<input type="checkbox"/> Nausea or vomiting		<input type="checkbox"/> Pain		<input type="checkbox"/> Dry, itchy or sore skin		<input type="checkbox"/> Sleep problems and/or nightmares		<input type="checkbox"/> Tingling in hands and/or feet		<input type="checkbox"/> Changes in how things taste		<input type="checkbox"/> Hot flushes		<input type="checkbox"/> Memory or concentration		<input type="checkbox"/> Speech problems		<input type="checkbox"/> Wound care after surgery	<table border="1" style="width: 100%; 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RANKING	Physical Problems																																																																																															
	<input type="checkbox"/> My appearance																																																																																															
	<input type="checkbox"/> Bathing or dressing																																																																																															
	<input type="checkbox"/> Breathing difficulties																																																																																															
	<input type="checkbox"/> Passing urine																																																																																															
	<input type="checkbox"/> Constipation																																																																																															
	<input type="checkbox"/> Diarrhoea																																																																																															
	<input type="checkbox"/> Eating or appetite																																																																																															
	<input type="checkbox"/> Fatigue, exhaustion or extreme tiredness																																																																																															
	<input type="checkbox"/> Feeling swollen																																																																																															
	<input type="checkbox"/> High temperature or fever																																																																																															
	<input type="checkbox"/> Getting around (e.g. walking)																																																																																															
	<input type="checkbox"/> Indigestion																																																																																															
	<input type="checkbox"/> Sore or dry mouth																																																																																															
	<input type="checkbox"/> Nausea or vomiting																																																																																															
	<input type="checkbox"/> Pain																																																																																															
	<input type="checkbox"/> Dry, itchy or sore skin																																																																																															
	<input type="checkbox"/> Sleep problems and/or nightmares																																																																																															
	<input type="checkbox"/> Tingling in hands and/or feet																																																																																															
	<input type="checkbox"/> Changes in how things taste																																																																																															
	<input type="checkbox"/> Hot flushes																																																																																															
	<input type="checkbox"/> Memory or concentration																																																																																															
	<input type="checkbox"/> Speech problems																																																																																															
	<input type="checkbox"/> Wound care after surgery																																																																																															
RANKING	Practical Problems																																																																																															
	<input type="checkbox"/> Caring responsibilities																																																																																															
	<input type="checkbox"/> Finance, work or housing																																																																																															
	<input type="checkbox"/> Transport or parking																																																																																															
	<input type="checkbox"/> Questions about my illness / treatment																																																																																															
	<input type="checkbox"/> Communication with NHS staff																																																																																															
	Family Problems																																																																																															
	<input type="checkbox"/> Relationship with my children																																																																																															
	<input type="checkbox"/> Relationship with my partner																																																																																															
	<input type="checkbox"/> Relationship with other relatives / friends																																																																																															
	Emotional Problems																																																																																															
	<input type="checkbox"/> Loneliness or isolation																																																																																															
	<input type="checkbox"/> Sadness or depression																																																																																															
	<input type="checkbox"/> Worry, fear or anxiety																																																																																															
	<input type="checkbox"/> Anger or frustration																																																																																															
	<input type="checkbox"/> Difficulty making plans																																																																																															
	<input type="checkbox"/> Guilt																																																																																															
	<input type="checkbox"/> Hopelessness																																																																																															
	<input type="checkbox"/> Sexual concerns																																																																																															
	Spiritual/religious concerns																																																																																															
	<input type="checkbox"/> Loss of faith or other spiritual concern																																																																																															
	<input type="checkbox"/> Loss of meaning or purpose in life																																																																																															
	<input type="checkbox"/> Not being at peace with, or feeling regret about the past																																																																																															

3- Attachment 3

Kessler K10 tool

K10

Patient Name		Outcome Tool	Result
DOB		K10	
Date of Assessment			
GPE			

Please place an X in the correct box.

Do not answer questions 3-6 if the answer to question 2 is "none of the time" in which case questions 3-6 automatically receive a score of one each.

The maximum score is 50 indicating severe distress and the minimum score is 10 indicating no distress.

In the past 4 weeks		1 None of the time	2 A little of the time	3 Some of the time	4 Most of the time	5 All the time
1	About how often did you feel tired out for no good reason?					
2	About how often did you feel nervous?					
3	About how often did you feel so nervous that nothing could calm you down?					
4	About how often did you feel hopeless?					
5	About how often did you feel restless or fidgety?					
6	About how often did you feel so restless you could not sit still?					
7	About how often did you feel depressed?					
8	About how often did you feel that everything is an effort?					
9	About how often did you feel so sad that nothing could cheer you up?					
10	About how often did you feel worthless?					

4- Attachment 4

Article submission to the Journal of Pain and Symptom Management

Blinded Patient Preference of Morphine Compared to Placebo in the Setting of Chronic Refractory Breathlessness – An Exploratory Study

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Word count

5- Attachment 5

ESMO Palliative Care certification project – front letter

