CATÓLICA
INSTITUTO DE CIÊNCIAS DA SAÚDE
LISBOA·PORTO·VISEU

REPORT ON INTERNSHIP IN PALLIATIVE CARE SOUTHERN ADELAIDE PALLIATIVE SERVICES (SOUTH AUSTRALIA)

&

UNIDADE DE CUIDADOS CONTINUADOS E PALIATIVOS (HOSPITAL DA LUZ, LISBOA)

Report submitted to The Catholic University of Portugal as a requirement in full for the degree of Masters in Palliative Care

By

Ana Carolina Pimenta Pedroso

Lisbon, 2018

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Under the supervision of

Kate Swetenham and Isabel Galriça Neto

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SUMMARY

My interest in Palliative Care culminated last year in the opportunity of two placements in national and international reference centers.

The Unidade de Cuidados Continuados e Paliativos has received me for two months and Southern Adelaide Palliative Services for three.

These experiences allowed me to apply on practice the theory learned before and to develop diverse competences, such as: symptomatic control, psychosocial and spiritual approaches, communication with end-of-live patients and their families.

During this period, I've been immersed in such different health systems, with diverse models of care, that inspired me for me future practice.

I've had also the opportunity to participate in a research project with CareSearch, which aims to understand the role of the new figure in end-of-life area – death doula – as well as the reasons and context that ended in their appearance.

This work made me reflect about the way we care for our patients, opposing to the way they wish to be treated and all the repercussions that this question raises. The statistical analysis is currently being performed and I look forward to contributing to the published article from my work.

Key Words: Palliative Care, Symptom Control, Psychosocial Approaches, Communication, Death doula

RESUMO

O meu interesse em Cuidados Paliativos culminou no último ano na oportunidade de fazer dois estágios em centros de referência nacional e internacional.

A Unidade de Cuidados Continuados e Paliativos recebeu-me durante um período de dois meses e os Southern Adelaide Palliative Services por um período de três meses.

Estas experiências permitiram-me aplicar na prática a teoria já aprendida, desenvolvendo inúmeras competências, a salientar: controlo sintomático, abordagem psicossocial e espiritual, comunicação com doentes em fim de vida e suas famílias.

Durante este período, consegui envolver-me em dois sistemas de saúde muito diferentes, com diferentes formas de cuidar, que me inspiraram para a minha prática futura.

Tive ainda a oportunidade de participar num projeto de investigação em conjunto com o grupo CareSearch, com intuito de entender o papel da nova figura em cuidados paliativos – a doula de fim de vida – bem como os motivos e contextos que levaram ao seu aparecimento.

Este trabalho fez-me refletir acerca da forma como cuidamos os doentes que tanto contrasta com a forma como eles desejariam ser cuidados e todas as implicações desta questão. A análise estatística está a ser efetuada, pelo que estou a aguardar poder contribuir para a publicação de um artigo acerca do trabalho que desenvolvi.

Palavras-Chave: Cuidados Paliativos, Controlo Sintomático, Abordagem Psicossocial, Comunicação, Doula de fim de vida.

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Abbreviation Key

AKPS	Australia-modified Karnofsky Performance Scale
APCP	Associação Portuguesa de Cuidados Paliativos
EAPC	European Association for Palliative Care
ESMO	European Society of Medical Oncology
FMC	Flinders Medical Centre
GP	General Practicioner
NHS	Noarlunga Health Services
PaCCCS	Palliative Care Clinical Collaborative Studies
RDNS	Royal District Nursing Society
SALHN	Southern Adelaide Local Health Service Network
SAPS	Southern Adelaide Palliative Services
UCCP	Unidade de Cuidados Continuados e Paliativos

Introduction

As a resident in Internal Medicine, at Hospital São Francisco Xavier, in Lisbon, now in my third year of residency, I consider my studies and practice in Palliative Care to be essential.

Last year, I presented a poster at the Portuguese National Congress of Internal Medicine, describing the use of health services that previous inpatients of our service had used in the 12 months following their discharge from hospital. According to that data, 25% of our patients died in the next year and most of them were never recognised as being a palliative patient, nor were they referred for this kind of service.[1]

If patients aren't recognized as being at the end of their life then, neither their problems nor their needs are adequately met; thus, they will never receive the care they need and deserve. I think education and training in Palliative Care is crucial during the residency in Internal Medicine, considering that we take care of dying patients daily. Formal education in this area is seriously lacking, leading the clinician to feel unprepared for the specific care required at the end of life

From my university years, I have discovered my interest in Palliative Care., I have recognised a lot of patient suffering, and concern that end of life care seemed to be unsatisfactory. During my daily practice, I could see the impact that proper holistic care has upon the patient and their families, and this observation has reinforced the need of knowledge in this area.

I have chosen Palliative Care as the optional area of interest worthy of more study. I had my first contact with Palliative Care in practice, at UCCP of Hospital da Luz, for 2 weeks. This experience confirmed my interest and desire to study Palliative Care.

At the beginning of the residency, I started the Master in Palliative Care, at Universidade Católica Portuguesa. Whenever I can, I participate in other workshops and congress within this area.

I planned to do an internship in national and international centers so that I could develop my skills and learn from centers that are recognized as offering best palliative care practice.

I took the UCCP in Hospital da Luz, as I really enjoyed this internship during my last year of University. I was really overwhelmed with the good quality of care they practice there. I've chosen Adelaide in Australia as well, because of a good personal reference and the positive experience they had there.

As my Australian experience was really different from my normal daily activity and I spent 3 months observing an international site, I'm going to describe it in closer detail. I would like to illustrate it better, without prejudice for the high-quality Portuguese experience I had, as this last experience is more familiar to those that I'm going to present it to.

I want to stress my research experience in Adelaide. I think I can say it was my biggest surprise and offered personal development during the period of those internships. It was a big challenge, not only on the scientific point of view, but an astonishing personal experience, that introduced me to a new world. I must thank this experience to every single person I worked with, who showed me the patient and families' point of view from the inside. They made me be more mindful and aware for their needs, desires and dignity.

I'm going to use the references in *American Medical Association* 10ª edition.

1. AIMS

The aims of this internship which are supported by the General Guidelines for the Master degree (Regulamento Geral do Mestrado)[2] and the *EAPC White Paper on Palliative Care Education*[3] are described below:

Clinical Aims

Symptom management and control

For me, it is essential to be able to screen, assess, prevent and manage different symptoms (the most common and rare and refractory ones). I wanted to do that by following senior doctors and nurses in all settings (outpatient, hospice, community) to learn from their approach to patients' symptomatic issues.

Psychosocial, spiritual approach and communication

I wish to meet patients' psychological, social and spiritual needs as well as their families' needs. Being involved in a multidisciplinary approach in these fields, learning how to assess and manage these matters, will also develop and improve my communication skills about illness understanding, prognosis and end-of-life preparation.

In Portugal, our studies do not include training in communication, so that's a main focus for me.

System implementation and functioning

I wanted to gain awareness about a complex and well established palliative care system, how it is structured, how it works and how it is integrated in the community. I started to do that in a reference center in Portugal and then in Australia, so I can bring the most I can to my daily practice in Portugal.

Research Aims

Research initiation in Palliative Care

Southern Adelaide Palliative Services (SAPS) is a great research center in Palliative Care, and provided great initiation into the research field of Palliative Care, centered

on improving patients' well-being and quality of life. I negotiated a research component for the internship so that I could develop research skills in clinical and translational settings, from a Center that is a leader in this area.

Using research to answer clinical questions and assist in the development of knowledge where there are gaps is a primary aim. A secondary aim would be gaining experience in writing a paper for peer review and publication from the research work undertaken during this internship.

2. HOST INSTITUTIONS

2.1 Unidade de Cuidados Continuados e Paliativos do Hospital da Luz Lisboa

The unit is open since 2007 and it is highly experienced in end-of-life care of patients with cancer, degenerative neurological pathologies, advanced organ failure, advanced forms of dementia, cerebral vascular accidents, neuromuscular illnesses, cystic fibrosis and incapacitating rheumatic illnesses. The Portuguese Association for Palliative Care (APCP) recognizes this Palliative Care Team for compliance with the recommendations of the association and it was distinguished by European Society of Medical Oncology (ESMO) as ESMO Designated Center of Excellence in Palliative Care and Oncology (2011 - 2013).

The head of department is Isabel Galriça Neto who is a Family Medicine Doctor with training and skills in education, research and palliative care clinical practice.

2.1.1 INPATIENT UNIT

The main activity of this unit is the in-patient unit. It is located on the 4th floor and it has 48 beds, one third in single rooms. The Unidade de Cuidados Continuados e Paliativos (UCCP) at Hospital da Luz (Lisboa) has two different facilities together: Continuous Care and Palliative Care. During this report, everything I will refer is related to the Palliative Care facility.

The UCCP is a short-term inpatient unit in which patients with uncontrolled symptoms are admitted, to better control their symptoms manage aiming the discharge or to comfort them in their last days of life. For some families it's also important to provide respite care.

The beds are used considering the needs, so the number varies every day. There is a medical office, nursing office, and some common areas for visits and the meals. There are some quiet rooms, which are used when a higher degree of privacy is needed, such as meetings where important news can be given and delicate matters can be discussed.

All the areas are decorated regarding a comfortable environment for patients and families. They are motivated to bring their own objects, so they can feel a homely background. Families can be present during the 24 hours.

The working team is composed by the following members: the medical team is led by Isabel Galriça Neto; with Rita Abril and some residents on internship and a group of physicians working in part time (Guilherme Magalhães, Inês Romero, Jorge Castro e Joana Rodrigues). The nursing staff is led by Nelia Trindade. They work together with the psychologist, physiotherapists and speech therapist, dietitian, pharmacist, chaplain, the administration officers and assistants.

The Unit works in close cooperation with all the services of the hospital, especially with Oncology, Neurology, Internal Medicine, General and Family Medicine and the Pain Unit.

The patients are stimulated to invite their own spiritual leaders if they wish so.

The team encourages patients and families to have special moments and to do meaningful activities. As example, they celebrate the birthdays with a party, weddings, they meet special people and sometimes they do outside visits to significant places, depending on patients' taste, dreams and desires.

2.1.2 OUTPATIENT CLINIC

The Unit also offers outpatient appointments, reviewing patients who are discharged or who are sent from other specialties or from emergency department.

2.1.3 LIAISON

The Unit provides support to patients hospitalized in other services at the Hospital, with close connection with Emergency department, Internal Medicine and Oncology, but also Neurosurgery, Intensive Care and others.

Usually, those specialties came to discuss the patients who they are concern about, regarding adjust of medication, transference to the unit or need of reevaluation in the outpatient clinic.

2.1.4 AFTER-HOURS SUPPORT

After-hour, the assistance to patients is assured by a specialized physician, who assurances 24-7-365 telephone advice to the nursing staff and in person, if needed.

During the weekends, there is a responsible physician who is going to the hospital during the day time.

2.1.5 MULTIDISCIPLINARY MEETINGS

The unit starts its daily activity with a team meeting for handover and updates on the plan of care for each patient. There is also a Unit meeting held weekly to discuss the main topics of the week. This meeting includes the more complex cases and another scientific meeting with journal club or a review of any topic.

2.1.6 EDUCATION

UCCP provides continuous education to staff and other health professionals, volunteers through multiple courses and workshops.

The service offers undergraduate and postgraduate medical and nursing education. They are a key service in training and improving the knowledge in the palliative-care area in Portugal.

2.1.7 RESEARCH ACTIVITIES

The service staff run some research projects, helping to review and create new knowledge about end-of-life care in Portugal.

2.2 Southern Adelaide Palliative Services (SAPS)

Palliative care in Adelaide dates back to 1976 with the opening of the Mary Potter Hospice. In 1988 the Daw House facility located at the Repatriation General Hospital was renovated and the Southern Community Hospice program was born. Throughout the decade there was an exponential increase in the number of inpatient units across South Australia. At the same time, the Royal District Nursing Society (RDNS) which provides primary nursing care services to people in their homes experienced an increase in services to the dying who wished to be cared for in their own home. Palliative care is nowadays divided into either specialist or generalist care. The RDNS provide the generalist care to those dying where care needs are not complicated. Specialist services like SAPS focus on those patients where care needs are complex and challenging to the generalist providers. Specialist metropolitan palliative-care services have supported regional nurse and GP teams in country towns and remote areas of South Australia.

The Southern Adelaide Local Health Service Network (SALHN) was created to provide medical care to the southern part of Metropolitan Adelaide. It works in close connection with Flinders University.

SAPS are SALHN's palliative-care services. Their mission is to provide care to patients with chronic, incapacitating diseases that limit life expectancy, therefore alleviating their suffering. SAPS are services of reference that provide highly-specialised care to patients, families and caretakers with complex needs. It also provides support to other less-resourced health units. Multiple services are provided to the community, such as: Laurel Hospice (Inpatients Unit), Outpatient Clinics, Community Support, Hospital Consultation, After-Hours Support, Research and Education.

The head of department is Kate Swetenham who is a Registered Nurse with training and skills in education, research and palliative care clinical practice.

2.2.1 LAUREL HOSPICE (INPATIENT UNIT)

Laurel Hospice is a short-term inpatient unit that mostly receives patients needing aggressive control of symptoms, aiming to better manage their last days of life, or to provide respite care.

The Laurel Hospice is a specialised 15-bed inpatient unit located centrally in Adelaide's southern region at Flinders Medical Centre (FMC) on the top floor of the new building, just moved last November from Daw House, at the Repatriation Hospital. There is a well-decorated, large common area, with couches, TV, piano, books, magazines and board games available to patients and their families, in which they can spend quality time. There is also an area for children. Associated to these rooms there is a kitchen where patients can prepare their own meals. There is a quiet room, more reserved, which is used in situations that require a higher degree of privacy, such as meetings where important news can be given and delicate matters can be discussed. During their stay, the patients are encouraged to dress in their own clothes and bring in personal objects in order to feel as at home as possible, and to diminish the discomfort associated to the hospital admission. The Hospice provides domestic bedding and hand quilted rugs to further reduce the clinical feel of a hospital environment. Families can visit patients at any hour and they are encouraged to spend as much time as possible with the patients, including staying overnight. There is a rooftop garden, with enough space to move the beds, which allows patients in bed to spend quality time outside, with a view that overlooks the sea and coast line of Adelaide. Volunteers support the functioning of the Hospice, assisting patients with their meals and providing gentle massage and support.

The work developed at the Hospice includes professionals from different fields:

- Palliative-Care Team is led by Doctor Michael Briffa. Peter Allcroft, Susan Haynes, Tim To, Paul Kleinig and Toula Christos complete the consultants' team, working part-time. A medical team constituted of one of those consultants, two residents and a registrar and a year-6 student. A member of this team is on call during the night for emergencies.

- Nursing Staff: The inpatient nursing team provides full-time assistance. They do the assessment of psychological, social, spiritual or family related issues to be identified and addressed.

- Psychiatrist: Karin Myhill is a senior consultant psychiatrist working part-time. The psychiatrist service is required in cases of psychological/psychiatric malfunctions of patients or families, when guidance is needed for family-dynamics issues. Patients

and /or families may benefit if they are showing deficient coping with the disease or families may be referred if they show a high risk of pathologic mourning.

- Pharmacists: The pharmacists are available during working hours and their role is to assist the clinical staff in questions related to the prescribed medicines, interactions between medicines and possible side effects. There is a project connecting the inpatient prescription with the community pharmacy services, which allows the hospice team to have updated information about the prescription at the admission, as well as give them information to continuation of the care at the discharge.

- Social Workers: This team is essential for the restructuring of family and social life of palliative patients. They are responsible for identifying, in each patient, the amount of distress caused by the illness. They also help patients to review their lives and provide guidance about community resources, residential care placements, Wills and power of attorney (legal document in which one person nominates and gives legal authority to another to act on affairs on their behalf).

- Pastoral-Care Team: A spiritual assistant is available during working hours to the patients. The patients are encouraged to invite their own spiritual leaders if they wish so.

- Complementary-Care Team: The Complementary-Care Centre is coordinated by a nurse with complementary therapy qualifications. The other elements of the team are volunteers, also with qualifications in the areas of care provided. They create an environment where patients can relax, listen to music or have a massage, or other therapy as kinesiology, reiki, aromatherapy, hypnotherapy, therapeutic touch, among others. These services are also offered to outpatients and families.

- Art Therapist: Art-based therapy allows patients and families to express emotions through artistic creation. They are encouraged to share stories and to develop artistic work such as painting, sculpture and patchworks, as a means to promote well-being.

- Pet Therapy: There are some volunteers who bring dogs to the hospice. These dogs are specifically trained for their therapy role and are tested to prevent disease transmission. Sometimes the patients can also receive their own pets at the hospice.

- Volunteers: The volunteers are specifically trained to be able to deal with palliative-needed patients. They provide assistance to the patients in several activities, for

example: meals, manicure, hair-dressing, reading, letter-writing, garden-walking and anamnesis. They are a great help to promote quality of life to the patients.

- Administration officers: Administration officers provide support to the clinicians.

SAPS do not have a dedicated Physiotherapist, Occupational therapist, Speech Pathologist or Dietician. When these services are common to FMC.

2.2.2 OUTPATIENTS CLINICS

2.2.2.1 Palliative Care Initial Assessment Clinic

The initial assessment for patients who are able to go out of their homes takes place outside the Hospital, in two clinics with several medical specialties: GP Plus Marion and GP Plus Noarlunga.

This innovative concept of an early approach to the patients with a limited prognosis referred by an assistant practitioner, in a neutral environment, allow a gradual coping with the disease.

Most of the patients evaluated do not need immediate palliative care, so they can discuss the problems they can have in the future and plan they lives.

This are assessed during 90 to 120 minutes in three stages:

1. A nurse practicioner does the evaluation of physical symptoms, an objective exam, therapeutic review and information provided to the patient on the services available at SAPS.
2. Evaluation by the social workers of the patient's practical needs: financial difficulties are evaluated, in-home assistance is guaranteed (meals, gardening, checking safety conditions, etc.), vouchers for transportation are provided, and the filling of an Advance Care Directive is promoted.
3. Then, the patient and carer are taken to separate rooms where their psychological needs are evaluated. A Psychosocial Nurse stays with the patient, applies depression evaluation scales and explores potential points of worries with the disease. The stress levels of the carer are evaluated by a Caregiver Facilitator, as well as their ability to adapt to the new circumstances

and possible assistance within the family environment. Some practical helps are provided and studied the need of a specialized care.

This system promotes strategies that avoid further deterioration of patient's condition, avoids unnecessary hospital admissions and promotes their well-being. The patient is referred to the appropriated medical specialty in particularly complex cases. A letter is sent to the assistant practitioner after every assessment, which allows for a proper articulation of the services.

2.2.2.2 Hospital Outpatients Clinics

The medical assessment is done at SALHN's hospitals (FMC and Noarlunga Health Services - NHS) to outpatients with frequent needs of medical observation. This is mainly for patients of difficult symptomatic control. This assessment is done by a physician and a nurse. While waiting for the appointment, the patient is given a Symptom Assessment Scale. The scale may clinicians focus on uncontrolled symptoms, followed by a physical, psychological, family and spiritual approach. A physical exam evaluating the patient's complaints is carried out, and the appropriated measures are taken. The collaboration between specialties is common. Subsequent appointments to reevaluate the patients in the majority of the cases.

There is a special consultation for patients with motor neuron disease. This is very interesting because of the specificity of this patients, usually younger. They have the collaboration of Pneumology, Neurology, Speech pathology, Rehabilitation, Community Nurses, Psychology. They have an integrated group consultation, as well as the meeting, when they discuss every patient they have.

2.2.3 COMMUNITY SUPPORT

The palliative-care unit provides assistance to general practitioners (GPs) and nurses in charge of in- home palliative-care-needed patients, with limited physical ability to travel, without enough family support, with financial difficulties or in end-of-life situations that wish to stay at home.

The community team includes registered and nurse practitioners. Usually, the assistance is provided by a specialized nurse that periodically evaluates the patient's needs. If needed, the nurse slightly adjusts the therapeutics and provides nursing services that help maintain the patient's well-being. If the symptom control becomes

more challenging the nurse refers it to a specialist practitioner, who then takes part on the next visit, therefore assuring the best possible care to the patient. The visits are as frequent as needed, including daily in the more complex cases.

2.2.4 LIAISON

The Liaison service works daily at FMC. This service is done by a physician and or a nurse. The objective is to provide specialized care to inpatients of other health units, usually for acute decompensated disease, that show palliative-care needs. The observation of the patients is focused on the problem that raised the request for assistance, and the physician then prescribes the appropriate therapeutics to be administrated by the medical team at the unit. Additional assessments are considered for following up the evolution of the patient. It allows the transference to the hospice, if needed, in a more harmonious way. The rest of the patients, at discharge, keep the connection to the SAPS, being referred for the first assessment clinic, the outpatient clinic or the community services, regarding their phases and needs.

Those services are provided by registered nurses and/or nurse practitioner, a resident and a consultant.

2.2.5 AFTER-HOURS SUPPORT

Outside normal working hours and during the weekends the assistance to patients is assured by a specialized physician and a specialized nurse, which guarantees 24-7-365 telephone advice to patients. This service is exclusively provided over the phone. If urgent, they give the advice call an ambulance to go to an emergency service; if the manageable at home, they are guided to solve the situation, avoiding unnecessary hospital admittances.

2.2.6 MULTIDISCIPLINARY MEETINGS

Several meetings are held at SAPS on a weekly basis aiming at organizing and coordinating services, optimizing care given to patients and families, and providing training to practitioners.

The multidisciplinary meeting is held weekly and is attended by all staff members. The Journal Club meeting is held every week; an article or a relevant topic is presented for the daily clinical practice.

The training sessions are held weekly, when a practitioner presents and discusses a relevant topic for the clinical practice.

The meeting with the Psychiatrist is held every week, with the residents and students, where the last ones propose topics based on actual patients and complex questions, for discussing. The Psychiatrist explain some theory and practical strategies that we can apply on dally basis.

Palliative Care Grand Round is held monthly, as well as the General Grand Round, improving multidisciplinary knowledge and collaboration between different specialties.

2.2.7 EDUCATION

SAPS provide continuous education to staff, other health professionals, volunteers and community members through multiple programs. The services are closely linked with the Flinders University providing undergraduate and postgraduate medical, nursing and allied health education. SAPS hosts health practitioners from around the world that wish to receive training and strengthen their knowledge in the palliative-care area.

2.2.8 RESEARCH ACTIVITIES

SAPS' research institute is dynamic in nature and counts with the vast majority of the staff. It is part of the Palliative Care Clinical Collaborative Studies (PaCCCS), which is a national research network. It is a world-leading research center in palliative care with a vast publication record. The unit has a policy on encouraging patients to collaborate on the research studies being carried out, and periodically reinforces the importance of patient referral for such studies by the practitioners. The patients seem keen in collaborating in research studies aiming to develop new interventions or medicines to help others. The research center runs several studies at a time with a strong focus on acquiring solid scientific knowledge to propose new interventions and medicines to contribute for a better quality of life to those on an end-of-life stage.

3. INTERNSHIP STRUCTURE

3.1 UCCP – Hospital da Luz, Lisboa

My first internship took place in UCCP at Hospital da Luz, in Lisbon, for two months, June and July 2017 - 5 days a week, from 8.30am to 5pm. It was discussed and organized with my mentor Isabel Galriça Neto, as follows in table 1:

First and second month - UCCP Hospice

Table 1. UCCP plan

Monday	Tuesday	Wednesday	Thursday	Friday
Multidisciplinary meeting UCCP Hospice	Multidisciplinary meeting UCCP Hospice	Multidisciplinary meeting UCCP Hospice	Multidisciplinary meeting UCCP Hospice	Multidisciplinary meeting UCCP Hospice
UCCP Hospice	Education, Clinical team meeting	UCCP Hospice	UCCP Hospice	UCCP Hospice

3.2 SAPS - Adelaide

My internship in SAPS, Adelaide, occur from February to April 2018 - 5 days a week, from 8.30am to 5pm - and it was discussed and organized with my mentor Kate Swetenham, as follows in tables 2, 3 and 4:

First month - Laurel Hospice

Table 2. Hospice plan

Monday	Tuesday	Wednesday	Thursday	Friday
Laurel Hospice Multidisciplinary meeting	Research	Research	Initial Assessment Clinic	Laurel Hospice
Education, Clinical team meeting Laurel Hospice	Research	Research	Laurel Hospice Meeting with the Psychiatrist	Laurel Hospice

Second Month – Community

Table 3. Community services plan

Monday	Tuesday	Wednesday	Thursday	Friday
Outpatient clinic	Outpatient clinic	Research	Journal club Home visits	Home visits
Community team meeting	Outpatient clinic	Research	Research	Research

Third Month –Liaison

Table 4. Liaison plan

Monday	Tuesday	Wednesday	Thursday	Friday
Research	FMC	FMC	Outpatient clinic	Research
Research	FMC	FMC	FMC	Research

4. CLINICAL ACTIVITIES

I don't want to be very descriptive, but to have a critical view about my experiences and learnings. In order to do it, I will start by a short table, trying to picture the variety of patients I've seen.

During the five months of those internships, I had the opportunity to accompany 235 patients, as follows in table 5:

Table 5. Patients characterization

Unit	UCCP Lisboa	Laurel Hospice	Home visits SAPS	Outpatient consults SAPS	Liaison SAPS	Total
Patients	101	36	16	43	39	235
Female, n (%)	44 (43,6%)	13 (36,1%)	9 (56,3%)	24 (55,8%)	19 (48,7%)	109
Male, n (%)	57 (56,4%)	23 (63,9%)	7 (43,7%)	19 (44,2%)	20 (51,3%)	126
Age, yrs (median)	76	73	63	65	69	NA
Age, yrs (min, max)	40, 100	32, 96	58, 89	28, 88	38, 99	28, 100
AKPS (median)	NA	30	50	60	40	NA
Oncologic patients	72 (71,3%)	28 (77,8%)	14 (87.5%)	25 (58,1%)	28 (71,8%)	167 (71,1%)
Mortality, n (%)	37 (36,6%)	28 (77,8%)	28 (77,8%)	NA	4 (10,3%)	NA

4.1 UCCP – Hospital da Luz, Lisboa

This was my first placement in Palliative Care, as clinician. Daily, I've accompanied the in-patients in this Unit, from the admission, to the discharge or to the end of their lives.

It was a great opportunity to learn with a high-quality Portuguese team of Palliative Care. I was in the daily multidisciplinary meeting and I had some patients attributed. I did the daily examination, talked with patients and their families; participated in family meetings, giving information and discussing the plan. In the end, I reviewed the plan, together with the rest of the team.

The group of professionals who make up this team is very experienced and one of the special topics I learnt with them was the communication. I've found it a fundamental base for a good quality palliative care and I was the first time I saw it in a Portuguese setting in such a systematic and correct way to each patient.

In UCCP, I had my first contact with the concept of 'Total pain'. I think it is a very important idea to have in mind, every time I have contact with a palliative patient. The human life is so complex that their pain is so. The pain is often a reflex of suffering in every other area of their lives. So, I will only help them controlling pain (or other symptoms), if I am able to understand the person as a whole being and help him/her comforting other problems which contribute to the suffering. I see this approach as a building block for care palliative patients or other patients I have.

4.2.1 Laurel Hospice

After having the opportunity of working in an in-patient unit in my country, I experienced it in a very different context, in Australia.

Regarding different cultures and different approaches and experiences, it was a unique chance to learn with a very experienced centre.

I accompanied the daily routine, from the admission, to everyday ward routines, passing by family meetings, celebrations, complementary care, ending in each patient end-of-life.

The daily systematic approach to each patient was really important for me, considering the importance of the symptomatic control, in the end-of-life plot.

The existence of a lot of complex patients, was a big point of learning, where a different range of tools were wisely put together: symptomatic control, family and social approach, communication, psychology, spirituality, complementary care. There I learnt in practice that we can only care of people if we consider each person as a special one, complex, with very specific needs and looking after their own fulfilment.

As it was the first part on my internship in Australia, the differences in communication had a lot of impact to me. Probably because of their different culture, the patients want to know more and to decide things by themselves; or at least, they express more their wishes. This background changes a lot the kind of communication that takes place there. Health professionals are much more transparent, clear and aiming to involve patients and families in decisions. Consequently, the communication is very different. I think I've learnt a lot about techniques on communication and I have this new model to inspire my interaction with patients in the future in Portugal.

4.2.2 Community

This experience was very surprising concerning the intimacy it took place in.

The possibility to live the end-part of their lives at home is a very common wish, however unfortunately it's not possible to a lot of patients for many reasons (lack of health or social resources, no family available to care for them, fears and superstitions). In Portugal, I think there are two main reasons for that: people actually don't see death as a natural part of life (as consequence of medicalization of life and death) and, because of this, society don't have the resources to take care of people who want to die at home.

In Australia, some of those stigmas are still present, but it is already possible to see a big group of people wanting to change it and creating ways to make it possible.

Regarding this wish, the community team have a plan to able patients and families who want to be at home while is possible, preferentially until their death, if they wish to.

They do home visits, first to know people and needs, and then to accompany them in their diseases, helping them to have what they need.

They do it in collaboration with district nurses who supply the basic care with more frequency, supported with the expertise of this group.

Make this possibility a reality in Palliative setting is, in my point of view, an upgrade in quality of life of the patients who want it. It allows those patients and families to live a more personal time, with the ones who they love, with dignity and fulfillment.

I want to highlight also the 'Initial Assessment Clinic'. It's a very complete approach to the patients who recently receive the news of their terminal illness that allows them, with a lot of dignity, to be informed, to plan their lives, respecting their wishes and desires. It also allows them to be more confident on the palliative care time who will accompany them, respecting what they want.

4.2.3 Liaison

The liaison team works in every department of Flinders Medical Center, where they are asked to. It is an authentic team work, since they are called to see patients of every condition and asked to help from symptomatic control to complex decisions or to integrate patients at the hospice.

The patients differ a lot in specific problems to solve, as well the teams of each specialty do; so, the level of intervention is really singular.

I think one of the most important competence I've developed here was the communication, in every level: from the communication with different professionals of the teams involved, to the patients and families. As I've referred previously, it's encouraging for me, when I back to Portugal, to have a more involving interaction with patients and families.

4.3 EDUCATION

During my placement in UCCP (Hospital da Luz, Lisboa) I integrated the education meetings, attending to that every week, and doing a presentation as planned.

I presented the journal club session about*" Infeções Urinárias Associadas a Cateter Vesical: Contributos para a prática clínica" (Urinary tract infections cathether-related: contributions for clinical practice").* This topic was chosen because of a patient we were caring for during that time.

During my placement in SAPS (Adelaide), I integrated the education meetings, attending to that every week, and doing a presentation as planned.

I was invited to do a reflection about Palliative Care in Portugal and my aims to do the internship in Adelaide. In the end, I did a presentation about the research work I did during my stay in Australia.

4.4 CASE ILLUSTRATIONS

T., 43-years old woman*, Portuguese, lives with his husband and 17-years-old sun. She was computer engineer and she is unemployed for 8 years, after the diagnosed of a brain tumor. She had a surgery and radiotherapy and she was the next years in remission. During this period, she couldn't go back to work, because she had diplopy. She was diagnosed of re-incidence of the tumor with big local extension, 7 months ago, after start feeling difficulty in moving her hands for precise movements. She did palliative radiotherapy. She knows about the diagnosis, but she keeps the hope of being cured, since she developed some periods of amnesia and a puerile behavior.*

She is admitted at the UCCP Hospital da Luz because of uncontrolled anxiety and insomnia, as well as for respite care (her husband is working and unable to sleep because she is awake all night long.

This period was an opportunity to manage some problems:

- Anxiety and insomnia – T. suffer with severe insomnia, very difficult to be controlled, need big doses of sedatives. Despite looks serene during the day, she has a lot of symptoms that after all were not confirmed, suggesting somatization of her anxiety. The psychologic approach was very helpful, but hard, regarding her behavior and amnesia. After the recent worsened in her dependence, we found out that she felt calmer at the hospice, because she was not feeling a burden for his wife.

- Tiredness - T's husband cares of her after work and he was feeling exhausted psychologically and physically because of the accumulation of 8 years of disease and he keeps working and unable to sleep during the night; the social worked reviewed the helps for T's family and all the team reinforced with his wife the importance of care for herself, so she can care of T.

- Denial – as her mother behavior and reason were unstable, her sun starts to deny all the situation. He grew up seeing a sick mother, so he said everything was ok. The work of the psychologist was really complex but very important to help him deal with his mother disease.

Some actions took place there just in continuity of his care and supporting his dignity:

- Beauty and wellbeing – she loved fashion and hairstyle, so the team motivated her family to make her participate in the choice of her clothes and she had the visit of her hairdresser and nail professional often.

- Family events – as family is really important for T., her family used to plan some events outside, so they could spend some time together: walking by the river, having dinner together.

- Plan of care – it was a big challenge since T. conscience and memory has huge variations, so the discussion of her plan was supported by her husband. They plan to go back home intermittently, coming back to hospice when the care at home would be unbearable for her family. It was what happened, but T. could spend a big time with quality at home, as she wished, in the meantime.

Through this case, I want to highlight some points of learning:

- Intensive symptom control – the symptom control is the basis for the wellbeing of the patient, only when controlled, the patients can be able to enjoy their lives.

- Communication and plan of care – communication with mentally disable people is a big challenge. They can keep some ideas, desires and dreams that should be respect and considerate for their plan.

- Psychological approach – in this family the psychological burden was huge, and it was the main problem creating and worsening the other problems. The intensive

psychological approach, not only by the psychologist, but all the team was determinant to reach some tranquility for this family.

- The concept of total pain – besides it wasn't a patient with uncontrolled pain; one of the somatizations was an unspecific pelvic pain. We realized that it was related to his son didn't want to visit her this day; it all resolved after his visit in the next day. This episode made me more aware of the concept of total pain, as complex symptom as patient is.

- Supporting dignity – all the small details able patients and family to enjoy more the time they have together, and they are essential for their quality of life.

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J., 40 years-old men, *Australian, lives with his wife and 6 years old daughter. He was diagnosed with a moto-neuron disease 4 years ago. Nowadays he is bedridden, unable to move any member, so he communicates with an adapted computer. During the last 9 months, he needs more and more support on the non-invasive ventilation, currently every 24h and becoming insufficient for an adequate ventilation.*

He is supported by the SAPS community team as well as the motor-neuron specialized team (both teams working together). Since the beginning they discuss together (J., wife and both teams) the plan for his disease. He established that we would like to have invasive measures, if it means prolongation of his life, so he could accompany his daughter life the more he could.

Now, regarding the insufficiency of the non-invasive ventilation, they re-discussed the plan and they decide the tracheostomy for mechanic ventilation in ambulatory.

J. was admitted for the procedure, with the plan of staying two nights in Intensive Care Unit. The intervention has happened without complications, so he has transferred to the hospice for immediate care and for family learning how to deal with the tracheostomy.

Both teams visited J during his stay at the hospice, improving the confidence to J. and his family and the continuity of care, with the share of information between teams.

This period was an opportunity to identify some problems that can be improved for better quality of life to J and his family, such us:
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- Anxiety and insomnia - both J. and his wife were overwhelmed with the care of the tracheostomy, the suction of secretions, doing it so often that it only increased the production), because of that, they weren't able to sleep, since his wife aspirated it every hour. After explanation and their understanding, they started to be calmer about it, and sleeping better after adjusting of sedatives.

- Tiredness - J's wife cares of him 24-7, so she was really exhausted psychologically and physically; the social worked reviewed the helps for J's family and all the team reinforced with his wife the importance of care for herself, so she can care of J.

Some actions took place there just in continuity of his care and supporting his dignity:

- Spirituality - he received frequent visits of his Buddhist spiritual leader and had some ceremonies together with family and friends

- Birthday party – during his stay, his birthday party took place. He was taken to the community room and outside to the rooftop and he received the surprise visit of his friends and family, as well as his daughter class that came to sing him some songs.

- Some personal affection – J. has specially fondness for reading and languages. Daily his family and some volunteers visited them to read books that he liked. He speaks some different languages, one of those, Portuguese (because he lived in Brazil in the past), so often I spoken in Portuguese with him, about what he used to do in Brazil and some other personal stories.

Through this case, I want to highlight some points of learning:

- Communication and plan of care – the adequate and clear communication and early approach of the palliative patients allows to establish a plan which is realistic and adequate for each patient, regarding his desires and supporting his dignity

- Organization and specialization of the teams – it's notable the difference that a specialized team can do in complex cases, ensuring the best care for patients and the continuity of care in all settings, which gives t patients and families de feeling of security and well-being.

- Supporting dignity – the smallest details can be the most important for patients and families, but this is only possible knowing people, with time, and with the help of well training volunteers.

5. RESEARCH

Death doulas: Is medicine giving patients what they are looking for?

5.1 Context

For 10 years, CareSearch palliative care knowledge network has been assembling and disseminating evidence, becoming the major online source for palliative care evidence in Australia, funded by the Australian Government Department of Health. It enables the provision of evidence based palliative care information and materials to be readily accessed to those that seek it. Conducting a “Dying to Learn Massive Open Online Course” in 2016, they discovered an emerging area of home support provided by a Death Doula.

If healthcare systems and professionals are not meeting the needs of the patients and their families, the gaps in their care will be replaced by other agents who can advocate for them. The role of Death Doula is developing in the end of life space.

During my placement I was invited to collaborate in the CareSearch project, aiming to better understand this new role in Palliative Care – Death Doula.

Doula is an Ancient Greek origin word, which means the woman who serves another woman[4]. It has become more commonly used again recently as a supportive lay woman who helps in birthing process[5]. Doulas have been described as non-clinical professionals, most of the time paid for their service. They complement the role of health professionals focusing on guidance and support for the pregnant women[6].

This informal role has been adapted into contemporary models of care such as illness doulas[7], delirium doulas[8] and cancer care doulas[9]. Following this trend in changing models of care, doulas are now emerging in the end of life domain. They are called a different range of names such as death midwife, end-of-life doula, deathwalker and Palliative Care doula.

There are some official organizations which support education and promotion of this role in UK, USA, Canada, Australia and New Zealand. Death doulas are also spreading into other countries in Europe, Latin America and Asia.

Besides the recent expansion and development, there are only a few articles which explain the role of a death doula. The death doula role was reviewed and described as a non-medical care worker that emphasizes personal happiness and satisfaction rather than an extension of life; sincerely heartfelt accompaniment based on intimate human relations; holistic care that encompasses the physical, emotional, social and spiritual facets of the dying person; continuous support by someone with the experience and maturity necessary to greet death as the culmination of life[10]. It includes conversation and education about disease and end-of-life, discussion of goals of care, advocating patient and family preferences and provides psychological and spiritual resources. The aim is to give patients and families a sense of control, increasing confidence in decision-making, decreasing stress and increasing peace and tranquility[11]. Some are paid as a job, others are volunteering, but they undertake learning through official training programs within health services, such as the "Doula to Accompany and Comfort Program" taking place in Dallas, USA. This is a program for volunteers trained by professionals in the stages of death and dying, grief and grieving, advocating for patient needs, comfort touch, compassionate presence, active listening, communication strategies and spiritual and cultural beliefs in end of life[12]. Death doulas are also involved in events addressing the promotion of death conversations within community, supporting discussion and awareness[13].

Assuming that an examination of written media may generate knowledge and evidence contributing to better understanding of their role, motivations and circumstances in which they can be useful for the process of dying for seriously ill people and within the family and the community, this study aims to describe and critically analyze the death doulas related news items which have appeared during the last year in the English written media.

5.2 Research questions

This study examined the followed questions:

1. What is the role and focus of a death doula?
2. What is the reason for the appearance of the death doula?
3. Why do people become a death doula?
4. How are they integrated in the framework of care and within the society?

5. What we can learn about this new role to improve the palliative care approach and the relationship between health services and informal carers like death doulas?

5.3 Methodology

Literature Review

A qualitative content analysis was used to describe the role of death doulas and their characteristics that can help us to understand better this new protagonist of end-of-life caring. We selected all the news items, printed or digital, publish in English during the period of a year (from December 2016 to November 2017), regarding better accessibility to recent news.

We engaged a media company who provided us the items by searching the terms “death doula” and “death midwife”. It was conducted from their database of print, television and radio (summaries) and online news archive. The search included international coverage of online media and Australian printed news. The initial search identified 127 articles.

This coverage reached a cumulative audience of 2,822,715 and had an advertising space rate of AUD 1,379,978. Online News had the highest volume of coverage (94 items or 73% of the total volume of coverage), Television (TV) reached the highest audience (1,274,000 or 45% of the cumulative audience) and TV had the highest advertising space rate (AUD 865,215 or 62% of the total advertising space rate).

These were read by researcher AP, and those not featuring any link to death doulas or death midwives were excluded – 22 articles (examples: a midwife who talks about death; news with a footer link to related articles talking about death doulas). Also the articles which the content was not available were excluded – (N=11 articles) – and 2 articles which were repeated were excluded as well.

Content Analysis

Due to a lack of a developed and validated questionnaire to characterize news related to the role of this new role, the researchers developed a two-part questionnaire to characterize each news item, regarding formal and content approaches. The first one included: the nature of publication, intended audience, length and tone of the article.

Regarding the content, the researchers defined the following coding system: author (death doula or not), nature of the content (interview with a death doula, written about a death doula, about a family experience with a death doula), role of a death doula, sentiment about a death doula, reasons why death doulas appear, reasons for people becoming a death doula and special topics).

A first draft of the questionnaire was developed by researcher DR and applied to 25 random news items. Researcher AP added commentaries and new topics, and then discussions were held with all of the researchers to reach a final agreement. AP then coded all of the articles and DR and JT conducted double coding. They combined the coding, and discussion to arrive at agreement with the final coding.

This was the extent of my direct involvement within the research project as my internship came to a conclusion. The statistical analysis is currently being performed and I look forward to contributing to the published article from my work in Australia. An abstract for a poster was submitted to presentation during EAPC 2019 Congress (Appendix 1).

5.4 Limitations

Concerning its limitations, our media review was based on the news articles provided by a media agency, through its database. The search included international coverage of online media, but only Australian printed news, limiting our reach.

5.5 Content Analysis

From that work, I understood that the role of a death doula provides psychological support, information and resources, and is present in the terminal phase and at the time of death. I also understand that they communicate with people in order to meet their needs and desires. They connect people, give meaning to the end of life, support and empower dying people and families to death and help families to cope with grief. Their arrival into the end of life space has come mostly from the need of empowerment during the dying process, giving alternatives to modern clinical approach, shifting towards awareness and choice. Death doulas are increasingly present in public events and some recognized as celebrities.

5.6 Implications for my clinical practice

For me, working on that review was a surprise. I was not reading about death doulas, but about patients and families perspectives, about their expectations, desires, fears and disappointments during the process of dying. I was learning not only about death, but about life as well.

During this time, I had an amazing opportunity to meet the inspiring Zenith Virago (one of the first “death doulas” in Australia) and to participle in her “Deathwalking training” (a weekend workshop for death doula training). It was an immersive experience in their reality and provided me contact with a group of people who were training to be death doulas. I listened to their point of view, their motivations to prepare themselves for this job and their questions and objectives. It was also a lovely time to think about my own, my family and my patients’ death and life.

My understanding is that the new role of death doulas came to embrace some spare space in end-of-life care. They seem to be created by the patients’ need to promote balance in their dying process: prevent or stop the excessive medicalization of end-of-life care, thus bringing meaning and spiritual comfort.

A lot of questions were raised for me: Can this new role at end-of-life care teach health systems about what dying people and their families want? Maybe they are showing us, health professionals, we should focus our practice more on patient needs and desires.

This experience made me realize deeply that human beings search for their personal development and interior fulfilment until the end of their lives. It’s as important as their symptom control to feel dignity, spiritual comfort and peace. As professionals taking care of people in the last part of their lives, while these dimensions are crucial for their quality of life, is our responsibility to recognize that and provide the means for them to access it. There are so many creative ways to do it. If not, the society, the patients and their families will find the way. It is in our hands to enable it by a more integrative approach, preventing additional suffering for patients.

Going back to Portugal and my job as an Internal Medicine Registrar, I have contact everyday with palliative care patients. I think I now have more awareness of the patients and families’ point of view. I aim to include their desires and wishes in my daily practice. And my experience with the deathwalker training has meant that I return to Portugal even more grateful for my life.

6. Discussion

Regarding my aims, I want to reflect about the work I developed during those two placements, supported by the General Guidelines for the Master degree *(Regulamento Geral do Mestrado)*[2] and the *EAPC White Paper on Palliative Care Education*[3], as described before:

Symptom management and control

During this period, I had the opportunity to accompany a lot of patients, learning with them and with the approach to each one of them. I attended to 235 patients, in all range of diseases, stages, symptom complexity and needs.

In all those experiences, I found out the utility of the systematic assessment to patient's symptoms and performance status.

In UCCP, they use to apply Karnovsky Scale at admission to assess performance status (if applied), and Edmonton Symptom Assessment Scale (ESAS) to assess symptom control at admission and every day. In SAPS, they use to apply the Australia-modified Karnofsky Performance Status (AKPS) scale to assess performance status at admission to the hospice or on every evaluation, as well as the palliative care phase (stable, unstable, deteriorating, terminal and bereavement) and the symptom assessment by ESAS.

The performance status assessment allows the clinician to understand the functional status of the patient, as well as the evolution of the disease, to adequate the measures and to do a plan, together with the patient and families. The symptomatic assessment allows the clinician to better understand the problems and needs of the patient, because it is very common to fail some areas if we are not doing that in a systematic way.

Psychosocial, spiritual approach and communication

Regarding my aim to learn how to meet patients' psychological, social and spiritual needs as well as their families' needs, I had the opportunity to accompany the teams approaching all of those areas of the existence. Being involved in a multidisciplinary

approach in these fields, I've learnt some techniques about how to assess and manage those matters.

I've also developed and improved my communication skills about illness understanding, prognosis and end-of-life preparation.

In Portugal, our studies in Medicine do not include training in communication, so that's a main focus for me. Starting in UCCP, this topic was really surprising. I was motivated to read about it and to learn methods of better communicate, listening to the staff every day contacting with patients and then I've applied it, with their help, doing it by myself.

In Australia, I've been astonished by the main focus on patients' needs and desires. Besides what we learn in Ethics - that patient should have the lead, deciding what he/she wants or not - in Portugal it's very common the paternalistic attitude in which doctors decide what they think it's the best for the patient. In contrast, in Australia health professionals are very direct, explaining clearly with the details patients ask for, regarding good information for good decisions. In that way, patients are more skilled to make their decisions and health professionals respect them and practice it.

System implementation and functioning

Working in those two excellence Palliative care centers allowed me to have awareness about a complex and well-established palliative care system, how it is structured, how it works and how it is integrated in the community.

It was really rich to do that in such different places, so I could understand the diverse possibilities we have to care in Palliative Care. Every different professional, patient, culture and reality taught me personal and professional competences in how to deal with varied situations, from simple to complex cases.

Research initiation in Palliative Care

In SAPS, I had the chance to introduce myself into the research field of Palliative Care, centered on improving patients' well-being and quality of life.

I was suggested to work in a completely new area for me, with qualitative methods, also a new experience, regarding the more common use of quantitative methods in Medicine.

This experience to study about death doulas and this big and interesting area of preferences in end-of-life care was a key point of reflection during my internship. This made me formulate the question: "*Is medicine giving patients what they are looking for?"* and I was reflecting long time about that.

As I've referred before, it showed me how patients and families are not satisfied with the kind of care we are giving them, so they are looking for someone else who can respect their decisions, desires and wishes. It gave me the awareness of the importance of respecting people decisions, allowing them first to understand their condition so then they can decide in accordance to it.

I've also gained experience in writing a paper for peer review and publication from the research work undertaken during this internship.

7. Conclusions

I've written this report aiming to do a reflection about the internships I've done and the competences I've acquired, regarding full for the degree of Masters in Palliative Care.

More than achieving this aim, I consider I got a professional upgrade and a personal fulfilment that I couldn't imagined before.

As acquired competences I want to highlight three: a good basis in symptomatic control; the understanding of the patient as a spiritual, psychosocial, social being throughout good communication and the knowledge and experience of diverse health systems.

Those experiences made me reflect a lot about the way we care of our patients. I should emphasize the idea I've realized about the huge difference from how patients want to be treated and how health professionals think they should be treated. Reflecting about it has a massive impact in the way I understand patients and families, communicate with them, plan and decide. I think this consideration will change my practice in Palliative Care, but also in Medicine.

For all of that and more, I want to thank the two teams of UCCP Hospital da Luz and SAPS Adelaide for the kindness welcome and integration as a team element that allowed me to learn actively with their own expertise. I want to acknowledge the research team of CareSearch for trusting me and allowed me to take part in their projects and Zenith Virago and her class for making me immerse in death doulas' edge. Finally, I want to thank specially all the patients and families who teach me so much about life and death.

I have the desire of work in Palliative Care, so I can apply all the knowledge and experience I got from these two internships. Anyway and anywhere I work, I know I can make difference in my daily practice in Medicine and I can help to change and improve the care of palliative patients in Portugal.

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9. Appendix

Appendix 1.

ABSTRACT: Death doulas media scoping: media review

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Aim

If health care systems are not meeting the needs of their population, people will find others to provide care, advocate, and fill in the gaps in care. The term, “doula” is a Greek word meaning a woman caregiver. Better known in their work in birthing, death doulas are a newly emerging phenomenon with little formal literature investigating this role.

This study looked at media reports on death doula to explore their role, care practices and characteristics as well as the meaning of their appearance for end-of-life care systems.

Methods

We engaged a media company at the end of 2017 to provide a report of media items retrieved by searching for “death doula” or “death midwives”. The search was conducted within their database of print, TV & radio summaries and online news archive. The initial search identified 127 articles with 93 items being included following removal of repeated and non-related articles.

Results

The media items included news reports, interviews, videos and reports of doula training. The following roles were described:

• providing psychological support, information and resources,

• being present around the time of death,

• understanding and the person's needs and desires,

• connecting people,

• giving meaning to the end of life,

• supporting and empowering dying people and their families, and

• helping families to cope with grief.

The media reports also suggest that the role has arisen in response to a need for empowerment during the dying process, giving alternatives to the modern clinical approach and shifting the emphasis towards awareness and choice.

Conclusion

This new role seems to reflect a desire for different approaches and ways of caring at the end-of-life. Such new roles remind us as health professionals that our practice needs to reflect the patients' needs and desires. Can the appearance of this new role in end-of-life care help health systems learn what dying peoples and their families want?