Caring in Palliative Care

Vitor Oliveira Parola

2018
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INSTITUTO DE CIÊNCIAS BIOMÉDICAS ABEL SALAZAR

Caring in Palliative Care
Vitor Sérgio de Oliveira Parola

Vitor Oliveira Parola. Caring in Palliative Care

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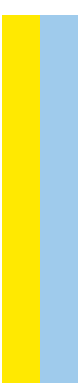
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CARING IN PALLIATIVE CARE

Thesis Application for the Doctor of Philosophy degree in Nursing Sciences, submitted to the Instituto de Ciências Biomédicas Abel Salazar.

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SCIENTIFIC PUBLICATIONS

Articles published in peer-reviewed journals

Parola, V., Coelho, A., Sandgren, A., Fernandes, O., & Apóstolo, J. (2018). Caring in palliative care—a phenomenological study of nurses' lived experiences. *Journal of Hospice & Palliative Nursing*, *20*(2), 180–186.
http://doi.org/ 10.1097/NJH.0000000000000428

> Nursing: Nursing
> JCR® Impact Factor (2017): 0.5
> Number of citations Scopus: 0
> Number of citations Google Scholar: 0

Parola, V., Coelho, A., Cardoso, D., Sandgren, A., & Apóstolo, J. (2017). Burnout in palliative care settings compared to other settings: a systematic review. *Journal of Hospice & Palliative Nursing*, *19*(5), 442–451.
http://doi.org/10.1097/NJH.0000000000000370

> Subject area: Nursing
> JCR® Impact Factor (2017): 0.5
> Number of citations Scopus: 1
> Number of citations Google Scholar: 1

Parola, V., Coelho, A., Cardoso, D., Sandgren, A., & Apóstolo, J. (2017). Prevalence of burnout in health professionals working in palliative care: a systematic review. *JBI Database of Systematic Reviews and Implementation Reports, 15*(7), 1905–1933.
http://doi.org/10.11124/JBISRIR-2016-003309

> Subject area: Nursing
> SJR® Impact Factor (2017): 0.3
> Number of citations Scopus: 5
> Number of citations Google Scholar: 6

Parola, V., Coelho, A., Cardoso, D., Gea-Sanchez, M., Blanco-Blanco, J., & Apóstolo, J. (2016). The prevalence of burnout in health professionals working in palliative care: a systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports, 14*(3), 45–50.
http://doi.org/10.11124/JBISRIR-2016-2633

> Subject area: Nursing
> SJR® Impact Factor (2017): 0.3
> Number of citations Scopus: 1
> Number of citations Google Scholar: 4

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http://doi.org/10.1016/j.pbj.0000000000000010

<div align="right">Subject area: Biomedical</div>

Abstracts published in peer-reviewed journals

Parola, V., Coelho, A., Sandgren, A., Fernandes, O., & Apóstolo, J. (2018). Caring in Palliative Care Context, Nurses' Lived Experiences: A Phenomenological Study. 10th World Research Congress of the European Association for Palliative Care (EAPC). Palliative Medicine. Volume 32, supplement 1, PO43, p.223.

http://doi:10.1177/0269216318769196

<div align="right">JCR® Impact Factor (2017): 3.780</div>

Parola, V., Coelho, A., Cardoso, D., Sandgren, A., & Apóstolo, J. (2018). The Prevalence of Burnout in Health Care Professionals Working in Palliative Care Setting: A Systematic Review. 10th World Research Congress of the European Association for Palliative Care (EAPC). Palliative Medicine. Volume 32, supplement 1, P53, p.80.

http://doi:10.1177/0269216318769196

<div align="right">JCR® Impact Factor (2017): 3.780</div>

Parola, V., Coelho, A., Cardoso, D., Sandgren, A., & Apóstolo, J. (2018). Burnout in Palliative Care Contexts Compared to Other Contexts: A Systematic Review. 10th World Research Congress of the European Association for Palliative Care (EAPC). Palliative Medicine. Volume 32, supplement 1, P55, p.81.

http://doi:10.1177/0269216318769196

<div align="right">JCR® Impact Factor (2017): 3.780</div>

Parola, V., Coelho, A., Alconada-Romero, A., Pastells-Peiró, R., BlancoBlanco, J., & Gea-Sanchez, M. (2016). The construction of the health care professional in palliative care contexts: a scoping review on caring for the person in the end of life. 9th World Reseach Congress of the European Association for Palliative Care (EAPC). Palliative Medicine, Volume 30, Issue 6, PO97 p.NP292.

http://doi.org/10.1177/0269216316646056

<div align="right">JCR® Impact Factor (2017): 3.780</div>

Parola, V., Coelho, A., Alconada-Romero, A., Pastells-Peiró, R., BlancoBlanco, J., & Gea-Sanchez, M. (2016). Construção do profissional de saúde no contexto dos cuidados paliativos: scoping review. Atas do V Congresso de Investigação em Enfermagem Ibero-americano e de países de língua oficial portuguesa. Revista de Enfermagem Referência, suplemento ao n.º 9, série IV, p.146.

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ABSTRACT

With the increase of people in need of Palliative Care, more and more nurses experience caring for the person in this context, which is a professional and personal challenge with implications that deserve to be analysed.

Objectives: To map of the literature on the elements contributing to the construction of the health care professional in the context of Palliative Care; To examine the evidence on the prevalence of burnout among health professionals working in palliative care; To review the literature on the effect of working in palliative care settings, compared to other settings, on burnout among health care professionals; To understand the experiences of nurses who provide care in a Palliative Care Unit.

Methodology: In order to respond to the 1rst goal was conducted a Scoping Review based on Arksey and O'Malley framework. For the 2nd objective it was conducted a Systematic Review of Prevalence. To accomplished the 3rd goal was performed a Systematic Review comparing contexts. Both Systematic Reviews followed the guideline of the Joanna Briggs Institute. To respond the 4th goal was conducted a phenomenological qualitative study in accordance with the procedural steps of Amadeo Giorgi and according to Joice Travelbee's Human-to-Human Relationship Model.

Results: In the Scoping Review from a total of 3632 articles, 22 met the inclusion criteria. Of these, 18 provided data related only to nursing professionals. The content of the studies were described and classified in five elements: Construction and application of the concept of care; Psychosocial effects that the daily care produce; Knowledge mobilized in the provision of care; Strategies adopted by health care professionals to build relationships; Working conditions that influence the caregiving provided. In Systematic Review of Prevalence eight cross-sectional studies have been identified. Data revealed a prevalence of burnout among health care professionals of 17.3%, and the sub-scale of the Maslach Burnout Inventory - Personal Accomplishment is the one with a biggest prevalence. Nurses have more high level of Emotional Exhaustion and Depersonalization and physicians have more low level of Personal Accomplishment. Nevertheless, the prevalence of burnout is bigger in Social Workers. Home Care is the context with the biggest prevalence of burnout. In the Systematic Review comparing contexts of the 539 studies retrieved, 7 cross-sectional studies were included. Of these, six were conducted with nurses, and it has been observed that working in palliative care was associated with lower levels of Emotional Exhaustion and Depersonalization, as well as higher levels of Personal Accomplishment, compared with working in other settings. In the qualitative study, five themes emerged and reflect the

essence of the lived experience: experience centred on the relationship with the other, experience centred on the relationship with one's own, team as a pillar, exhausting experience, and rewarding experience.

Conclusions: From the construction of the health care professional some aspects in future investigations should be addressed: prevention of emotional exhaustion, depersonalization and achievement of a greater personal accomplishment. Data revealed also a prevalence of burnout among health professionals of 17.3%, however working in PC was associated with lower levels of burnout compared to working in other settings. Caring for palliative care favours an experience centred in the relationship with the patient and the family, but also in the relationship with the self, opening space for personal development. It is an exhausting experience because of the frustrated attempt to distance oneself and the feeling of powerlessness in the face of the suffering of the other; however it conquers the living undergoing an enriching experience, mediated by recognition and a sense of usefulness. Among the team there is a sharing relationship that represents the pillar of the whole experience.

RESUMO

Com o incremento de pessoas com necessidade de Cuidados Paliativos, cada vez mais Enfermeiros vivenciam o Cuidar da pessoa neste contexto, sendo este um desafio profissional e pessoal com repercussões que devem ser alvo de análise.

Objetivos: Mapear a literatura acerca dos elementos que participam na construção do profissional de saúde em Cuidados Paliativos; Sintetizar a melhor evidência disponível sobre a prevalência de *burnout* nos profissionais de saúde que prestam cuidados em Cuidados Paliativos; Sintetizar a melhor evidência disponível sobre qual o efeito de trabalhar em Cuidados Paliativos no nível de *burnout* dos profissionais de saúde, em comparação com profissionais que trabalham noutros contextos; Compreender as vivências dos enfermeiros que prestam cuidados numa Unidade de Cuidados Paliativos.

Metodologia: Para dar resposta ao 1º objetivo foi realizada uma Scoping Review em concordância com a metodologia proposta por Arksey e O'Malley. Para dar resposta ao 2º objetivo foi realizada uma Revisão Sistemática da Literatura de Prevalência. Para cumprir o 3º objetivo realizou-se uma Revisão Sistemática da Literatura comparando Contextos. Em ambas as Revisões Sistemáticas da Literatura foi usada a metodologia proposta pela *Joanna Briggs Institute's*. Para concretizar o 4º objetivo realizou-se um Estudo Qualitativo Fenomenológico, seguindo o método proposto por Giorgi e tendo como referencial o Modelo de Relação Pessoa-a-Pessoa de Joice Travelbee.

Resultados: Na realização da Scoping Review, dos 3632 estudos identificados através da pesquisa, foram incluídos 22 na revisão. Destes, 18 aportavam dados relacionados unicamente com os profissionais de enfermagem. Foram identificados cinco elementos do conceito em estudo: Significado do conceito de cuidar; Efeitos psicossociais que o cuidado diário da pessoa em fim de vida produz; Conhecimentos mobilizados na prestação do cuidar; Estratégias adoptadas pelos profissionais no processo de construção das relações; e Factores que afectam a prestação do cuidado prestado. Na Revisão Sistemática da Literatura de Prevalência foram identificados oito estudos transversais. Os dados revelaram uma prevalência de *burnout* nos profissionais de saúde de 17,3%, sendo a subescala do *Maslach Burnout Inventory* - Realização Pessoal a que apresenta uma maior prevalência. Os Enfermeiros apresentam valores mais elevados de Exaustão Emocional e Despersonalização e os Médicos apresentam menor Realização Pessoal. No entanto, a prevalência global de *burnout* é superior em Assistentes Sociais, sendo os Cuidados Paliativos Domiciliários o contexto com maior prevalência de *burnout.* Na realização da Revisão Sistemática da Literatura Comparando Contextos de cuidados foram incluídos sete

estudos transversais, dos 539 estudos identificados. Destes, seis foram realizados com profissionais de enfermagem, verificando-se que os profissionais que prestam cuidados no contexto dos cuidados paliativos apresentam níveis inferiores de Exaustão Emocional, níveis inferiores de Despersonalização e maior Realização Pessoal do que os profissionais que exercem em outros contextos. Relativamente ao estudo qualitativo, cinco temas reflectem a essência da experiência vivida: Experiência centrada na relação com o outro; Experiência centrada no próprio; Experiência desgastante; Experiência gratificante; A equipa como pilar.

Conclusões: Os estudos realizados evidenciam a necessidade de em futuras investigações se abordar a prevenção da Exaustão Emocional, da Despersonalização e consecução de uma maior Realização Pessoal/Profissional. Evidenciam ainda uma prevalência de 17,3% de *burnout* em profissionais que prestam cuidados em cuidados paliativos, e que os níveis de *burnout* são inferiores em profissionais que cuidam em cuidados paliativos em comparação com profissionais que cuidam em outros contextos. Cuidar em cuidados paliativos favorece a vivência de uma experiencia centrada na relação com o doente e com a família, mas também na relação com o próprio, abrindo espaço para o desenvolvimento pessoal. Tratando-se de uma experiência desgastante pela tentativa frustrada de distanciamento e pelo sentimento de impotência face ao sofrimento do outro. Contudo predomina a vivência de uma experiência enriquecedora, mediada pelo reconhecimento e pelo sentimento de utilidade. Entre a equipa existe uma relação de partilha que representa o pilar de toda a vivência.

Palavras – chave

Burnout; enfermagem; cuidados paliativos; pesquisa qualitativa; revisão sistemática

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OVERVIEW AND FUTURE DIRECTIONS

ABBREVIATIONS AND ACRONYMS LIST

ABTI   Abstract and Title

ABTIK   Abstact, Title and Keywords

AW   Areas of Worklife

CAPES   Coordenação de Aperfeiçoamento de Pessoal de Nível Superior

CoCoPop   Condition, Context and Population

EoL   End of Life

ESEnfC   Nursing School of Coimbra

Fig.   Figure

HCP   Health Care Professional

HPCT   Home PC Teams

HPCST   Hospital PC Support Teams

i.e.   Example

ID   Identification

JBI   Joanna Briggs Institute

MBI   Maslach Burnout Inventory

MH   MeSHTerms

RNCCI   National Network for Integrated Continuous Care

p.   Page

PC   Palliative Care

PCC   Populacion, Concept, Context

PCU   Palliative Care Unit

PICO   Population, Intervention, Comparator, and Outcome

PRISMA   Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RCAAP   Repositório Cientifico de Acesso Aberto de Portugal

SD   Standart Desviation

TDX   Tesis Doctorals en Xarxa

Teseo   Base de datos de Tesis Doctorales

TI   Title

UICISA: E   Health Sciences Research Unit: Nursing

UK   United Kingdom

USA   United States of America

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Appendix 6: Permission to reproduce the papers: *Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review* and *Caring in palliative care — a phenomenological study of nurses' lived experiences*.

INTRODUCTION

This thesis was developed within the Doctoral Program in Nursing Sciences at the Institute of Biomedical Sciences Abel Salazar - University of Porto, in partnership with the Nursing School of Porto, in order to achieve the degree of Doctor of Philosophy (PhD) in Nursing Sciences.

It is known that any research is presented as a process which will reveal a number of problems to solve. Investigate is purely to give simple answers to intelligent questions. This is done in a planned, rigorous and with the intention of conceiving knowledge. There are multiple reasons that may trigger interest in a particular research theme. As mentioned by Travelbee (1963, p. 72), "we must continually question the value of our achievement, continue learning, and actively seek to improve our ability (...) to gain increased understanding of our human condition".

The interest in the theme "Caring in Palliative Care" has grown over the years of experience in PC and therefore with the increasingly closer contact with this reality. The time spent with the patient's in this context, provided the tools to appreciate the value of PC in this unique moment of life, if it is meaningful and necessary the holistic care of the patient with PC needs, it is also important the ability to care and understand the health professionals which contact daily with patients in such unique circumstances.

As a result of medical advances, life expectancy is gradually increasing. Consequently, the number of people living with a chronic degenerative and disabling disease has increased (Worldwide Palliative Care Alliance, 2014). This has contributed to a growing need for palliative care (PC). According to the World Health Organization, PC is ''an approach that improves the quality of life of patients and their families facing the problems 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" (2002, p. 84).

Specifically, in Portugal, palliative care units (PCUs) are designed to provide comprehensive care for patients with more complex palliative needs, in situations of clinical decompensation or social emergency, such as severe caregiver exhaustion (Comissão Nacional de Cuidados Paliativos, 2016). It is estimated that each year over 40 million people need PC, including 20 million who are at the end of their life. Therefore, more health care professionals (HCPs) than before are needed to provide this care at the end of life (EoL) (Worldwide Palliative Care Alliance, 2014) .

The literature reveals that working in PC causes intense emotions that, which could lead to multiple stressful and demanding challenges, including establishing intense interpersonal relationships; addressing the multiple complex needs of patients and caregivers; making

significant ethical end-of-life decisions; and being in constant contact with people's suffering (Hernandez-Marrero, Pereira, & Carvalho, 2016; Kirsten A Tornoe et al., 2014). These challenges, if not treated in time, put the HCPs at risk of burnout (Maslach & Leiter, 2017; Pavelková & Bužgová, 2015). According to Pavelková and Bužgová (2015), working with dying patients is considered to pose an even higher risk of burnout than working in other areas of health care. On the other hand, there is also empirical evidence of greater professional satisfaction in professionals working in this field compared to those working in other contexts (Browall, Melin-Johansson, Strang, Danielson, & Henoch, 2010; García, Cortés, Sanz-Rubiales, & Valle, 2009).

This ambiguity demonstrates that nursing practice in PC is a complex endeavor and that more evidence is needed about caring in PC.

There are several studies in the literature about caring in PC, yet this literature is scattered, lacking therefore a map; is ambiguous, lacking the identification of the best evidence; and it has gaps, lacking the understanding of the experiences of the nurses caring in PC.

Considering the need for secondary and primary studies in this area, we have chosen to investigate Caring in PC in order to map of the literature on the elements contributing to the construction of the HCP in the context of PC; to examine the evidence on the prevalence of burnout among HCPs working in PC; to review the literature on the effect of working in PC settings, compared to other settings, on burnout among HCPs; and to understand the lived experiences of nurses caring in PC, having as theoretical basis the Joice Travelbee's Human-to-Human Relationship Model.

To achieve the research objectives, four studies were developed: a Scoping Review of literature, two Systematic Reviews, the realization of these studies, evidenced the need to perform a qualitative phenomenological study about caring in PC.

The thesis is organized in 5 chapters. In Chapter 1 we present the theoretical and scientific background of this thesis, we start this Chapter with the theme art of caring, and after we explain the evolution of PC. Then we explain the nursing theory supporting the PC approach of this thesis. This chapter ends with the theme burnout and health care.

In Chapter 2 we present the course of the research, offering a more global vision of the problem, presenting the guidelines that guide the research, with a general presentation of the aims to be achieved.

In Chapter 3, we present the Phase I of this thesis, the results of a scoping review of literature with the aim to map of the literature on the elements contributing to the construction of the HCP in the context of PC.

In Chapter 4, corresponding to the Phase II, we present a Systematic Review Protocol of Prevalence designed to examine the evidence on the prevalence of burnout among HCPs working in PC, based on data from the previous chapter. We also present, the results achieved by the realization of the Systematic Review of Prevalence, which objective, inclusion criteria and methods of analysis were fully documented in the Systematic Review Protocol. Furthermore, we present the results of a Systematic Review of literature conducted to explore the effect of working in PC settings, compared with other settings, on burnout among HCPs.

In Chapter 5, corresponding to the Phase III, we present a qualitative phenomenological study to understand the experiences of nurses who provide care in a PCU, following the method of Giorgi and according to Joice Travelbee's Human-to-Human Relationship Model.

To conclude we present a systematization of the most relevant results by objective, in an integrated perspective, in order to discuss the relevance and implications of the studies presented in this thesis.

CHAPTER I

THEORETICAL AND SCIENTIFIC BACKGROUND

The first chapter presents the theoretical and scientific framework that supports the development of the studies, and is divided into four sub-headings.

The first sub-heading presents the Art of Caring. In the second sub-heading is presented the Evolution of Palliative Care. In the third sub-heading is presented the Travelbee's Theory: "Human-to-Human Relationship Model", which was adopted to support this thesis. Finally, in the four sub-heading, Burnout and Health Care is presented.

1.1. The Art of Caring

Care is understood as a way of being, without care, we cease to be human. That care is what gives the condition of humanity to people (Waldow & Borges, 2011). In fact, caring is part of the basic needs for the survival of human life: caring for oneself, caring for others and being cared for (Collière, 1999).

According Waldow and Borge (2011, p. 417), "today, care assumes prominence in Nursing; with a need to review it, from a different perspective and to broaden its interpretation, considering it not only a scientific-technical activity, but elevating it to the status of art."

Art can be considered a medium for human-to-human contact, in which feelings are transmitted. Therefore, caring can be seen as a form of artistic expression, an art, to the extent that through this practice, the human being has the ability to clearly express personal feelings experienced, which, in turn, are also experienced by the receiver of care. The art of caring then emerges as a form of communication and expression of human feelings (Watson, 2002).

Morse, Solberg, Neander, Bottorff,and Johnson (1990) carried out an analysis of the definition of caring for thirty-five authors, arriving at the identification of a set of five categories for which caring is described in the nursing literature: 1) caring as a human state; 2) caring as a moral imperative or ideal; 3) caring as an affect; 4) caring as an interpersonal relationship; 5) caring as a therapeutic intervention.

The results of this study reveal the variety of components that constitute the care, but they reinforce that, whatever the perspective adopted, caring has the ultimate purpose of the person.

Caring is defined by different authors (Hesbeen, 2000; Honoré, 2004; Waldow & Borges, 2011) as being innate and a human characteristic. However from a professional perspective, more than a natural skill is required, nursing care is then provided with a particular knowledge (McCance, 2005).

In Morse et al. study (1990) they make an allusion to a possible distance of Jean Watson's theory (Theory of Transpersonal Caring) with practice, in that it proposes a model in which the relational dimension is highlighted, rather than the technical dimension. Despite some criticism, it is clearly recognized in Watson's proposal that the purpose is the cared person,

and that his work seeks above all to draw attention to the human dimension, because the technical one, and also very important, is the one that most easily seduces the nurses, who for some reason protect themselves from the involvement.

In fact, according to Urra, Jana and Garcia (2011), the theory of Jean Watson is useful, since it allows to propose a philosophy of care and a relationship between theory and practice that revitalizes lost aspects of nursing. Thus, caring for the nursing discipline comprises a human component but also a technical component and it is this partnership that characterizes and distinguishes nursing care from human daily care.

Still in this line of thought, it is important to distinguish between treating and caring. In this sense, Collière (1999), affirms that the terms should not be confused because, when confusing the care with the treat, all the living forces of the person remain passive, since they are not stimulated.

Treat is characterized by being objective, scientific and technical; ignoring the existence of the other, and the coexistence (the self and the other). Caring, without renouncing the scientific aspect, highlights the humanity between two humans beings (Watson, 2002). The care provided by the nurse must, therefore, focus on the person in a holistic/integrative perspective (Waldow, 2009; Watson, 2002)

Despite the existence of different definitions of Caring, it is possible to verify that all of them are based on an interrelationship between the cared person and the caregiver, being this interpersonal relationship the essence of Nursing care.

According to Hesbeen (2000) nursing care are the particular attention given by a nurse to a person and/or their relatives in order to help them in their situation. They encompass everything that professionals do, within their competencies, to provide care to people. By their nature allow always do something for somebody in order to contribute to their well-being, whatever their status. Also adds that what makes the essence of caring practice is the interpersonal relationship between the caregiver and the person receiving care (Hesbeen, 2000).

Also for Watson (2002), caring in nursing is above all a response in which the emphasis is placed on the relationship.

Likewise, for Levinas (as cited in Lavoie, De Koninck, & Blondeau, 2006), Caring is a responsibility that leads us to take care of the other. This responsible condition implies entering into relationship with the other, which refers us to caring as an interpersonal relationship. Levina (as cited in Lavoie et al., 2006) also mention that the attitude of compassion where one shares the suffering of the other is a difficult and demanding task; however, the absence of this impoverishes and distorts care.

Reinforcing how Caring is demanding, Hesbeen (2000) and Collière (1999) reported that the nursing care are complex since they are constituted by an universal dimension, but also cultural, situational and personal. In addition, they also deal with essential elements of human existence such as life, death, suffering, the person realization.

Waldon (2008) in turn, highlights the potential power of transformation that Caring represents for nurses and patients, referring that the caring process consists of all the activities developed by, for and with the care person, based on scientific knowledge, ability, intuition, critical thinking, creativity, accompanied by behaviours and attitudes of care in the sense of promoting, maintaining and/or recovering their dignity and totality. This includes the physical, mental, moral, emotional, social and spiritual dimensions in the stages of living and dying, constituting, ultimately, in a process of transformation of both, caregiver and cared person.

In summary, nursing care is characterized by scientific knowledge, technical and human dimensions that are interdependent between them. It aims at the holistic wellbeing of the cared person, being a demanding and challenging practice for the caregiver, and is potentially transformative for both.

1.2. The Evolution of Palliative Care

Let us begin by remembering where the term PC arises, which is Hospice, which calls institutions that care for the dying and is first used in 1842 by Jeanne Garnier in Lyon, France (Bruera, Higginson, Ripamonti, & Gunten, 2009; Doyle, Hanks, & Cherny, 2005).

Within this context in 1905 is founded St. Joseph's Hospice in London. It is important to note further that Cicely Saunders founded the St. Christopher Hospital in London in 1967, from which the hospice movement spread throughout the world (Bruera et al., 2009; James & Field, 1992).

In this regard, it should be noted that Cecily Saunders was the first to orient her professional practice towards the search for specific solutions for the needs of patients in EoL situation, giving rise to the philosophy and principles of what is now known as PC (Bruera et al., 2009; Richmond, 2005).

In addition, in 1963 Cecily Saunders visited Yale University. This contact facilitates the development of the hospice movement in the United States. This development was largely accomplished by the contributions of the Swiss psychiatrist, Elizabeth Kluber-Ross, who resides in the United States, and promotes a new view of the patient and his emotional phases in the process of dead from psychology. The first American hospice was founded in Connecticut in 1974 (Amenta, 1985; Bruera et al., 2009).

It is necessary to emphasize that in 1975 the term PC or palliative medicine, is replacing the term hospice in Royal Victoria Hospital of Canada. The term is more universal; less linked to a cultural environment and allows referring to all types of programs. In 1982 the World Health Organization also uses this denomination (Bruera et al., 2009). In Portugal, the PC movement began only in the 1990s, with the establishment of the Unit for the Treatment of Chronic Pain at the Fundão Hospital in 1992, emerging in 1995 the National Association of PC, an association of professionals from multiple health areas, focused on the development and practice of PC (Comissão Nacional de Cuidados Paliativos, 2016; Neto, 2010).

The World Health Organization revised the definition of PC for the last time in 2002, with the aim of extending the concept and making it applicable to all diseases, defining it as an approach that improves the quality of life of patients and their families, addressing the problems associated with serious illnesses through prevention, alleviation of suffering,

through prompt identification, proper assessment, treatment of pain and other physical, psychological and spiritual problems (World Health Organization, 2002).

Therefore, PC, although started with cancer, has progressed from this area and undergone an evolution, advancing in other areas of knowledge, so they go from cancer patients to patients with advanced and chronic diseases of any age (World Health Organization, 2004).

PC takes into account the concept of an active care that seeks to achieve comfort and autonomy. It tries to surpass the passive and resigned concept of the there is nothing else to do, as much on the part of the patient, of the family, as of the medicine in his curative vision (Gómez-Batiste, 2003; World Health Organization, 2014).

This new palliative mentality care, has been outlined, arguing that PC should not be limited to the last days of life, rather applied progressively as the disease progresses and depending on the needs of patients and families (World Health Organization, 1990, 2016). Patients can, of course, continue to have an active treatment, although aware of their advanced chronic disease.

On this subject mentioned that as a result of medical advances, life expectancy is gradually increasing. Consequently, the number of people living with a chronic degenerative and disabling disease has increased (Worldwide Palliative Care Alliance, 2014). This has contributed to a growing need for PC. In this regard, the World Atlas of PC, also reports that only one in ten persons in the world, in need of PC, is currently receiving it. In addition, it is estimated that each year more than 20 million patients need PC at the EoL (Worldwide Palliative Care Alliance, 2014).

In this context, the number of people requiring this type of care easily surpasses 40 million, if we include all the people who could benefit from this care at an earlier stage of their illness. Within this framework, it is still necessary to consider, as the definition of PC indicates, the support provided to the patient's family, which would more than double the number of care needs (Worldwide Palliative Care Alliance, 2014).

In Portugal, it is estimated that, in 2015, there are around 82.000 patients with palliative needs. In addition to these data, 62% of people die in the hospital in Portugal, which translates into about 66,000 deaths per year occurring in a hospital setting, and about 27,000 occurring at home. All services of primary health care, pre-hospital, hospital and National Network for Integrated Continuous Care (RNCCI) should be able to identify patients with palliative needs, provide an appropriate palliative approach (for example, the RNCCI has 169 beds designed for less complex situations - RNCCI-PCUs), and, in the event of increased clinical complexity, seek support from specific PC teams. Thus, when there is a need for specialized PC, there are, in particular, support teams (Home PC Teams (HPCT) and

Hospital PC Support Teams (HPCST)) and inpatient PCU's in hospitals, designed to respond to this need (Comissão Nacional de Cuidados Paliativos, 2016; Gonçalves, 2018; Observatório Português de Cuidados Paliativos, 2017).

In Portugal, in 2017, 70 hospitals were identified having HPCST and there are two Pediatric-HPCST. In 27 hospitals, the support is timely, provided when requested by a team based at another nearby hospital. There are 26 known HPCT, highlighting the lack of HPCT in more than half of the regions, and the inner center of Portugal a particularly deprived area in this type of offer. In relation to PCU`s, 32 were identified, noting that seven regions do not have any PCU (Gonçalves, 2018; Observatório Português de Cuidados Paliativos, 2017). In Portugal, specifically, PCUs are designed to provide comprehensive care for patients with more complex palliative needs, in situations of clinical decompensation or social emergency, such as severe caregiver exhaustion (Comissão Nacional de Cuidados Paliativos, 2016). Additionally, with respect to the curriculum, several protocols were signed between the Ministry of Health and Schools of Medicine, Nursing, Psychology and Social Work to introduce PC in the undergraduate curriculum (Gonçalves, 2018). Figure 1 presents the organisational model of the portuguese palliative care network.

Figure 1: The Portuguese Palliative Care Network – Organisational Model (Gonçalves, 2018).

We could say that the development of PC will depend in great part on the capacity of HCPs to incorporate in their daily practice palliative therapeutic orientation, so that patients affected by advances and chronical diseases can have the least possible suffering and the best accompaniment available (Benítez Del Rosario & Asensio Fraile, 2002; World Health Organization, 2016).

The HCP, in the case of the death of a patient, will be by force of circumstances, someone who will endure the tense situation that this whole process can generate, since the HCP finds

himself with the inevitable end of a person for whom nothing more can be done to save his life, even though there are innumerable contributions of care that can be lend, and for that the HCPs must manage faithfully their values and emotions, trying to use forms that legitimize their professional and personal identity (Cruz Quintana, García Caro, Schmidt Riovalle, Navarro Rivera, & Prados Peña, 2001; Sekse, Hunskår, & Ellingsen, 2017; Sleeman, 2013; Kirsten Anne Tornoe, Danbolt, Kvigne, & Sorlie, 2015). This reminds us of the fact that although the caring in PC is based on interdisciplinary team work, care for the person is essentially a nursing concern, since the nurse deals closely and for longer with the suffering of the patient (Martins & Basto, 2011; Sekse et al., 2017; Thornburg, Schim, Paige, & Grubaugh, 2008).

Therefore it is important that the HCP, and specially nurses, has the capacity to adapt the way of facing the PC situation of the patient, and to the extent possible to incorporate wise knowledge of the whole event.

Therefore the primary objective of PC is to give priority to the best quality of life possible for the patient and his family throughout the process, offering an integral attention that will help to live as actively as possible, reducing as much as possible the suffering by offering the possibility of making decisions, respecting convictions and values that have guided their existence until their death (Coelho, Parola, Escobar-Bravo, & Apóstolo, 2016; Ortiz, 2014; Tsalatsanis, Hozo, & Djulbegovic, 2017). For that reason, being nursing practice in PC complex, more evidence is needed about caring in PC.

1.3. Travelbee's Theory: "Human-to-Human Relationship Model"

A nursing theory provides the theoretical background to this research – the "Human-to-Human Relationship Model".

Joyce Travelbee develops the Human-to-Human Relationship Model presented in her book entitled *Interpersonal Aspects of Nursing* (1966, 1971). Travelbee was a nurse that was born in 1926, she published several articles predominantly in the mid-1960s and died at a young age (47) in 1973. Travelbee's theory extended the interpersonal relationship theories of Hildegard Peplau and Jean Orlando, and her distinctive synthesis of their ideas distinguished her work in terms of the therapeutic human relationship (Pokorny, 2014).

Travelbee's theory has significantly influenced the hospice movement, according to her, nurses should find meaning in their experiences of caring for the patients, and human-to-human relationship is the means through which the purpose of nursing if fulfilled (Pokorny, 2014; Travelbee, 1971). Therefore, this theory provides an adequate framework for Palliative nursing care.

Travelbee believed nursing evolved through human-to-human relationships, involving empathy and sympathy, and being the achieving of a genuine nurse to patient contact a prerequisite to meet the goals of being a nurse. Furthermore, the goal of nursing is assist a person and/or family to prevent or cope with the experiences of illness and suffering and, if needed, to find meaning in these experiences, with the ultimate goal being the presence of hope (Pokorny, 2014; Travelbee, 1966, 1971).

The relationships established by nurses with the patients are crucial therapeutic interventions. Professional relationships and interactions are purposeful, being a resource to patients experiencing crises or in making transitions, with the intention to produce beneficial outcomes for patients, such as enhanced coping. The relationship between a nurse and a person or family is a central concept in nursing professional practice (Pokorny, 2014; Travelbee, 1964, 1971). Travelbee mentioned nursing needed a "humanistic revolution", an improved focus on compassion (Pokorny, 2014; Travelbee, 1971).

The human-to-human relationship is significantly important when the provision of nursing care occurs during the process/transition to the PC situation. As this is a transition, vulnerabilities are inherently associated with it and "the quality of nursing care given is

determined by the nurse's beliefs about illness, suffering, and death" (Travelbee, 1966, p. 55). As mention by Travelbee (1963, 1964), both the nurse and the patient are human beings.

A human being is unique, irreplaceable individual, being in the continuous process of becoming, evolving and changing. For that reason it needs to have in consideration the objective health (absence of discernible disease, disability of defect as measured by any physical examination, laboratory tests and assessment by spiritual director or psychological counselor), but also the subjective health of the patient, the state of wellbeing in accord with self-appraisal of physical-emotional-spiritual status. Based on this assumption, nurses will be able to more easily understand, respect and accept the patient as a unique person, building a closer and trust relationship (Pokorny, 2014; Travelbee, 1963, 1971).

Travelbee viewed this human-to-human relationship process formed during illness and an expected suffering experience. It is nurse's intervention to support the patient to maintain hope and avoid hopelessness, and also to provide help when patient need it. This relationship can only be established by an interaction process. Travelbee emphasized that the nurses must be able to "assist patients to find meaning in the experience of illness, suffering and pain" (Travelbee, 1966, p. 165). Being able to connect with the patient and form a relationship that goes beyond pill pushing and checking blood pressures, nurses assurance a better, more productive and meaningful experience for patients.

Travelbee believed nursing is accomplished through human-to-human relationships (Figure 2) that begin with the original encounter, which is the first impression by the nurse to the patient and vice-versa; and then progress through stages of emerging identities, the time when relationships are being started, where the nurse and patient perceives each other's uniqueness; developing feelings of empathy, the ability to share in the person's experience; and later feelings of sympathy, when the nurse wants to lessen the cause of the patient's suffering (Pokorny, 2014; Travelbee, 1971).

At this point it seems relevant to clarify that empathy is a forerunner of sympathy, since an emotional comprehension of the other person, it is important and desirable since it helps nurses to predict that person's behavior and to perceive accurately his thinking and feeling, however, it is an essentially neutral process, it does not really imply that a person takes action on the basis of the comprehension which has been gained. Sympathy, on the other hand, implies a desire, almost an urge, to assist the patient in order to relieve his distress, when one sympathizes; it is involved but not incapacitated by the involvement (Travelbee, 1964). As Travelbee referred sympathy is "(…) a process wherein an individual is able to comprehend the distress of another, be moved or touched by another's distress, and desires

to alleviate the cause. One 'shares' in the feelings of another and experiences compassion" (Travelbee, 1966, p. 146). The empathic nurse can perceive another's distress, recognize its source, and anticipate the behaviour that will result from it. Nevertheless the sympathetic nurse feels another's distress, being touched and moved by it and actively wants to do something to alleviate it (Travelbee, 1964, 1966). "There is a warmth, an urge to action, in sympathy that is not present in empathy"(Travelbee, 1964, p. 69).

Being sympathetic, in the minds of some, means that the nurse becomes so enmeshed in the patient's problems that she cannot meet his needs because she is too busy meeting her own. A picture is painted of the "too sympathetic" nurse, such as, cries when he cries, becomes depressed when the patient is depressed (Travelbee, 1964). However, quoting Travelbee (1964, p. 69), "This is not sympathy. The nurse in such a situation is not focusing on the patient, but on "herself" in the patient. She is not attempting to alleviate the patient's distress but is using the patient in order to relieve the tension of her own unmet needs."

Sympathize is to provide a part of ourselves to the other and, in the giving and sharing, even becoming vulnerable. The act of entering into, sharing, and giving of ourselves in a deep personal way exposes nurses to the shocks of commitment and all that this entails. It is probably an act of courage, permitting ourselves to feel sympathy for another since, with the feeling and expression of sympathy, can come pain (Travelbee, 1964, 1971).

This is particularly correct in those instances when nurses are powerless to help the person with whom they feel sympathetic or when, in spite of the greatest efforts, nurses are not capable to relieve his distress. By taking action to relieve distress, nurses reduce, in some measure, the tension of the urge to help. When nurses succeed they feel personally enriched and fulfilled. However when nurses fail, they may become frustrated, and because of that, the hurts of failure could cause nurses to take measures to protect themselves, to deny their feelings or crush them, lest they arise and catch them unprepared (Travelbee, 1964, 1966).

Nurses might not be willing to pay the price of failure, for that reason nurses detach themselves from further feeling, "as a matter of fact, nurses are usually encouraged to empathize, but cautioned not to sympathize" (Travelbee, 1964, p. 68). Therefore, nurses are then not hurt by others or moved by their distress but neither is their experience enriched by the contacts with others.

To be sympathetic means that this helping human being, we call the nurse, is concerned with this human being, we call the patient, seeking to alleviate patient distress since of, and in spite of, his role and hers (Travelbee, 1963, 1964).

The nurse is not afraid to demonstrate interest or to feel concern, but she is not engulfed to the point of inactivity. In the simplest terms, sympathy means that she cares (Travelbee,

1964, 1966). Then, in and through that caring, the nurse can provide what it call`s emotional support, can sustain another human being in his time of crisis (Travelbee, 1963, 1964, 1966).

The sympathetic nurse is an authentic human being. Absent of sympathy, the nurse is a dehumanized abstraction communicating with other abstractions called "patients," and nursing turn into thereby a mechanical, dehumanized process (Travelbee, 1963, 1964, 1969).

The nurse and patient attain a rapport in the final stage, rapport is a way in which the nurse perceive and relate to the other human being/patient-family, composed by inter-related thoughts and feelings – interest and concerns for the others, through a non-judgment attitude, and respect for each person as a unique human being. As Travelbee mention (1963, p. 70), rapport is "empathy, compassion, and sympathy; a non-judgmental attitude, and respect for each individual as a unique human being".

Rapport, fundamentally, is the catalyst which transforms a series of nurse-patient interactions into a meaningful nurse-patient relationship, is a concern for others and an active and genuine interest in them. Even taking into consideration that more than interest is necessary, there must also be present a belief in the worth, dignity, uniqueness, and irreplaceability of each individual human being. However it is important to refer that rapport doesn't "just happen", it must be built day by day in the nurse's contacts and interactions with the patient, and it will change as changes occur in the interpersonal situation (Pokorny, 2014; Travelbee, 1963).
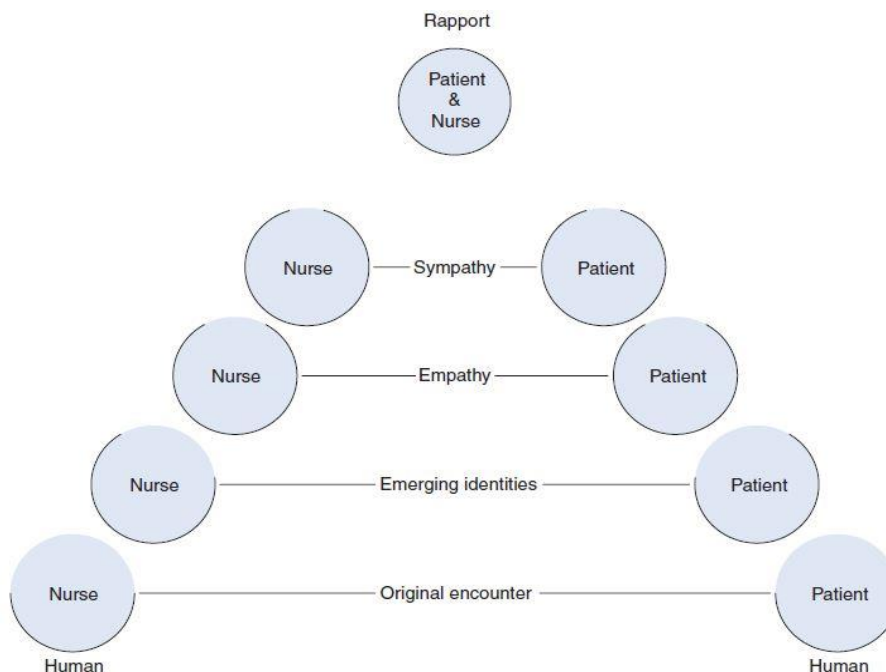
Figure 2: Human-to-Human Relationship *(Conceptualized by William Hobble and Theresa Lansinger, based on Joyce Travelbee's writings)* (Pokorny, 2014)

Caring the patient holistically, in an integrative way via communication and attention, benefit the caring process. An active interest in the patients can build upon the human-to-human relationship. For Travelbee (1963, p. 71) "the amount of time spent with a patient is not as important as what the nurse does with that time". This involvement require insight, and knowledge but it also requires the nurse to possess the "openness and freedom to expose self as human being to another human being, namely the patient" (Travelbee, 1969, p. 49). In addition, Travelbeee was clear about the patient's and the nurse's spirituality, referring that "it is believed the spiritual values a person holds will determine, to a great extent, his perception of illness. The spiritual values of the nurse or her philosophical beliefs about illness and suffering will determine the degree to which he or she will be able to help ill persons find meaning, or no meaning, in these situations" (Travelbee, 1971, p. 16).

Travelbee's theory, encourages the nurse to take a step closer to their patients and families. Considering the vision of nursing that this "Human-to-Human Relationship Model" presents, as an interpersonal process whereby the nurse assists a patient/family to prevent or cope with experience or illness and suffering, and also if necessary to find meaning in these experiences, we believe that this theory is a suitable framework for the development of this project.

In the word of Travelbee (1964, p. 71),"it all depends on what we wish to give priority to in nursing practice: a superficial nurse-patient interaction characterized by empathy but lacking warmth and sympathy or a nurse-patient relationship in which one human being relates to another and which is characterized by the compassion and sympathy that lie at the very heart of nursing. The challenge is clear; the choice is ours."

1.4. Burnout and Health Care

The burnout concept was first mentioned by Herbert Freudenberg (Freudenberger, 1974) in the 1970s, as comprising a series of unspecified physical and psychosocial symptoms, produced by an excessive energy requirement at work. This first defining of the concept served to identify, describe, and name an existing social problem based on observations, nevertheless those observations were not systematic or standardized (Maslach, 2003; Maslach & Schaufeli, 1993). However with the development of standardized instruments, in 1980s, such as Maslach Burnout Inventory and Burnout Measure, burnout starts to be studied empirically.

Maslach and Leiter (1997) expanded the concept of burnout and redefined it as a crisis in relationships with work and not necessarily a crisis with work people. Burnout is believed to be the result of continued exposure to work-related stressful events (Maslach & Goldberg, 1998; Maslach & Leiter, 2017). Maslach and colleagues clearly indicated that burnout research had its roots in caregiving and service occupations, in which the main core of the job was the relationship between the cared person and the caregiver (Maslach, 2003; Maslach & Leiter, 2000; Maslach, Schaufeli, & Leiter, 2001). Professions involving human interactions, commonly involve emotional engagement, especially when the cared person is in need of assistance and support, as it is the primary concern in nursing profession.

According to Maslach & Leiter (1997, 2000), burnout is defined as a syndrome with three dimensions: Emotional Exhaustion, Depersonalization and a lack of Personal Accomplishment at the workplace that arise when functional coping strategies fail.

1. Emotional Exhaustion occurs when health professionals reach the limits of their capacity, exists a lack of emotional energy and also a perception that emotional resources are depleted, and for that reason cannot respond at an emotional level (Cordes & Dougherty, 1993; Maslach, 2003; Maslach & Leiter, 2000).

   Emotional exhaustion is the reaction to chronic stressors in the workplace, for instance work overload, being these stressors constant over time and put pressure on people, causing emotional exhaustion. It is the lack of emotional energy, not directly physical energy (Maslach, 2003; Maslach & Leiter, 2000, 2016). People are not

physically fatigued from performing a strenuous job; the main issue is the feeling of being emotionally drained from the lack of resources to deal with demands and stressors. Exhaustion increases the possibility of one to distance oneself emotionally and cognitively from work, apparently as a way to cope with work overload. This lack of energy, perceived as a further loss of resources, can lead to maladaptive coping strategies such as, emotional detachment from work/depersonalization (Cordes & Dougherty, 1993; Maslach, 2003; Maslach & Leiter, 2000, 2017).

2. Depersonalization refers to an impersonal and distant contact, where a nurse, for example, start to develop distant approaches towards patients and colleagues, actively ignoring the other's unique and engaging qualities, as well as developing negative feelings and cynical attitudes. Depersonalization usually develops as a reaction to the overload of exhaustion, being self-protective at first – an emotional buffer of "detached concern". It is seen as a form of coping because it distances workers from the job and the others, colleague's, patients. The human service workers, as the case of nurses, who depersonalize at their job, are attempting to block negative emotions, to decrease emotional exhaustion and recover resources, increasing energy (Brotheridge & Lee, 2002; Maslach & Leiter, 2000, 2015, 2017).

   Distancing arises as a coping mechanism to emotional exhaustion, to disengage the person from the work, preventing additional emotional exhaustion. An attempt to cope with emotional exhaustion by becoming emotionally detached using distancing occurs. However the risk is that the detachment can cause the loss of idealism and the dehumanization of others. Over time the nurse is not simply creating a buffer and cutting back on the amount of work but is also developing a negative reaction to the other and to the job. As a result the nurse shifts from trying to do her very best to doing the bare minimum (Consiglio, Borgogni, Vecchione, & Maslach, 2014; Maslach, 2003; Maslach & Leiter, 1997, 2000, 2017).

3. Lack of Personal Accomplishment refers to negative feelings about competence and professional success, which can manifest itself in a lack of motivation and decreased productivity at work (Maslach, 2003; Maslach & Leiter, 2000). This dimension represents the self-evaluation component of burnout. An expectable part of the job of a nurse is caring others, but if the nurse is with emotional exhaustion and depersonalizing she will perceive she is not doing an adequate job, being lack of

personal accomplishment a reduction in one's perceived professional efficacy (Maslach, 2003; Maslach & Leiter, 1997, 2000, 2017).

This sense of inefficacy may make burned-out nurses dislike the kind of person they think they have become, leading to a loss of confidence, with the risk of having a negative regard for themselves, as well as for others (Maslach, 2003; Maslach & Leiter, 2000, 2017; Maslach & Schaufeli, 1993).

Taking into consideration the three dimensions, Maslach and Leiter (2017, p. 2) mentioned, "experience and etiology of burnout builds on a foundation of exhaustion, which starts a landslide resulting in a personal career crisis. Cynicism/depersonalization takes the experience of exhaustion to another level, and is compounded by inefficacy. Instead of healthcare work bringing the greatest satisfaction, fulfilment, and confirmation of one's identity, work becomes a joyless burden to be minimized, avoided, and escaped".

Therefore, when a workplace is seen as extremely demanding, emotional, mental, and spiritual exhaustion can arise because of a concomitant decrease in people's level of energy and enthusiasm (Consiglio et al., 2014; Maslach & Leiter, 2017). Ultimately, workers' enthusiasm, organizational commitment, and dedication to their work disappear, which influences not only HCPs' job performance and quality of care but also their job satisfaction and personal health (Koh et al., 2015; Maslach, 2003).

When talking about burnout there are some aspect relevant that should be also clarified, since they are interrelated concepts. One of these aspects is the distinction between burnout and stress. The difference between them is a matter of time. Burnout refers to the long-term breakdown in adaptation accompanied by chronic malfunctioning at workplace (Schaufeli & Enzmann, 1998). That is, a HCP who suffered from a job stress would return to normal, however one suffering from burnout would not do so since burnout is the result of chronic stressors in the workplace (Maslach & Leiter, 2016; Maslach et al., 2001).

Other aspect to clarify is that, one should not confuse burnout with compassion fatigue. Compassion fatigue is often thought of as the caregiver's cost of caring and results when HCPs are exposed to repeated interactions requiring high levels of empathic engagement with distressed patients. Although compassion fatigue can be a significant contributing factor in HCP burnout (Figley, 2002; Sorenson, Bolick, Wright, & Hamilton, 2016).

Nursing is a stressful profession dealing with human aspects of health and illness, and can eventually lead to job dissatisfaction and burnout (Hunnibell, Reed, Quinn-Griffin, & Fitzpatrick, 2008; Pavelková & Bužgová, 2015; Sabbah, Sabbah, Sabbah, Akoum, & Droubi, 2012). The impact, on the HCP, of caring for people with life-limiting illness should be

acknowledged and PC professionals should be able to recognise early signs of burnout and seek appropriate help (Gamondi, Larkin, & Payne, 2013).

The experience of burnout has been related to a long list of negative outcomes – personal, social, and organizational. In health care, these outcomes include more medical errors and poor quality of patient care (Maslach & Leiter, 2017). It is not unreasonable to presume that nurses burnout interfere with the nurse's performance and subsequently with the care process (Garman, Corrigan, & Morris, 2002; Maslach & Leiter, 2017; Schaufeli & Enzmann, 1998). For example, "when hospital staff are experiencing higher levels of burnout, their patients are less satisfied with the care they are receiving" (Maslach & Leiter, 2017, p. 2).

Burnout is also related to dysfunctional relationships with colleagues, and with a stronger intention to leave the health profession altogether (Maslach & Leiter, 2017; Shanafelt et al., 2012). For that reason "the urgency for addressing burnout arises not simply from the discomfort inherent in the syndrome, but from all these other serious consequences in the workplace" (Maslach & Leiter, 2017, p. 2).

The majority of the research evidence indicates that burnout does not reflect something that has gone wrong with the professional, but that there has been a essential change in the workplace and the nature of the job, for that reason does not arise as a personal failing (Maslach & Leiter, 1997, 2016, 2017). Burnout develops in response to challenging relationships among employees and their workplaces, and is therefore a social and organizational issue. Both, the person/professional and the organization, have a role to play in improving the workplace and people's performance within it (Maslach & Leiter, 1997, 2017; Maslach et al., 2001). As Montgomery (2014, p. 50) indicate, "burnout is an important indicator of how the organization itself is functioning".

From Maslach and Leiter's (1997) perspective, burnout arises from chronic mismatches between the person and the job in the terms of some or all of the six areas of worklife (AW), described in the following table (Table1) (Maslach & Leiter, 2017, p. 2):

Table 1: Description of the AW model (adapted from Maslach and Leiter (2017, p. 2))

Area	Description
Workload	Contending with more demands than one can manage aggravates burnout, especially the exhaustion dimension of the syndrome. Professionals with a deep dedication to their work, experience significant frustration when failing to complete tasks that they consider important. The propensity of work to spill over into their personal lives creates a distinct burden, partly because that situation interrupts opportunities for recovering depleted energy.
Control	Relates to participating in decisions that affect one's work. People vary in the extent to which they aspire to exercising choice and control at work. Some find comfort in others looking after the details, while some feel compelled to contribute actively in workplace decisions. Control allows people to exercise initiative in their work, giving them a sense of agency and volition.
Reward	Recognition for one's contributions at work defines the third AW. Once more, people vary, with some content with the intrinsic rewards of their work activities, and others especially concerned with receiving confirmation from colleagues and leaders. The extent to which the workplace aligns with the extent and the type of recognition one seeks influences one's vulnerability to burnout.
Community	The quality of relationships with others at work has a central role. People vary in the extent to which they value close friendships or limited professional associations at work. Nevertheless, people do always want positive social exchanges within whichever mode they prefer to encounter one another. It is often mentioned that people do not quit a job, but they quit a boss. They may also quit a team when relationships are strained between colleagues.

Fairness	A sense of justice engages people with their workplace while the experience of injustice exhausts and discourages them, prompting them to distance themselves emotionally and physically from the workplace. Unjust treatment excludes people from being considered full members of the workplace community. HCPs often feel alienated from workplaces that they perceive as treating patients unjustly.
Values	The alignment of personal and organizational values characterizes the sixth AW. The nature of healthcare as value-driven work makes this area especially pertinent to all HCPs. Working with a team with whom one shares core values energizes people, while doing work that seems useless or even damaging to patients generates both exhaustion and depersonalization.

The AW model points toward management areas where professionals encounter frustrations contributing to burnout. As Maslach and Leiter (2016, p. 105) mention, "mismatches in these areas affect an individual's level of experienced burnout, which in turn determines various outcomes, such as job performance, social behaviours, and personal wellbeing. The greater is the mismatch between the person and the job, the greater the likelihood of burnout (…)". The positive think about this model is that any of the six areas as the leverage for improvement, they are remediable areas (Maslach & Leiter, 2016, 2017; Pisanti, Lombardo, Lucidi, Violani, & Lazzari, 2013). "Processes that improve the alignment of people with their work setting hold potential for positive change" (Maslach & Leiter, 2017, p. 3).

The areas of the AW model are also in accordance with the Supportive Care Model (B. Davies & Oberle, 1990; Newton & McVicar, 2014) which reflect the hospice PC nursing practice, and has been adopted as framework for hospice PC nursing. The nurse's role in PC encompasses many interconnected dimensions. These dimensions include: valuing; finding meaning; empowering; connecting; doing for; and preserving own integrity (B. Davies & Oberle, 1990; Newton & McVicar, 2014). Any of those dimensions have a potential role to play in preventing burnout, for this reason they should be subject of investment.

Addressing burnout embraces both alleviating burnout, when it arises, and also preventing it before it occurs (Gamondi et al., 2013; Maslach & Goldberg, 1998; Maslach & Leiter, 2016, 2017). Alleviation interventions occur with individuals or workgroups experiencing levels of burnout that, even elevated, are not necessarily severe to prevent them from working.

Prevention strategies tend to focus on professionals, generally in good shape, and to help them to not become at risk for burnout (Maslach & Leiter, 2017).

Some individual strategies have been adapted from other work done on stress, coping, and health. Such as: a) changing work patterns (i.e., working less, avoiding overtime work, balancing work with the rest of one's life); b) developing coping skills (i.e., cognitive restructuring, conflict resolution, time management); c) obtaining social support (from colleagues and family); d) utilizing relaxation strategies; e) promoting good health and fitness; and f) developing a better self-understanding (via various self-analytic techniques, counselling, or therapy) (Maslach & Goldberg, 1998; Maslach & Leiter, 2016). If the aim is to act in depersonalization/cynism, an intervention that enhanced workplace civility between HCP showed that cynicism declined. In contrast, if the intervention is more focus on the sense of efficacy, could be more responsive to improvements, for example, a more clear culture of recognition from colleagues and leaders (Maslach & Leiter, 2016).

Some studies, on the context of PC, have made further recommendations on how to deal with burnout. For example, the need to take care of oneself – and not only in terms of personal health and physical fitness, but also in terms of psychological wellbeing; the encouragement to focus on spirituality and human nature; advocating for better social recognition of the challenging work that is being accomplished; and focusing on the positive aspects of life, at work and home too (Aycock & Boyle, 2009; Källström Karlsson, Ehnfors, & Ternestedt, 2008; Maslach & Leiter, 2016; Pavelková & Bužgová, 2015; Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009). Taking into consideration the previous mentioned, Supportive Care Model (B. Davies & Oberle, 1990; Newton & McVicar, 2014), those recommendations focus on nurses dimensions, such as valuing, empowering and preserving own integrity.

Being burnout in health care services an undoubtedly important issue; it needs to be addressed not only within the workplace, enhancing teamwork perspective for example, but also in the educational process that prepares people for a health career too (Maslach, 2001, 2003; Maslach & Leiter, 2017). Maslach and Leiter (2017, p. 4) state that burnout should be "on the educational agenda – students need to know about it, discuss it on a regular basis, work with others on how to deal with it (i.e. burnout needs to be a legitimate, ongoing part of the educational curriculum)".

Even take into consideration that the primary focus of our work was not burnout, but the care provided in PC, our initial results guided us to this relevant issue. For this reason emerge the necessity to systematize the evidence about the prevalence of burnout in the specific context of PC, and in turn, put into perspective the levels of burnout founded, with the reality of other

contexts. Although aware that one of the limitations of our work is the absence of a specific intervention to deal with burnout. We are also aware that the work done, in the systematization of all the evidence about the subject, with the realization of two systematic reviews, is central for those future studies with the aim of develop interventions. Any future intervention designed in this area with the aim of preventing or alleviating burnout will benefit from the work we have done.

CHAPTER II
RESEARCH COURSE

This chapter introduces the research course, and consists of two sub-headings.

The first sub-heading presents the objectives of the study.

The second sub-heading presents an explanation of each of the Phases that comprise the study as well as a diagram of the study design.

Specific information about the methodological approach, population and ethical procedures is described in each study.

2.1. Aims

This study intends to develop evidence about caring in PC. The objectives of this thesis were progressively delineated, according to the evidence / gaps identified in previous studies. The objectives are:

1) To map of the literature on the elements contributing to the construction of the HCP in the context of PC;

2) To examine the evidence on the prevalence of burnout among HCPs working in PC;

3) To review the literature on the effect of working in PC settings, compared to other settings, on burnout among HCPs;

4) To understand the experiences of nurses who provide care in a PCU.

2.2. Study Design

To achieve the research objectives, four studies were developed: a scoping review, a systematic review of prevalence, a systematic review comparing contexts and a qualitative study of phenomenological approach. Therefore the study is composed of 3 Phases (Figure 3):
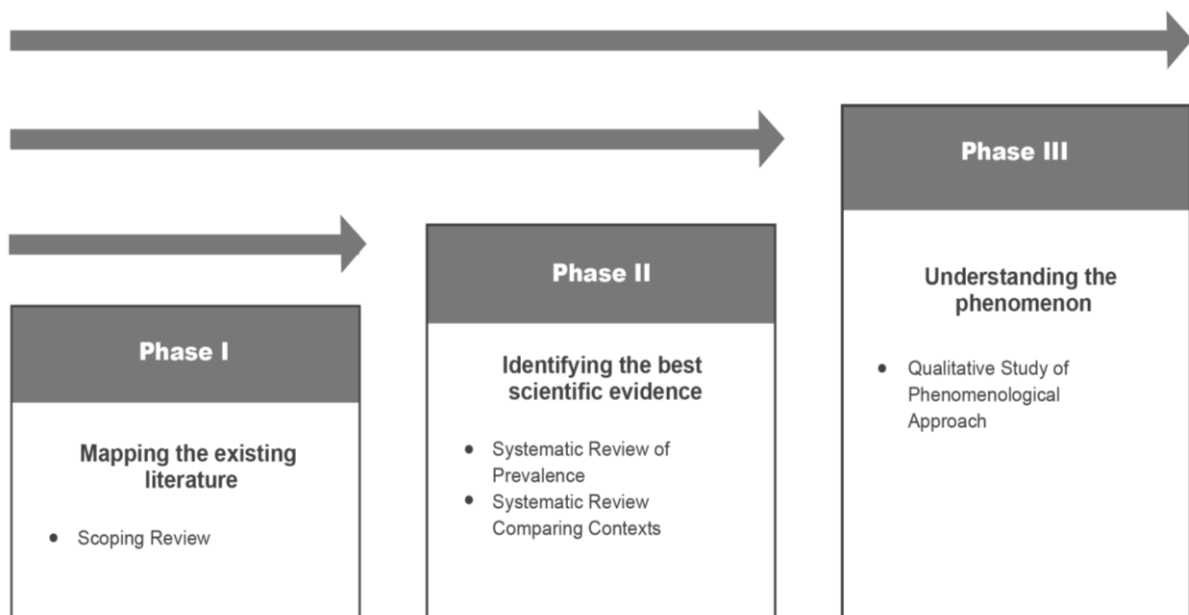
Figure 3: Study Design

Phase I

In the first Phase, called mapping the existing literature, was performed a Scoping Review about the extent, range and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC. A review of primary studies in the scientific literature was made. We performed this Scoping Review taking into account the Framework of Arksey and O'Malley (2005).

The scoping review of literature is already published in the journal *"Porto Biomedical Journal"*.

From this it was verified the need to identify the best scientific evidence about HCPs burnout in PC, as well as to develop evidence that favours the understanding of nurses' experiences in PC.

Phase II

In the second Phase, called identifying of the best scientific evidence, a Systematic Review of Prevalence was then performed on the prevalence of burnout among HCPs working in PC. More specifically, the review focuses on the following objectives: to examine the prevalence of burnout among HCPs working in PC; to examine if there is a difference in the prevalence of burnout in different subgroups of HCPs working in PC (such as, but not limited to, nurses, physicians, social workers, psychologists); to examine if there is a difference in the prevalence of burnout among HCPs working in different contexts of PC (PCUs, home care, hospices). We performed this Systematic Review using the guideline of the Joanna Briggs Institute for Systematic Reviews of Prevalence (Z. Munn, Moola, Lisy, & Rittano, 2014).

The Systematic Review and protocol of the Systematic Review of Literature is already published in the journal *"JBI Database of Systematic Reviews and Implementation Reports"*.

In order to contextualize the prevalence of burnout within the PC, we considered it necessary to perform a further Systematic Review with the objective to explore the effect of working in PC settings, compared with other settings, on burnout among HCPs. It was important to performed this Systematic Review Comparing Contexts since although we knew the burnout among HCPs working in PC and in the different contexts of PC, through the accomplishment of the previous review, it was important to realize if comparing with other contexts of care these burnout were higher or lower, allowing besides producing new knowledge, a proper framing of the findings obtained so far. We performed this Systematic Review using also the guideline of the Joanna Briggs Institute (2014a).

The Systematic Review of Literature is already published in the journal "*Journal of Hospice & Palliative Nursing*".

Both Systematic Review of Literature performed at the Phase II evidenced once again the need for evidence that favours the understanding of nurses' experiences in PC. Even more taking into consideration that burnout had its backgrounds in caregiving occupations, in which the main core of the job was the relationship between the cared person and the caregiver, especially when the cared person is in need of assistance and support as it is the primary concern in nursing profession.

Phase III

In the third Phase, called understanding the phenomenon, we performed a phenomenological qualitative study in order to understand the experiences of nurses who provide care in a PCU. In appendix (Appendix 1) we present the Data Collection Instrument used and the informed consent (Appendix 2). All participants gave their written consent. Results are presented anonymously with full respect for confidentiality of all participants.

This study was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing (Appendix 3) and the Ethics Committee of the Hospital Arcebispo João Crisóstomo (Appendix 4) before commencement.

This article is already published in the journal "*Journal of Hospice & Palliative Nursing*".

CHAPTER III

PHASE I: MAPPING THE EXISTING LITERATURE

This chapter addresses the Phase I of the study, and is divided into two sub-heading.

The first sub-heading presents the methodological approach Systematic Scoping Review.

The second sub-heading presents the article: The construction of the health professional in palliative care contexts: a scoping review on caring for the person at the end of life.

This Scoping Review provide a map of the key elements of the construction of the HCP and put in evidence that future research (primary and secondary) should be addressed with the intention to explore the emotional exhaustion, depersonalization, and the personal accomplishment among HCPs in PC.

So this Phase oriented the remaining two Phases of the thesis.

3.1. Systematic Scoping Review

The synthesis of evidence in systematic reviews is at the center of evidence-based practice (Jordan, Lockwood, Aromataris, & Munn, 2016; Peters, Godfrey, McInerney, et al., 2015). Different objectives and review questions require the development of new approaches, such as scoping reviews, to synthesize evidence in a more effective and rigorous way (Peters, Godfrey, McInerney, et al., 2015)

Scoping reviews, also called "mapping" reviews (Colquhoun et al., 2014; Daudt, van Mossel, & Scott, 2013; Levac, Colquhoun, & O'Brien, 2010), are one of these types of review, and was the methodology selected to performed the Phase I.

There are different reasons why a scoping review might be conducted. Different of other reviews that aims to address relatively specific questions, such as a systematic review of the effectiveness of a particular intervention based on a precise set of outcomes, scoping reviews can be used to map the key concepts underpinning a research area, also to clarify working definitions, and/or the conceptual boundaries of an issue (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Peters, Godfrey, McInerney, et al., 2015). Therefore, a scoping review could focus on one of these aims or all of them as a set. For this reason, scoping reviews can be usefully to map evidence in different ways. For example, scoping reviews with the objective of providing a map of the range of the available evidence, can be undertaken as a preliminary exercise prior to the conduct of a systematic review and can be also useful for examining emerging evidence when it is still unclear (Davis, Drey, & Gould, 2009; Peters, Godfrey, McInerney, et al., 2015). Scoping reviews can also be conducted independently to examine broad areas, providing a broad overview of a topic, identify gaps in the evidence literature, clarify concepts, and report on the types of evidence that address and inform practice in a topic area (Arksey & O'Malley, 2005; Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010; Peters, Godfrey, McInerney, et al., 2015), being those the great value of scoping reviews to evidence-based practice.

A traditional systematic review aims to answer a specific question (or series of questions) based on precise inclusion criteria, established upon the PICO (Population, Intervention, Comparator, and Outcome) elements. On contraire, a scoping review have a broader "scope" with respectively less restrictive inclusion criteria, based upon the PCC (Population, Concept and Context) elements of the inclusion criteria (Peters, Godfrey, McInerney, et al., 2015; The

Joanna Briggs Institute, 2014a). Because of the broad nature of scoping reviews, they are particularly useful for bringing together evidence from disparate or heterogeneous sources (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Peters, Godfrey, McInerney, et al., 2015; The Joanna Briggs Institute, 2014a).

Other difference between scoping reviews and systematic reviews is that scoping reviews provide an overview of the existing evidence, regardless of quality, since scoping reviews aim to provide a map of what evidence has been produced as opposed to seeking only the best available evidence to answer a particular question. For that reason, a formal assessment of methodological quality of the included studies was not performed, in our scoping review (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Peters, Godfrey, McInerney, et al., 2015; The Joanna Briggs Institute, 2014a).

Taking into consideration that in Phase I the aim was to examine the extent, range and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC and to identify research gaps in the existing literature this methodology was adopted. In effect, performing the Scoping Review provide us an broad overview of a specific topic, clarify the concept under study, reports evidence that address and inform practice in PC, and also the opportunity to identify gaps in the evidence literature.

Arksey and O'Malley developed a framework for conducting scoping reviews. Guidelines have been further developed and improved over time (Colquhoun et al., 2014; Daudt et al., 2013; Levac et al., 2010; Peters, Godfrey, Khalil, et al., 2015; Peters, Godfrey, McInerney, et al., 2015). For example, Levac and colleagues provide additional explicit information concerning what happens at each stage of the scoping review process and this enhancement increases the clarity and rigor of the review process (Colquhoun et al., 2014; Levac et al., 2010) (Table 2).

Table 2: Overview of the Arksey and O'Malley methodological framework for conducting a scoping review, with the Levac et al. enhancements (adapted from Levac et al.(2010, p. 4) and Colquhoun et al.(2014, p. 1293))

Arksey and O'Malley Framework Stage	Description of scoping review stage	Levac et al. enhancements
#1 Identifying the research question	The scoping review question must be clearly defined as it plays a role in all subsequent stages including search strategy. To examine and summarize breadth, scoping review questions are broad.	1. Despite the broad nature of the question, clearly articulate the research question that will guide the scope of inquiry. Consider the concept, target population, and health outcomes of interest to clarify the focus of the scoping study. 2. Mutually consider the purpose for conducting the scoping review with the research question.
#2 Identifying relevant studies	This stage implicates identifying the relevant studies and developing a plan for where to search, which terms to use, which type of sources to search, time span, and language. Sources include electronic databases, reference lists, hand searching, and grey literature. Comprehensiveness and breadth is important; however, so too are the feasibilities of time, budget and personnel resources.	1. Research question and purpose should guide decision-making around the scope of the review. 2. Assemble a suitable team, ensuring they have the content and methodological expertise that will ensure successful completion of the study. 3. Justify all decisions for limiting the scope of the review and acknowledge potential limitations to the study.
#3 Study selection	Study selection involves post-hoc inclusion and exclusion criteria. These criteria are based on the details of the research question and on new familiarity with the subject matter through reading the studies.	1. This stage should be considered an iterative process, is not linear, that involves searching the literature, refining the search strategy, and reviewing articles for study inclusion. 2. Improved clarity in decision-making for study selection can be achieved using the following steps: -At the beginning of the process, the team should meet to discuss decisions surrounding study inclusion and exclusion. -Use two reviewers to independently review abstracts and full text articles. -Incorporate a third reviewer in situations of disagreement to determine final inclusion. -Reviewers should meet at the beginning, midpoint and final stages of the abstract review process to discuss challenges and uncertainties related to study selection and, if needed, go back and refine the search strategy.

#4 Charting the data	A data charting form is developed and used to extract data from each study. A "narrative review" or "descriptive analytical" method is used to extract information from each study.	1. The research team must collectively develop the data- charting form and determine which variables to extract, to answer the research question. 2. Charting must be considered an iterative process in which reviewers continually extract data and update the data charting form. 3. Two reviewers should independently extract data from the first five to ten included studies using the pilot data-charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose. 4. Contextual or process-oriented data may require extra planning, for analysis.
#5 Collating, summarizing, and reporting the results	An analytic framework or thematic construction is used to present an overview of the breadth of the literature. A numerical analysis of the nature and extent of studies using tables and charts is presented. A thematic analysis is then offered. Reporting results required clarity and consistency.	Researchers should break this stage into the following three distinct steps: 1. Analysis (containing descriptive numerical summary analysis and qualitative thematic analysis); 2. Reporting the results and producing the outcome that refers to the overall purpose/research question; 3. Consider the meaning of the findings as they relate to the overall study purpose; discuss implications for future research, practice and policy.
#6 Consultation	This optional stage provides opportunities for consumer and stakeholder involvement to suggest additional references and provide insights beyond those in the literature	1. Consultation should be an essential component of scoping study methodology, and should be considered. However, if considered, consultation process should include the following steps: -Clearly establish a purpose for the consultation. -Preliminary findings can be used to inform the consultation. -Clearly articulate the type of stakeholders to consult. -Incorporate opportunities for knowledge transfer and exchange with stakeholders.

3.2. The construction of the health professional in palliative care contexts: a scoping review on caring for the person at the end of life

Review Article

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The construction of the health professional in palliative care contexts: a scoping review on caring for the person at the end of life

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Abstract

Aim: The aim of the study was to map of the literature on the elements contributing to the construction of the health care professional in the context of palliative care.

Methods: Scoping review based on Arksey and O'Malley framework. PubMed, Embase, CINAHL, Scopus databases, and gray literature were the sources searched (2005–2015), completed by reference searching, hand searching, and expert consultations. Primary studies focusing on different professionals working in palliative care units or hospice centers were eligible for inclusion.

Results: From a total of 3632 articles, 22 met the inclusion criteria. The content of the studies was described and classified in 5 elements: (i) construction and application of the concept of care; (ii) psychosocial effects that the daily care produces; (iii) working conditions that influence the caregiving provided; (iv) knowledge mobilized in the provision of care; and (v) strategies adopted by health care professionals to build relationships. Data about nurses, physicians, and psychologists were found, but no data were found about social workers. Gaps identified in the publications were as follows: relationship competencies and strategies adopted; the real needs from educational programs; and the view of other professionals.

Conclusions: Key elements identified in the concept of the construction of the health care professional should be addressed in future interventions: prevention of emotional exhaustion, depersonalization, and achievement of a greater personal accomplishment. In addition, none of the articles retrieved offered the different perspectives of all the disciplines in a multidisciplinary team.

Keywords: end of life care, health care worker, literature review, palliative care, staff attitude

Introduction

As a result of medical advances, life expectancy is progressively increasing. Consequently, the number of people living with a chronic disease has increased. This has contributed to a growing need for palliative care (PC), and therefore, more health care professionals (HCPs) will provide care at the end of life (EoL).[1] The World Health Organization defines PC as "an approach that improves the quality of life of patients and their families facing the problems associated with a 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."[2]

However, along with the perception that science has all the answers, doubts and restlessness arise on how to implement some of the knowledge when we come across patients at the EoL. Literature has shown that PC has been proven to be more effective than standard approaches, improving the quality of life of patients and their families at a lower cost.[3–7] Nevertheless, contact with people at EoL is conducive to feeling intense emotions that evidence the fragility and limitations of human life. The important role of emotions in human life becomes even more important as death approaches.[8]

Hospital experiences that produce the greatest emotional impact are related to death, suffering, and caring for patients at the EoL.[9] Taking into account that the above statement is significant because most people in developed countries die in hospitals; therefore, attention to the quality of life in these contexts has increased.[10–13]

Previous studies conclude that the HCPs who feel more competent and face the EoL with more personal resources provide more effective care[14,15] and those who have more knowledge in PC score higher with regard to control of negative emotions and fear of death.[16]

Previous personal experience related to death can provide the HCPs with a better perception of the EoL of their patients and with better personal resources.[17] In addition, HCPs who spend a greater percentage of time in contact with patients in EoL situation reported more positive attitudes toward death.[18]

It is known that effective communication is an element that allows the delivery of excellent health care, being an essential

factor to face EoL care. In fact, patients at EoL valued HCP trained in communication skills.[19] HCPs play a key role supporting the informal caregivers, providing them with knowledge and evaluating their needs.[20,21]

Although previous studies provide a representation of what happens at the EoL, they do not explain the elements involved in the construction of the HCP that provide EoL care. Moreover, if we want to achieve the main goals of PC,[2] we must have highly qualified HCPs. It is therefore important to understand what factors are involved in the construction of this caregiver.

As the population continues to age and PC becomes more present in health care practice, having an understanding of the necessary elements of HCPs, who effectively manage care in EoL, is essential.

HCPs in PC are working daily with people who are dying and are exposed to intense emotional reactions. Therefore, it is essential to understand the elements that contribute to the construction of the HCP in this unique context.

To date, despite the unique nature of this context, no review has examined the specific elements that contribute to the construction of the HCP in the context of the PC, which supports the need for this scoping review.

Aims

The aim of this scoping review is to examine the extent, range, and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC and to identify research gaps in the existing literature.[22]

Methods

This scoping review was guided by the methodology proposed by the Joanna Briggs Institute Scoping Reviews, and is based on the framework by Arksey and O'Malley[23] for conducting scoping reviews. It takes into account the works by Levac et al[24] and Daudt et al,[22] which included: (i) identifying the research question; (ii) finding relevant studies; (iii) selecting appropriate studies; (iv) charting the data; and (v) collating, summarizing, and reporting the results.

Inclusion criteria

This scoping review considered quantitative and qualitative primary studies published in English, Spanish, Catalan, and Portuguese during the last 10 years that focus on HCPs (physicians, nurses, social workers, and psychologists) working in palliative care units (PCUs) or hospice centers and caring for inpatients >18 years at the EoL.

Search strategy

According to different terms and rules for searching in each database, the effective combination of search terms was designed by one reviewer (RPP) (librarian expert in health science) and discussed with 3 other reviewers (VOP, AAR, and JBB).

Once relevant material was selected from electronic literature databases (CINAHL Plus, PubMed, Embase, Scopus, DART-Europe, OpenGrey, Grey Literature Report), relevant websites were searched, key journals were hand-searched, and reference lists were retrieved from articles, to increase our capture of relevant material. Finally, recommendations from experts in the field were also used to identify further published, unpublished,

and ongoing studies. The process was documented in detail to enable the study to be replicated by others (Table 1).

The Mendeley software was used to manage the list of all the articles retrieved and any duplication was removed.

Selection criteria

The review pursues to identify all the published research about which elements contribute to the construction of the HCP in the context of the PC. Articles searched were assessed for relevance by 2 independent reviewers (VOP and ANC). Those that meet the inclusion criteria, based on the information provided in the title and abstract, were included. When the relevance of a study was unclear in the abstract, the full article was reviewed.

The full article was retrieved for all studies that met the inclusion criteria. Based on full texts, 2 reviewers (VOP and ANC) examined independently whether the studies met the inclusion criteria. The disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer (MGS).

Data extraction

Quantitative and qualitative data were extracted from papers in the review using a data extraction table, taking into account the review question (Table 2). In this process, 2 reviewers (VOP and ANC), independently of one another, charted the "first five to ten studies using the data-charting form and met to determine whether their approach to data extraction was consistent with the research question and purpose," as suggested by Levac et al.[24] Any disagreement was resolved through discussion, or with a third reviewer (MGS). In addition, when it was necessary, primary authors were contacted for further information/clarification of data.

Results

After the duplicates were removed, 3632 records were identified for study selection. A total of 163 documents met the inclusion criteria, based on the titles and abstracts; therefore, the full-text articles were obtained. Full-text articles were read, after which 22 fulfilled the inclusion criteria. As a result, 22 studies were analyzed.

The stages of the scoping review process can be seen in the PRISMA flow diagram (Fig. 1).

The overview of the reviewed material is presented and discussed in narrative form. Tables and figures are included to aid in data presentation.[23] The overview of the studies included is presented in Table 2.

About the geographical source 9 studies were conducted outside Europe (n=9): the United States, Brazil, and Japan.[25–29] The other 14 were from the United Kingdom, Spain, Belgium, Norway, Scotland, Sweden, and Portugal.

Regarding the year of publication, most of the articles had been published between 2007 and 2014 (n=21), 1 had been published in 2006,[30] and none had been published in 2005 or 2015 (until April). Regarding the research methods used, the majority of the studies were qualitative (n=12), 4 collected quantitative data, and another 4 studies used mixed methods.

Data about nurses were found in twenty out of the twenty two articles included, four articles had data about physicians, one had data about psychologists, and no data were found about social

Table 1

Final database search strategy

Database: PubMed
Filters: Languages; Publication Dates
Total: 1995
Strategy (April 2015):
(End of Life[Title/Abstract] OR hospice[Title/Abstract] OR hospices[Title/Abstract] OR palliative[Title/Abstract] OR palliatives[Title/Abstract] OR Palliative Care[Majr] OR Hospices [Majr] OR terminal care[Majr]) AND (Nurse[MeSH Terms] OR Physicians[MeSH Terms] OR Social worker[MeSH Terms] OR "formal caregiver"[Title/Abstract] OR "professional caregiver"[Title/Abstract] OR "formal caregivers"[Title/Abstract] OR "professional caregivers"[Title/Abstract] OR Psychologists[MeSH Terms] OR Patient Care Team[MeSH Terms]) AND (Portuguese[lang] OR Spanish[lang] OR Catalan[lang] OR English[lang]) AND "last 10 years"[PDat] NOT (paediatric*[Title/Abstract] OR child[MeSH Terms] OR pedriatic*[Title/Abstract] OR minors[MeSH Terms] OR Adolescent[MeSH Terms] OR infant[MeSH Terms])
Database: CinahlPlus
Filters: Languages; Publication Dates
Total: 985 (242 excluding MEDLINE)
Strategy (April 2015):
(TI ("end of life" OR hospice OR hospices OR palliative OR palliatives) OR AB ("end of life" OR hospice OR hospices OR palliative OR palliatives) OR ((MM "Palliative Care") OR (MM "Hospices") OR (MM "Terminal Care"))) AND (TI ("formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers") OR AB ("formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers") OR ((MH "Nurses+") OR (MH "Physicians+") OR (MH "Social Workers") OR (MH "Psychologists") OR (MH "Multidisciplinary Care Team"))) NOT (TI paediatric* OR AB paediatric*)
Database: EMBASE
Filters: Languages; Publication Dates; Adult
Total: 2095 (103 excluding MEDLINE)
Strategy (April 2015):
(("end of life" or "hospice" or "hospices" or "palliative" or "palliatives" or "palliative care" or "terminal care") and ("nurse" or "nurses" or "physicians" or "social workers" or "formal caregivers" or "professional caregivers" or "psychologists")).ti,ab.
Database: Scopus
Filters: Languages; Publication Dates
Total: 5102 (1514 excluding MEDLINE)
Strategy (April 2015):
TITLE-ABS ("end of life" OR "hospice" OR "palliative") AND TITLE-ABS ("nurse" OR "physician" OR "social worker" OR "formal caregiver" OR "psychologist") AND NOT TITLE-ABS (adolescent OR pediatric* OR paediatric* OR infant* OR child) AND (LIMIT-TO(PUBYEAR,2015) OR LIMIT-TO(PUBYEAR,2014) OR LIMIT-TO(PUBYEAR,2013) OR LIMIT-TO(PUBYEAR,2012) OR LIMIT-TO(PUBYEAR,2011) OR LIMIT-TO(PUBYEAR,2010) OR LIMIT-TO(PUBYEAR,2009) OR LIMIT-TO(PUBYEAR,2008) OR LIMIT-TO(PUBYEAR,2007) OR LIMIT-TO(PUBYEAR,2006) OR LIMIT-TO(PUBYEAR,2005)) AND (LIMIT-TO(SUBJAREA,"MEDI") OR LIMIT-TO(SUBJAREA,"NURS") OR LIMIT-TO(SUBJAREA,"HEAL")) AND (LIMIT-TO(LANGUAGE,"English") OR LIMIT-TO(LANGUAGE,"Spanish") OR LIMIT-TO(LANGUAGE,"Portuguese")) AND NOT (PMID (1*) OR PMID (2*))
Database: DART-Europe
Filters: Languages; Publication Dates
Total: 19
Strategy (April 2015):
("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)
Database: OpenGrey
Filters: Languages; Publication Dates
Total: 5
Strategy (April 2015):
("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)
Database: Grey Literature Report
Total: 0
Strategy (April 2015):
("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)

workers. From the 22 articles identified, 14 were conducted in PCUs and the other 8 in inpatients hospices.

The content of the studies was described and classified in 5 main elements identified in the articles: (i) construction and application of the concept of care (including what caring for HCPs means, how they provided this care, and with what objectives. It also includes the factors that intervened in the development [construction] of this meaning, provision, and purpose); (ii) psychosocial effects that daily care produces (including the personal, professional, emotional, and psychological repercussions that come from working in PC); (iii) working conditions that influence the caregiving provided (including facilitating factors and difficulties that are extrinsic to the professional, but that influence the care provided, such as the time available for caring, teamwork, or the paradigm of healing still prevalent in some professional teams); (iv) knowledge mobilized in the provision of care (including not only academic knowledge but also the knowledge that derived from the professional experience and the personal experience of each professional; and (v) strategies adopted by HCP to build relationships (including the strategies adopted to build relationships with the team and the patient). All these elements are interrelated and mutually influential, and none of these elements is absolutely distinct from others, existing the possibility of a cross between them.

3

Porto Biomedical Journal

Parola *et al* Porto Biomed. J. (2018) 3:2   **Porto Biomedical Journal**
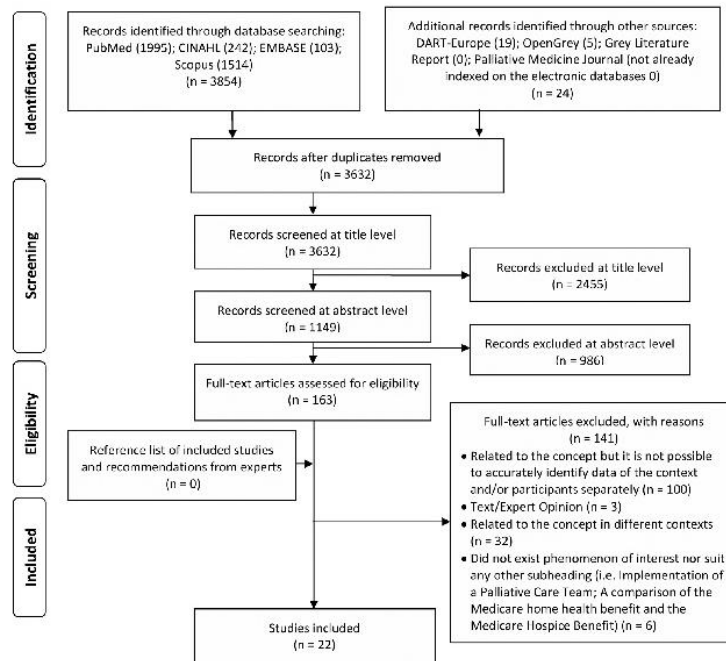
Figure 1. PRISMA flow diagram of the scoping review process.

Construction and application of the concept of care by HCPs

HCPs mention that for them care means a sense of purpose and honor and devote a high degree of commitment to their role.[29,31] The findings of the studies included mention that the goal of care is to provide a peaceful death. They also mention total pain as a reason for PC sedation and that the care provided should ensure that the bereaved would not have memories of their loved ones dying in distress.[32]

Therefore, to achieve freedom from pain is one of the priorities of comfort care, but pain relief and minimizing the pathophysiological symptoms were insufficient for the patients' fully experience of comfort.[33] Care means to provide calm and relaxation, sometimes with a silent compassion and caring touch, a feeling of rest and freedom from the mental and emotional distress. It is about alleviation of patient suffering, relief from mental and emotional distress, and the different ways in which people express their spirituality and their fear of death and dying. It means providing care in a physical, emotional, and spiritual way, not only helping patients to live but also helping patients to die serenely. The mental focus of care has shifted from doing something for the patient to being with the patient and enhancing their quality of life. The focus is now on the individual, and the concept of care has a holistic approach.[31,33–35]

HCPs report not considering death as a failure but as something that needs to be lived; this perspective gives them a motivation to find the meaning of care in their work. This sense of commitment also influences caregiving.[36] HCPs were still concerned about life as the most valuable commodity, regardless of the time remaining.[33] Furthermore, considering death as a part of life became an expression of their consideration for life itself as a cycle.[29] HCPs' experiences of care contributed to greater understanding of death as a part of life[37]; death was not seen as something aggressive, and they did not feel powerlessness before death.[30] The explanation could be the experience that nothing could be done to change the outcome of the disease.[34]

Such reality shows that it is possible to care for patients at the EoL differently and make death more human while fostering one's personal development.[36] Comforting the patients in their vulnerable EoL situation, recognizing patient autonomy, and providing a care sustained by ethics were the motivation that guided their work; they feel passion for their work in this context even when it is seen as stressful.[29,37–39]

Psychosocial effects that the daily care of people at EoL produces in HCPs

The daily care of EoL patients spurs an awareness of the HCPs' own spirituality, mortality, and finitude of their own existence.[31,34,37,38] Findings show that this perception led to reflect about the meaning of life and death. Accompanying the patients at the moment of death brought on less anxiety about their own death. Participants expressed that this experience makes them more aware and understanding, and leads them to bringing up the subject of death when talking with their own families.[35] Through this experience, HCPs gain greater human and communication competency. Moreover, their close witnessing of death becomes a reminder of the importance and meaning of taking care of their health.[34,37] They perceive positive changes in their thinking on the subject of death since their work in PC.[30] We need also to be aware that facing patients' suffering could sometimes trigger feelings of uncertainty and vulnerability.[35]

Gama et al[40] show that PC nurses had a statistically significant higher Purpose in Life score (112.00) compared with internal

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Table 2

Extraction instrument

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Ablett and Jones (2007); UK [31]	To understand the factors that help to promote resilience and mitigate the effects of workplace stress.	Qualitative methodology (Grounded Theory)	Hospice	Nurses (n=10)	HCP mentioned a high degree of commitment to their role. An active election to work in PC. Meaning to their work, and a sense of purpose. Some saw the challenge associated with their work as a significant factor in gaining a sense of satisfaction and achievement and some stated that that they disliked change and preferred a degree of stability. An awareness of their own mortality and spirituality led them to perceive aspects of their work as comprehensible. Cope strategies as have a proper support system at home, social life, talk to colleagues and actually discuss feelings. HCP acquire knowledge through past personal experience (close relative dying, previous experience working in hospitals) and nursing training.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Bezerra do Amaral et al (2012); Brazil [44]	To analyze ethic and bioethics dilemmas experienced by nurses who take PC for hospitalized elderly.	Qualitative methodology (Explanatory-Descriptive)	PCU	Nurses (n=10)	Participants do not issue information, nor do they wish to inform patients on their state of health and closeness of death. Adequately structured PC, with guidelines established for difficult decision making, is of fundamental importance. It is impossible to disassociate the historical and cultural aspects in the daily lives of HCP. The influence of curative training is still strongly linked to the difficulties found in the credible comprehension of the principles and philosophies of PC.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Dee and Endacott (2011); UK [45]	To identify factors that clinicians consider when a patient is dying.	Qualitative methodology (Husserlian Phenomenological study)	Hospice	Nurses (n=5) Doctors (n=5)	Participants mentioned the importance of multidisciplinary teamwork. However, some nursing staff may have felt their opinions were somewhat ignored. Experienced clinicians would recognise when a patient was close to death, but not necessarily know when death would occur. When carers accepted that the patient was dying, this was a positive factor. HCPs might be avoiding talking about the difficult issue of death to relatives who are in denial about their loved one's imminent death. Managing staff may need to ensure that clinical staff receives suitable training to improve their communication skills.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care Strategies Adopted by HCP to Build Relationships
Evans and Hallett (2007); UK [33]	To explore the meaning of comfort care for hospice nurses. To examine the means by which hospice nurses provide comfort to hospice patients.	Qualitative methodology (Hermeneutic Phenomenological study)	Hospice	Nurses (n=15)	Many participants referred to pain relief as a priority and an important goal for nurses to provide comfort. Pain relief and minimizing physio-pathologic symptoms were insufficient to achieve patients' total comfort. Spiritual comfort was a relief from emotional anguish and the expression of their spirituality. Comfort was also about helping people deal with the heavy burden of a near death. Nurses are aware that life is a valuable commodity, regardless how long or short the time remaining. Effective comfort requires time. Attention to patients and relatives should take time.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Källström Karlsson et al (2008); Sweden [37]	To explore five nurses' experiences of regularly having to face patients' incurable illnesses, dying, and death.	Qualitative methodology (Interpretive descriptive)	Hospice	Nurses (n=5)	Dealing with dying patients had a great impact on nurses' daily work and their private lives. Supporting patients in such a vulnerable situation was inspiring for nurses in their work, but was also experienced as a stress factor. The feeling of reward for the work done compensated for the difficulties encountered. Nurses' experiences contributed to a deeper understanding of life and death. Dealing with dying patients, being present and caring for them at the time of their death seemed to make them feel less anxious about their own death.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Knowledge Mobilized in the Provision of Care

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Table 2
(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
					This reality became a reminder to better care for their own health, and led them to talk about the topic of death with their own relatives. As a means to prevent pain and anxiety, most HCPs tried not to think too much or too often about their patients when not at work. The capacity to establish a border between work and leisure time improved with time in the job.	
Martins and Basto (2011); Portugal [34]	To understand the nursing intervention process used in relieving the suffering of end-of-life inpatients.	Qualitative methodology (Grounded Theory)	PCU	Total (n=47) nurses (n=19) patients (n=9) relatives (n=19)	Patient pain relief at the EoL is achieved through the nurse's accompaniment. Nurses help patients die serenely by providing support for their EoL comfort and spiritual needs, and by facilitating relatives to be present. Nothing can be done to alter the course of the illness. Close contact with suffering provides nurses with skills to enable more humane relationships and helps them deal better with their own grief and that of others. When facing suffering and death, nurses become aware of the finitude of their own existence. The state of almost permanent suffering makes nurses more mature, energetic and able to deal with suffering and death.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Oliveira et al (2007); Brazil [38]	To analyze the nursing concept of autonomy of terminal patients and what is the nurse perspective in the presence of autonomy while has being structure in Brazil.	Qualitative methodology (Content Analysis)	PCU	Nurses (n=7)	The care of PC patient requires that HCP is responsible for articulating the relationships within patient; family; health professional and to communicate effectively with them. Patient autonomy challenges nurses in their work routine because it confronts them with their own mortality. Some nurses react with judgments and neglect the patient's autonomy, faced with a Care model in which the paradigm of healing is prevalent.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided
Oliveira and Silva (2010); Brazil [39]	To analyze the concept the health team applies relating to autonomy of patients and identify what is the attitude of such professionals before the manifestation of this autonomy.	Qualitative methodology (Descriptive exploratory)	PCU	Physicians (n=4) Psychologist (n=1)	HCPs in this area allow sufficient autonomy to establish a solid trajectory in treating EoL patients, making sure that physical conditions such as decreased levels of consciousness are not a limiting factor in developing a care plan sustained by ethics. Verbal and non-verbal communication was reported as key for human relationships, sustainability and autonomy according to the individual's expectations. Communication in health care environments, PC in particular, is seen as a natural principle.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Shimoinaba et al (2014); Japan [29]	To describe Japanese PC nurses' experience of loss and grief.	Qualitative methodology (Grounded Theory)	PCU	Nurses (n=13)	Witnessing death in the daily work led nurses to recall personal losses and to experience grief again. It is not always possible to optimally meet the needs; there is ground for reduced confidence and self-esteem and a sense of failure. Grief could only be accepted when nurses acknowledged their own emotions related to loss. It was helpful when the multidisciplinary team was open to share feelings. Most participants expressed their passion for their work at PCU and their sense of honour in caring for dying patients and their relatives. Participants expressed gratitude and feeling privileged at helping a person in the last moments of their life.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

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Table 2

(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Tornøe et al (2014); Norway [35]	To describe the meaning of hospice nurses' lived experience with alleviating dying patients' spiritual and existential suffering.	Qualitative methodology (Phenomenological hermeneutical)	Hospice	Nurses (n = 8)	The nurses' frame of mind had shifted from "doing something for the patient" to "being with the patient". Past experiences and personal beliefs also have an impact on well-being. Advanced PC treatment sometimes caused nurses to spend less time with the patient, which created ethical dilemmas. Facing patient's suffering could sometimes bring memories of past grief to nurses and feelings of powerlessness, vulnerability and uncertainty. Support meetings with work colleagues were helpful in coping with the stress of caring for dying patients.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Zinn and Moriarty (2012); Scotland [32]	The aim of this study was to explore the knowledge, perceptions, and experiences of hospice nurses with palliative sedation.	Qualitative methodology (Exploratory cross-sectional design)	Hospice	Nurses (n = 5)	Nurses explain palliative sedation as a proportionate response to terminal suffering. They reported patients' fear and anxiety, along with physical symptoms and overall pain as reasons for palliative sedation. Nurses acknowledged team support as important to cope with the decision of using palliative sedation. They saw palliative sedation as a brave and collaborative initiative, while they also acknowledged the ethical implications. Nurses described team support and clinical and practical supervision as key to improving their coping strategies. All nurses agreed that the goal was to help patients die in peace and comfort.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Gama et al (2014b); Portugal [40]	To identify professional exposure to dying, training degree and personal factors relevant to burnout dimensions in nurses coping with death issues.	Quantitative, descriptive and correlational (Maslach Burnout Inventory, Death Attitude Profile Scale, Purpose in Life Test and Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	Significant differences were found between medical departments in burnout scores when comparing those with PCU. In medical units there are a higher percentage of nurses with undergraduate training in PC and in PCU a higher percentage of nurses with postgraduate training in PC.	Psychosocial Effects that the Daily Care of People at EoL Produce Knowledge Mobilized in the Provision of Care
Gama et al (2012); Portugal [41]	To identify the most frequent attitudes that nurse have toward death and to see which sociodemographic, professional, and training factors significantly affect attitudes toward death.	Quantitative, descriptive, Cross-sectional and correlational (Death Attitude Profile, Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	The PC nurses had significantly lower levels of the fear of death, death avoidance, and escape acceptance dimensions than the other groups, a significantly higher score for neutral acceptance, and similar scores for religious acceptance. The study suggests that nurses with more work experience with terminally ill patients show higher escape acceptance and religious acceptance. Background/personal experience with death appears as a facilitator to dealing positively with new confrontations, whether work-related or personal, which is to say that more work experience leads to less anxiety toward death and to more positive attitudes toward caring.	Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Gama et al (2014a); Portugal [36]	To identify which factors can positively impact the construction of meaning of life in nurses.	Quantitative, descriptive correlational (Purpose in Life test and Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	PC nurses had a statistically significant higher Purpose in Life score (112.00) compared with internal medicine nurses (107.46), oncology nurses (105.37) and hematology nurses (104.51). Positive statistically significant correlations exist between Purpose in Life scores and PC training. The higher Purpose in Life scores found in PC departments tend to show that PC nurses do not consider death as a failure but as	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

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Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
					something that needs to be lived.	
Henoch et al (2014); Sweden [43]	To compare Attitude Toward Care of the Dying among Swedish nurses and nursing students with those from other languages, and to evaluate influences of experiences on attitudes toward care of dying patients.	Quantitative, descriptive, cross-sectional, and predictive (FATCOD).	Department: 3 Hospices Oncology Surgical Palliative home care Students	Nurses (n=213) (n=46) (n=23) (n=27) (n=17) (n=100)	With regard to place of work, hospice registered nurses had the most positive attitudes. There were significant differences on Attitude Toward Care of the Dying between nurses at hospices compared with nurses in surgical wards and in oncology. This may be explained by the culturally different attitudes toward care in hospices and hospital wards. More emphasis on the care of dying patients is deemed necessary in nurse training, at theoretical and practical levels, preferably by HCPs with experience and positive attitudes toward the care of dying patients.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Martens (2009); USA [42]	To determine the perceived stress factors of inpatient and home hospice nurses and their correlation to perceived self-efficacy.	Quantitative, descriptive cross-sectional (Nursing Stress Scale);	Department: Home hospice Hospice	Total nurses (n=146) (n=79) (n=63)	Research has shown that excessive workload demands and conflicting expectations are examples of stressful working conditions.	Working Conditions that Influence the Caregiving Provided
Miyashita et al (2008); Japan [25]	To clarify nurses' views of discussions among nurses and physicians regarding artificial hydration for terminally ill cancer patients.	Quantitative survey (Questionnaire developed and validated by the Japan Palliative Oncology Study Group).	Department: Oncology PCU	Total nurses (n=3328) (n=2735) (n=593)	Only 68% of palliative care nurses report being heard on artificial hydration. Nurses deem their influence on decision-making as insufficient. Eo patients tend to reject medical treatment, which puts nurses in a difficult position when artificial hydration is prescribed for symptom relief. PC nurses evaluate discussion in the units as positive.	Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Nakazawa et al (2013); Japan [27]	To clarify physicians' practices and attitudes regarding advance care planning in PCU in Japan.	Quantitative nationwide cross-sectional survey (Questionnaire developed and validated by the authors).	PCU	Physicians (n=99)	Physicians who had negative practices regarding Advance Care Planning and Advance Directives experienced significantly more difficulties in assessing patients' decision-making capacity (p=0.005) and in listening to patients regarding their EOL care wishes (p=0.026), compared with physicians with positive practices. Physicians who had negative practices showed significantly less trust in the guided decision making by the Advance Directives in a catastrophic situation (p=0.020).	Working Conditions that Influence the Caregiving Provided
Murakawa and Nihei (2009); Japan [26]	To understand differences in how Japanese cancer care staff perceive a "good death."	Mixed method (28 components of a "good death," identified in a previous study); One freely question.	Cancer Centre:PCU Non PCU	Physicians (n=14) surgeons (n=15) nurses (n=13) nurses (n=122)	When asked how they would help patients prepare for dying, doctors mainly used taking approaches; palliative ward nurses mainly used listening and discussing approaches. Nurses of both types were more likely to use more concrete means (for example, 'help to have time with family and friends' and 'ask for the help of a psychotherapist).	Strategies Adopted by HCP to Build Relationships
Santisteban Etxeburu and Mier (2006); Spain [30]	To know what stressors impact on each profession directly dealing with end-stage patients.	Mixed method (Death Anxiety Scale; Maslach Burnout Inventory; questionnaire developed by the authors).	PCU	Physicians (n=4) nurses (n=4)	HCPs perceive positive changes in their thinking on the subject of death since they started working in PC. No HCPs considered seeing death as more aggressive or felt powerless before death. The most marked stressors are team relationships (communication, feeling valued, recognition tasks, decision making). All nurses recognized viewing the death of patients in a more natural manner.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided

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(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Shimoinaba and Lee (2007); Japan [28]	To identify the personal support needs of general nurses and PC nurses caring for PC patients in Kyushu, Japan.	Mixed method (Questionnaire developed by the authors).	Department: 6 PCU 6 General Hospitals	Total nurses (n = 207) (n = 90) (n = 117)	There was a statistically significant difference between the 2 groups regarding 'anxiety' (p = 0.029), with general nurses claiming significantly more 'anxiety' while caring for PC patients than PC nurses. Family and friends were valued support for both groups too. PC nurses ranked the need for support from staff/colleagues more highly than general nurses. Low confidence about the care they are providing leads to lower job satisfaction.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care Strategies Adopted by HCP to Build Relationships
Timmermann et al (2009); Belgium [46]	The relationship between defence mechanisms, coping strategies, palliative attitude, and the well-being of caregivers in PCU.	Mixed method (semistructured interview; Thematic Apperception Test; COPE inventory; Ways of Coping and Defence Style Questionnaires; Palliative Care Attitude and Well-being Scales)	PCU	Nurses (n = 18)	HCP prefer to use mature defence mechanisms (humour, altruism, affiliation). The older a caregiver is, the more he or she uses the defence mechanism of self-assertion and the coping strategy of acceptance. The longer his or her experience, the more the caregiver uses the defence mechanism of self-assertion through the expression of feelings. A weak score for well-being is predicted by high number of defence mechanisms (narcissistic, denial and distortion; and acting out) and of coping strategies (disengagement, around problem coping, and humour). Anxiety is also decreased by group exchange.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

medicine nurses (PIL 107.46, $t = 2.07$, $P < .040$), oncology nurses (PIL 105.37, $t = 2.52$, $P < 0.013$), and hematology nurses (PIL 104.51, $t = 2.98$, $P < 0.003$), and also lower burnout scores when comparing those medical departments with PCUs (significant lesser levels of emotional exhaustion [$t = 2.71$; $P < 0.008$], depersonalization [$t = 3.07$; $P < 0.003$], and higher levels of personal accomplishment [$t = 2.24$; $P < 0.027$]).[36] This is in accordance with the article which mentions that palliative HCP had significantly lower levels in the fear of death, death avoidance, and escape acceptance dimensions than the other departments, a significantly higher score for neutral acceptance, and similar scores for religious acceptance.[41]

Working conditions that influence the caregiving provided

Excessive workload demands and conflicting expectations are examples of stressful working conditions for nurses.[25,42] Studies mentioned that past personal experience, professional experience (more work experience leads to less anxiety toward death and to more positive attitudes toward caring), and the establishment of personal and professional boundaries help to deal with these issues when providing care.[31,35,41,43] HCPs become skilful in coping with the suffering of others and their own,[34] and gain awareness of how meaningful the relationships established through their role can become.[29]

Nonetheless, it is impossible to disassociate the historical and cultural aspects in the daily lives of HCPs, and it is a constant challenge due to their own prejudices and values.[38,43,44] The influence of curative training is still strongly related with the difficulties found for the real understanding of the principles and philosophies of PC.[36,44] In a health care model in which the paradigm of healing is prevalent, some professionals react with judgments and neglect the patient's autonomy.[38]

The importance of multidisciplinary teamwork was mentioned too. However, 2 of the articles suggested that some HCPs may feel that their opinions are not considered, which could be frustrating and affect the caregiving.[29,45] One study even mentioned that team relationships are the most marked stressors,[30] instead of being an opportunity for sharing experiences and looking for support.[36]

In addition, communication skills were mentioned as a factor that could improve the care provided. Communication, particularly in PC, is viewed as a natural principle, and communication skills training should be provided by the managers.[32,35,39,45]

Other fundamental factors that influence the caregiving in PC are as follows: an adequately structured PC, with guidelines established for difficult decision making[44]; the participation in the decision-making process, and how the professional is closely involved[25]; and time because comfort care takes time. Time is needed to develop a sense of dependability with patients and families, to establish meaningful communication, and to deliver sensitive and effective clinical care. Taking the time to be present, ensuring that people are made to feel that they "matter" when they reach the point of greatest overcoming vulnerability.[33,35,36]

Physicians, who displayed negative practices regarding advance care planning and advance directives, found significant added difficulties in appraising the patient's decision-making capacity ($P = .005$), letting the patients express their wishes for EoL care ($P = .026$) and lower confidence in treatment decisions in a catastrophic situation ($P = .020$), compared with physicians with positive practices.[27]

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One of the studies mentioned that low confidence in the care provided leads to lower job satisfaction.[28] As it is not always possible to address a numerous variety of needs to fully satisfy patients, trust is likely to be reduced, as self-esteem, and sometimes one may experience a feeling of failure as a palliative professional. This could cause doubts as to whether or not the full professional ability has been displayed to support patients, and could influence the way care is provided.[29] Confidence, trust, and experience are necessary in the provision of care,[32] meaning that it seems essential that HCPs use defense mechanisms and coping strategies simultaneously.[32,46]

The last factor mentioned by the included studies was the support from staff, including the unit manager, educator (supervisor) colleagues,[28,32,35] family and friends.[28]

Knowledge mobilized in the provision of care

In the provision of care, HCPs need to possess several coping strategies such as having a good support system at home, social life, psychological strength, balance of mind and body, and assuming responsibility in caring for their own feelings by talking to colleagues and discussing their feelings or how to manage cases.[28,31] Furthermore, as previously mentioned, the HCP knowledge and personal experiences have an important influence in the care provided,[29,32,43,44] for example, being able to use silence for therapeutic and comforting purposes.[35]

In fact, HCPs with more work experience with terminally ill patients had higher escape and religious acceptance, which is explained by the developed strategies in dealing with their emotional response to death and dying.[41]

For example, after having worked for an extended period, they improved the ability to clearly differentiate between work and leisure time.[37] An experienced clinician would acknowledge when a patient's EoL is near and take the necessary action to accompany a patient during the last hours of their life.[29,34,45] Personal experience with death appears as a facilitator to dealing positively with new confrontations, whether work-related or personal.[41,46]

A study shows that there is a higher percentage of nurses with undergraduate training in PC in medical units such as hematology; internal medicine; and oncology, than in PCUs, where there is a higher percentage of nurses with postgraduate training. Further training seems to provide more coping strategies in dealing with EoL care, as PC professionals had less levels of burnout compared with other departments.[40] As a positive statistically significant correlation between Purpose in Life scores and PC training was also found, knowledge about coping strategies seems to be important.[36]

Strategies adopted by HCPs to build relationships

Dee and Endacott[45] and Shimoinaba and Lee[28] mentioned that seeking the support of colleagues could be a way to develop a strong relationship between team members. One way to build relationships was to help people "to deal with the heavy burden of death awareness by entering into their world in a compassionate and connected interpersonal relationship."[33] HCPs also recommend more active communication between team members.[25] Verbal and nonverbal communication was considered key in mediating between relatives, individuals, and professionals.[39] Palliative HCPs mainly used listening and discussing approaches to help patients prepare for death. They were more likely to use more concrete means than nonpalliative professionals.[26]

Discussion

This scoping review identifies 5 key elements around the construction of the HCP concept in the context of PC: construction and application of the concept of care; psychosocial effects that daily care produces; working conditions that influence the caregiving provided; knowledge mobilized in the provision of care; and strategies adopted by HCP to build relationships; and it also identifies research gaps in the existing literature such as the absence of the perspective of all the members of the multidisciplinary team.

As mentioned by HCPs in the studies included care means a sense of purpose and honor with a high degree of commitment to their role.[29,31] Nevertheless, other studies showed that the experience of witnessing patients' dying and death overtime had a great impact on the professionals' day-to-day work and in their private lives, and is also seen as stressful. In a way of preventing grief and anxiety, most professionals "tried to avoid thinking too much, too often, or too intensely about their patients when they were not at work."[37] However, it seems that the feeling of reward and recognition obtained through their commitment compensated for any difficulties and was even the inspiration that guided their work.[37]

From the analysis of the included articles, it seems that the daily care of people at EoL is not affecting the HCP at a high level compared with other units. The levels of burnout are lower in PC professionals,[40] as they undergo positive changes in their perception of the subject of death from their work in a PC context. However, it is necessary to interpret the data (self-reported questionnaires), through the participants' contribution.

Miyashita et al[25] mention that sometimes PC nurses are put in uncomfortable situations by physicians. However, data were gathered retrospectively on nurses' views only, which might be subject to incomplete or mistaken recalling and does not take into consideration the view of other professionals. Further studies should address which strategies should be adopted to deal with such an uncomfortable situation. In this sense, it is important to mention that the sample of most included studies is constituted by nurses, which is perhaps justified by nurses constitute the HCP that remains more time with patients, ensuring its caring 24 hours a day.[47–49]

HCPs might be avoiding talking about the difficult issue of death to relatives who are in denial about their loved one's imminent death, and therefore appropriate communication skills training is required.[45] Even mentioning the importance of these programs, it is still not clear which are the real needs or strategies that need to be adopted. As mentioned in Henoch et al,[43] a first step could be to take into consideration that both theoretical and practical education should be provided, preferably under the supervision of HCPs with positive attitudes toward care of dying patients.

HCPs seem to acquire greater human and communication capacities[34]; however, the literature did not mention precisely those relationship competencies. HCPs are responsible for articulating the relationships between patient, family, and other HCPs, and to communicate effectively with them, but the reality is that the strategies they use in this process are not clear.[38]

The most marked stress factors, however, seem to be team relationships. It seemed that some nursing staff were feeling somewhat ignored in their opinions, which could be a source of frustration.[30,45] Further investigations should try to provide understanding on which strategies should be adopted to avoid this element of stress.

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The element of communication is considered as a natural element of team cohesion and a means of influencing others.[39] HCPs should enter into their patients' worlds in a kind-hearted way and have an interpersonal relationship; they therefore need time for meaningful communication.[33]

Another aspect to be discussed is the fact that this scoping includes studies conducted in 10 countries; however, the countries with the most articles included are Japan (5 studies) and Portugal (4 studies). This data is curious given that Japan was one of the first countries which emerged PCUs (70s)[50] and is one of the countries that has PC well integrated into his health care system.[51] Portugal, for its part, where CP started only in the 90s,[50] is recognized for actively developing PC in the country.[51] Perhaps this data (although distinct) justifies the high research activity in these 2 countries. Although in all the included studies the elements can be considered universals, in these 2 countries it is noteworthy that none of the studies published in Japan addresses the element "Psychosocial Effects that the Daily Care of People at EoL Produce," and none of the studies published in Portugal addresses the element "Strategies Adopted by HCP to Build Relationships," which is possibly due to cultural issues.

This study is unique in including publications not only in English but also in Spanish, Catalan, and Portuguese, thus broadening the scope and enabling these cultural comparisons.

Limitations of the scoping review

This scoping review has some particularities that limited our capacity to comprehensively understand the problem under analysis.

In the articles mentioning social workers these had been included in larger samples with participants who did not fit our inclusion criteria and had not followed the analysis separately.[30] Most of the studies analyzed in this scoping review were not carried out taking into account all team members of the multidisciplinary team. In 18 articles data were only gathered retrospectively on nurses' views. Although we use the term HCPs because our study is centered upon the multidisciplinary team, most of the data relate to nurses. Therefore, this limits any possible generalization among other HCPS involved in the EOL care.

It was not the main purpose of this scoping review to examine which palliative team members were the focus of the studies; however, our results suggest that it would be positive to incorporate other team members' perspectives into PC team discussions to inform about their work and to have an input in drawing up multidisciplinary team planning.

In addition, the scoping review included studies with imbalanced sample sizes and concerns exist about the rigor of study designs. However, a clear research question, a clear research strategy, and appropriate and strong inclusion criteria provide validity to its findings.[52]

Finally, due to the fact that the number of included studies is high, and a broader description would have repercussions on a table of high dimensions, the findings presented in Table 2 are only the main findings; however, in "Results" section we presented a more detailed exploration in narrative form.

Implications for research

The analysis of the existing evidence does identify gaps in the literature, resulting in recommendations for future research.

It seems necessary in future research to understand whether the impact of care at EoL and the stress and anxiety suffered by HCP are ever compensated by the satisfaction, sense of commitment, and purpose of the work they do, compared with other health care departments. It is also important to understand whether the lower levels of burnout reported by PC professionals are specific to Portugal or they could be generalized to other countries. A systematic review of the literature focused on the prevalence of burnout could help in this understanding.

The state of the science on HCPs' concerns and needs is evolving. Research evidence requires further research in these areas to find the best strategies and theories on how to provide this care in the most possibly efficient manner. An intentional focus on understanding the elements that contribute to the construction of the HCP in the specific context of PC is needed to improve not only the welfare of the HCP but also the care provided to the patient at EoL. This assumes a role of significant relevance for the caregiver and the patient who receives care at this singular moment.

It is also recommended the realization of studies that address the element "psychosocial effects that daily care produces" in the Japanese context, and studies that address the "strategies adopted by HCP to build relationships" element in the Portuguese context. This could be an important theme of analysis in future research because this lack of evidence incurs caregiving costs that may not be tangible. The empirical knowledge that facilitates the professional growth of PC teams should become a priority.

Finally, the literature reveals that working in PC leads to feelings of intense emotions, evidencing the fragility and limitations of human life, which could lead to several stressful and demanding challenges. However, comparing to nurses in other contexts, nurses working in PC have lower levels of burnout.[53] This ambiguity demonstrates the importance to develop more primary studies to understand how nurses experience the caring in PC.

Conclusions

This scoping review examined the extent, range, and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC and identifies 5 key elements: construction and application of the concept of care; psychosocial effects that daily care produces; working conditions that influence the caregiving provided; knowledge mobilized in the provision of care; strategies adopted by HCP to build relationships.

This scoping review contributes to the generation of a solid body of empirical knowledge that facilitates the professional growth of PC teams becausre it identifies key elements in the concept of the HCP construction, revealing the importance of developing specialized training programs and adding new elements to define strategies of action, showing the necessity of promoting interpersonal skills and emotional management mechanisms. It also reinforces the need to incorporate all team members' perspectives, such as social workers, in PC team discussions, evidencing that none of the articles retrieved offered the perspective of all the disciplines of the multidisciplinary team.

Acknowledgments

Author contributions

VOP participated in the design of the study, carried out the study and had the main responsibility for writing the manuscript. ANC, AAR, and MGS participated in conceiving the study and writing the manuscript. RPP, JAA, and JBB supported data analysis and writing the manuscript. All authors helped in revising and making substantial contributions to the manuscript, and also read and approved the final manuscript.

Conflicts of interest

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CHAPTER IV

PHASE II: IDENTIFYING THE

BEST SCIENTIFIC EVIDENCE

This chapter addresses the Phase II of the study, and is divided into three sub-heading.

The first sub-heading presents the methodological approach Systematic Reviews (quantitative evidence).

The second sub-heading presents an article about the protocol developed for the first systematic review: The prevalence of burnout in health professionals working in palliative care: a systematic review protocol.

The third sub-heading presents the article: Prevalence of burnout in health professionals working in palliative care: a systematic review.

The fourth sub-heading presents the article: Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review.

This phase revealed a prevalence of burnout of 17.3% among HCPs in PC. Nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%), and physicians had lower levels of Personal Accomplishment (41.2%). Also provided evidence that burnout among HCPs working in PC (6 studies about nurses and 1 study about physicians) is lower than that of HCPs working in other health care contexts.

This Phase emphasizes that research should be undertaken with the objective of understand the experiences of nurses who provide care in PC.

4.1. Systematic Reviews: quantitative evidence

Quantitative evidence is generated by research based on more traditional scientific methods generating numerical data, usually seeks to establish relationships between two or more variables and the significance of those relationships (Borenstein, Hedges, Higgins, & Rothstein, 2009; The Joanna Briggs Institute, 2014a).

Specifically, quantitative reviews focus on evidence of effectiveness, being effectiveness the extent to which an intervention achieves the intended effect (The Joanna Briggs Institute, 2014a). Quantitative research designs use two central approaches to making measurements and collecting data: those that aim to establish a causal relationship between two variables by intentionally manipulating one of them and looking at variations in the other (experimental studies), and those that imply a correlation or association between variables (observational studies). For those systematic reviews, JBI methodology uses specific checklists, taking into consideration the study design, to critically appraise a study (Zachary Munn, Moola, Lisy, Riitano, & Tufanaru, 2015; The Joanna Briggs Institute, 2014a, 2014b).

The developments of experimental studies are often not feasible due to a variety of reasons as well as: ethical issues, financial costs and/or difficulties in recruiting participants. In these cases, observational study design provides an alternative approach of collecting information and is a much used study design in healthcare research. They are exclusively based on observing what happens or what has happened, in this type of study there are no experimental features, do not involve manipulation on the part of the researcher (The Joanna Briggs Institute, 2014a).

In the Phase II we focus on observational studies since we only focus on primary studies that observe what happens, with no manipulation. The intention was to examine the evidence on the prevalence of burnout among HCPs working in PC. After having this information of the specific context of PC, it becomes necessary to review the literature on the effect of working in PC settings, compared to other settings, on burnout among HCPs, in this case we performed a more "traditional" systematic review (of effectiveness).

Systematic Review of Prevalence

The precise measurement of disease/condition among populations, being that local, national, or in global level, is of critical significance for governments, policy makers, health professionals, and the general population, enabling them to inform the development and delivery of health services (Zachary Munn et al., 2015; The Joanna Briggs Institute, 2014b). This accurate information can assist in planning management of disease services (ensuring resources are accessible to cope with the burden of disease/condition), setting of priorities regarding public health initiatives, and also evaluation of changes and trends in diseases over time.

The prevalence of a disease indicates the number of individuals in a population that have the disease at a given point in time, being often presented as a proportion or percentage, and sometimes as the number of cases out of a certain population. This is also known as "point" prevalence as it offers an image of what is happening at a certain point of time. "Period" prevalence it can also be used, being similar to "point" prevalence, excepting it assesses the proportion of a population that has a disease at any time within a specified period of time (Zachary Munn et al., 2015; The Joanna Briggs Institute, 2014b).

The point prevalence is calculated using the following formula:

Prevalence = <u>Number of people with disease at a given point in time</u>

Total number of people in the population

When determining the inclusion criteria, the CoCoPop mnemonic (Condition, Context and Population) can be used for assessing prevalence data. Mention that Condition refers to the variable of interest and may refer to a health condition, disease, symptom, event or factor, even it is more common use the expression disease, prevalence does not exclusively refer to disease (The Joanna Briggs Institute, 2014b).

To address questions regarding prevalence, epidemiological studies, such as observational and descriptive studies, are required. As previous mentioned these studies rely on the natural or "ecological" events of exposures and disease, for that reason the researcher simply observes certain characteristics of the sample population as they occur "naturally", and records the relevant data. Data from observational studies can consequently be useful in formulating hypotheses concerning risk or preventive factors in disease development and progression (The Joanna Briggs Institute, 2014b).

Questions of disease prevalence are often asked by researchers and the results of their research offers crucial data for policy makers. These measures enable health researchers to quantify disease/conditions amongst populations (The Joanna Briggs Institute, 2014b).

Systematic reviews of prevalence data can therefore contribute in answering questions of national or global disease burden, such as global data about the Burnout in PC context, and for those reasons are becoming gradually more important, since policy makers acknowledge the usefulness of syntheses of this type of information (Zachary Munn et al., 2015; The Joanna Briggs Institute, 2014b).

Concluding, it is important to mention that the generation of new knowledge may occur through either primary or secondary research. Being systematic reviews equally important as primary research in the generation of new knowledge, being capable also of, clarify concepts and identify important gaps in what is known about a particular field, intervention or practice (Jordan et al., 2016).

4.2. The prevalence of burnout in health professionals working in palliative care: a systematic review protocol

The prevalence of burnout in health professionals working in palliative care: a systematic review protocol

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Review question/objective The objective of this review is to examine the evidence on the prevalence of burnout among health professionals working in palliative care.
More specifically, the review focuses on the following questions: What is the prevalence of burnout among health professionals working in palliative care? Is there a difference in the prevalence of burnout in different subgroups of health professionals working in palliative care (such as, but not limited to, nurses, physicians, social workers, psychologists)? Is there a difference in the prevalence of burnout among health professionals working in different contexts of palliative care (palliative care units, home care, hospices)?

Keywords burnout; end of life care; hospice; palliative care

Background

As a consequence of medical advances, life expectancy is increasing; therefore, the number of people with incurable advanced disease is also increasing. This reality contributes to an increasing need of palliative care.[1]

According to the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problems 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".[2(p.84)]

The increased need for palliative care leads to, more than ever, health professionals providing this type of care, which further leads to multiple, stressful and demanding challenges: caring with scientific technical knowledge, caring with relational and human competencies, making important ethical decisions and constant contact with suffering, end of life and death of people for whom they care.[3,4] These challenges, according to several authors, can cause physical, psychological and emotional distress as well as work-related stress, which if not treated in time put the health professionals members of the palliative care team (physicians, nurses, physiotherapists, psychologists, social workers, occupational therapists) working in different contexts of palliative care (palliative care units, home care, hospices) at risk of burnout.[5-7] The burnout concept was first mentioned in the 1970s by Herbert Freudenberg,[8] as a series of unspecified physical and psychosocial symptoms produced by an excessive energy requirement in the work, emerging usually in professions involving helping relationships.

Maslach and Leiter[9] expanded the concept of burnout. They redefined it as a crisis in relations with work and not necessarily a crisis with work people. According to these authors, burnout is defined as a syndrome of three dimensions: emotional exhaustion, depersonalization and a lack of personal accomplishment at the workplace that arise when functional coping strategies fail.[9,10]

Emotional exhaustion is produced when health professionals reach the limits of their capacity and cannot respond at an emotional level, which leads to emotional detachment from their work. Depersonalization refers to impersonal and distant contact whereby health professionals start to develop distant approaches with patients and colleagues, besides

developing negative feelings and cynical attitudes. This reflects a lack of personal accomplishment, feelings of competence and professional success, manifested by a lack of motivation and decreased productivity at work, in other words, one's own accomplishments and achievements.[5,10]

Global crises have forced many health systems to undergo structural reform, which lead to a faster pace of work and greater demands. Ultimately it led to the increasingly high prevalence of burnout among health care professionals.[9] Freudenberger[8] identifies those predisposed to developing burnout as being overly dedicated professionals, perfectionists and compulsive, whose work is a substitute their social life. According to Sá,[11] causes of burnout include personal factors such as the characteristics of employees and professional factors such as the working environment and organizational dynamics.

Maslach and Goldberg[12] report that burnout is a consequence of continued exposure to stressful events related to work. Maslach and Leiter[9] argue that burnout is not exactly a problem intrinsic to the person, but fundamentally results from the features of the organizational environment in which the person performs his professional functions.

When the workplace is viewed as hostile and excessively demanding, both economically and psychologically, emotional, mental and spiritual exhaustion develops because of decreased levels of energy and enthusiasm. Thus, dedication and commitment to work are significantly reduced, health professionals become cynical and distant, and they disengage from their work.[5,10]

According to Pavelková and Bužgová,[7] working with dying patients is considered to pose an even high risk of burnout, and the difficult situations faced by hospice nurses has drawn attention to the concept of burnout for the first time. In palliative care, high demands are placed on the health professionals, because "they encounter suffering and the transience of life, seemingly futile battle, helplessness and grief".[7(p.218)]

In this context, some studies have been conducted to identify the impact of burnout on health professionals working in palliative care. The studies showed that the level of burnout among professionals working in palliative care was lower than that of professionals working in other contexts.[13−15] These studies, however, have not been systematically assessed.

An initial search of the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, the Cochrane Library, PROSPERO, PubMed and CINAHL found no existing systematic review on the epidemiology of burnout among health professionals working in palliative care.

There has been a previous review that examined burnout among health professionals working in palliative care but was primarily limited to nurses and doctors, focused on an ethical perspective, in a limited period of time, and did not assess the methodological quality of included studies; the focus was only on mapping the research activity around the subject.[16]

This systematic review will synthesize the best available literature, between 1974 and 2015, across a wider range of professionals.

This review is guided by the methodology proposed by Joanna Briggs Institute for the conduct of the systematic review of prevalence and incidence data[17] and examines the available evidence on the prevalence of burnout among health professionals working in palliative care.

A precise estimate of prevalence for burnout among health professionals working in palliative care has immediate implications, in that vulnerable groups could be identified and measures could be taken to reduce their risk of burnout. It also has research implications, whereby interventions could be tested in high prevalence subgroups. This is important because, where there is a happy worker there is a satisfied patient; therefore, high-quality care for patients is preceded by high-quality care for employees.[7]

Inclusion criteria

Types of participants

This review will consider studies, conducted worldwide, that include all health professionals with qualifications (physicians, registered nurses, physiotherapists, psychologists, social workers, occupational therapists), caring for patients 18 years of age or older, working in palliative care.

Studies that include participants working in other contexts, different to palliative care, will be excluded unless the data are separated and analyzed by palliative care versus others areas of care.

Phenomena of interest

This review will consider studies reporting on the point prevalence of "burnout" measured by any

burnout scale, such as, but not limited to, Maslach Burnout Inventory, Burnout Measure and Copenhagen Burnout Inventory.

Context

This review will consider studies conducted in the context of palliative care, more specifically, palliative care units, home care or hospices.

Types of studies

This review will consider any observational study designs including prospective and retrospective cohort studies, case-control studies and cross-sectional studies for inclusion.

Search strategy

The search strategy aims to find published and unpublished studies. A three-step search strategy will be used in this review. An initial limited search of MEDLINE and CINAHL will be undertaken, followed by the analysis of text words in the titles and abstracts, and of the index terms used to describe the article. A second search using all of the identified keywords and index terms will then be undertaken across all databases included. Third, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English, Spanish and Portuguese will be considered for inclusion in this review. Studies published after 1974 will be considered for inclusion in this review. This year was chosen because publications related to burnout in health care began to appear in the literature after 1974.

The databases to be searched will include:

CINAHL Plus with Full Text; PubMed; Scopus; SciELO.

The search for unpublished studies will include:

DART-Europe; OpenGrey; RCAAP – Repositório Científico de Acesso Aberto de Portugal; ProQuest – Health & Medical Complete; Banco de teses da CAPES (www.capes.gov.br).

Initial English language keywords to be used will be:

Burnout; Palliative; Hospice; "Home Care"; "End of Life"; "Health professionals".

Assessment of methodological quality

Articles selected for retrieval will be assessed by two independent reviewers for methodological validity before inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute – Critical Appraisal Checklist for Studies Reporting Prevalence Data (Appendix I). Any disagreements that will arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data extraction

Data will be extracted from articles included in the review independently by the two reviewers, using a data extraction form, taking into account the review questions (Appendix II). Any disagreements arise between the reviewers will be resolved through discussion, or with a third reviewer. The authors of the primary studies will be contacted to provide missing or additional data.

Data synthesis

If appropriate, statistical meta-analysis using the Cochrane RevMan software will be used to combine quantitative data extracted from the included studies in statistical meta-analysis; all results will be subject to double data entry. Data will be pooled using either the random-effect or the fixed-effect model depending on the heterogeneity of the included studies. When pooling proportions for meta-analysis, a transformation of the data will be required. *Logit* transformation of the prevalences will be applied, because *logits* are more likely to have a normal distribution, which is essential for pooling data. Prevalence estimates will be transformed to logits to improve their statistical properties. The final pooled *logit* will be back transformed, resulting in pooled prevalence and 95% confidence intervals.[17,18]

Heterogeneity will be statistically assessed using the standard χ^2 test (subgroup analyses based on healthcare professional classes included in this review will be also explored) and a significance level of 0.05 will be adopted. However, when statistical pooling is not possible, because of substantial heterogeneity of the included studies data, we will present the forest plot resulting of the multiple studies; this is useful for displaying how prevalence estimates vary between studies. In addition, data will be presented in narrative form including tables and figures to aid in data presentation wherever appropriate.[17,18]

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Appendix I: Appraisal instruments

JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data

Reviewer_____ Date_____

Author _____Year_____Record Number_____

		Yes	No	Unclear	Not applicable
1.	Was the sample representative of the target population?	☐	☐	☐	☐
2.	Were study participants recruited in an appropriate way?	☐	☐	☐	☐
3.	Was the sample size adequate?	☐	☐	☐	☐
4.	Were the study subjects and the setting described in detail?	☐	☐	☐	☐
5.	Was the data analysis conducted with sufficient coverage of the identified sample?	☐	☐	☐	☐
6.	Were objective, standard criteria used for the measurement of the condition?	☐	☐	☐	☐
7.	Was the condition measured reliably?	☐	☐	☐	☐
8.	Was there appropriate statistical analysis?	☐	☐	☐	☐
9.	Are all important confounding factors/ subgroups/ differences identified and accounted for?	☐	☐	☐	☐
10.	Were subpopulations identified using objective criteria?	☐	☐	☐	☐

Overall appraisal: Include ☐   Exclude ☐   Seek further info ☐

_____

_____

_____

Appendix II: Data extraction instruments

Reviewer ID: (*ID given by the primary reviewer*)
Revision date: (*Date of when the form is filled in*)
Title: (*Title of the study*)
Author(s): (*Names of all the authors of the study*)
Journal: (*Journal in which the article has been published*)
Year of publication: (*Year in which the article has been published*)
Aims of the study: (*Objective of the study*)

Study design: (*prospective and retrospective cohort studies, case-control studies, cross-sectional studies, case series, case reports*)
Measurement instrument: (*description of the measurement instrument, validity and reliability of the instrument, measurement bias, time point of data collection*)
Setting: (*Palliative care units, hospices, home care*)
Sample characteristic
    Sample size: (*number of patients*)
    Type of Participants: (*Nurses, social workers, physicians, physiologists, others*)

Results (*Point prevalence will be reported as percentage with a 95% CI. When the number of health professionals is reported, the percentage can be calculated using the equation: number of health professionals with the condition/sample size*)

Prevalence n/N (%)
Proportion of health professionals with burnout
    ☐ Nurses _____
    ☐ Social workers_____
    ☐ Physicians_____
    ☐ Psychologists_____
    ☐ Others_____
Proportion of health professionals with burnout in different contexts
    ☐ Palliative care units
        ☐ Nurses _____
        ☐ Social workers_____
        ☐ Physicians_____
        ☐ Psychologists_____
        ☐ Others_____
    ☐ Hospice
        ☐ Nurses _____
        ☐ Social workers_____
        ☐ Physicians_____
        ☐ Psychologists_____
        ☐ Others_____
    ☐ Home care
        ☐ Nurses _____
        ☐ Social workers_____
        ☐ Physicians_____
        ☐ Psychologists_____
        ☐ Others_____

Authors' comments

Reviewer comments

4.3. Prevalence of burnout in health professionals working in palliative care: a systematic review

SYSTEMATIC REVIEW

Prevalence of burnout in health professionals working in palliative care: a systematic review

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EXECUTIVE SUMMARY

Background
More than ever, the current increasing need for palliative care leads to health professionals providing this type of care which further leads to multiple challenges, and stressful and demanding situations. The multiple challenges of working in palliative care put health professionals working in this context at the risk of burnout.

Objectives
To examine the evidence on the prevalence of burnout among health professionals working in palliative care.

Inclusion criteria
Types of participants
The current review included studies that encompass qualified health professionals working in palliative care, caring for patients 18 years of age or older.

Condition
The current review considered studies reporting on the point prevalence of burnout, measured by a burnout scale, such as, but not limited to, the Maslach Burnout Inventory, Burnout Measure and Copenhagen Burnout Inventory.

Context
The current review considered studies conducted in the context of specialist palliative care, more specifically, palliative care units, specialized palliative home care or hospices.

Types of studies
The current review considered observational study designs, including prospective and retrospective cohort, case-control and cross-sectional studies.

Search strategy
An initial search of MEDLINE (via PubMed) and CINAHL was undertaken, followed by a second search for published and unpublished studies since 1975 in major healthcare-related electronic databases. Studies written in English, Spanish and Portuguese were included.

Methodological quality
Two independent reviewers assessed the methodological quality of studies using the standardized critical appraisal instrument from the Joanna Briggs Institute. No studies were excluded from the review based on the methodological appraisal.

Data extraction
Data were extracted using a data extraction table, taking into account the review questions.

Data synthesis
Significant differences were found between condition measures, thus we were unable to perform a meta-analysis.

Results
Eight cross-sectional studies met the inclusion criteria, with a total of 1406 health professionals. The sample was limited to nurses, physicians and social workers. None of the included articles presented data about other health

professionals. Seven of the included studies assessed the prevalence of burnout using the same instrument – the Maslach Burnout Inventory. Data revealed a prevalence of burnout of 17.3% among health professionals. Personal Accomplishment was the sub-scale from the Maslach Burnout Inventory that had the highest prevalence (19.5%). Nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%), and physicians had lower levels of Personal Accomplishment (41.2%). The prevalence of burnout was, however, higher in social workers (27%). The palliative care context with the highest prevalence of burnout was home care (19.6%).

Conclusion

The current systematic review contributes to a body of empirical knowledge that can facilitate the professional development of palliative care teams by highlighting the prevalence of burnout in health professionals, which staff category is the most affected (social workers), and which palliative care context has the highest prevalence (home care).

Keywords Burnout; end-of-life care; health professionals; palliative care; systematic review

Background

Life expectancy is increasing as a consequence of medical advances, as a result of this, the number of people with incurable advanced diseases has risen, leading to an increasing need for palliative care.[1] According to the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problems 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".[2(p.84)]

The increased need for palliative care leads to greater stress and more demanding challenges for health professionals in terms of: caring that requires advanced technical knowledge, caring that requires relational and human competencies, making important ethical decisions, and being in constant contact with suffering and the end-of-life and death of people they care for.[3-5] Those working in palliative care teams (physicians, nurses, physiotherapists, psychologists, social workers and occupational therapists) in a number of different contexts are subjected to such challenges that can cause physical, psychological and emotional distress as well as work-related stress, and if these are not treated in time, there is a risk of burnout.[6-8]

The burnout concept was first written about by Freudenberger[9] in the 1970s, as comprising a series of unspecified physical and psychosocial symptoms, produced by an excessive energy requirement at work, and usually occurring among professions involved a helping relationship. Maslach and Leiter[10] expanded the concept of burnout and redefined it as a crisis in relationships with work and not necessarily a crisis

with work people. According to these authors, burnout is defined as a syndrome with three dimensions: Emotional Exhaustion, Depersonalization and a lack of Personal Accomplishment at the workplace that arise when functional coping strategies fail.[10,11]

Emotional Exhaustion occurs when health professionals reach the limits of their capacity and cannot respond at an emotional level, which leads to emotional detachment from work. Depersonalization refers to an impersonal and distant contact, where health professionals start to develop distant approaches toward patients and colleagues, as well as negative feelings and cynical attitudes. The latter may also be linked to a Lack of Personal Accomplishment and negative feelings about competence and professional success, which can manifest itself in a lack of motivation and decreased productivity at work.[6,11] Despite the aforementioned, there are authors who consider the existence of burnout when only one of these sub-dimensions is affected.[12,13] The various definitions/ interpretations of burnout concept will also be the subject of discussion of this review.

The world's population has suffered a global crisis, forcing many health systems to face structural reform. This has in turn generated an increase in the pace of work and demands on staff, and causing burnout to affect a greater number of professionals.[10] Freudenberger[9] identifies those predisposed to developing burnout as being overly dedicated professionals, perfectionists and having a compulsive nature, whose work is a substitute for their social life. The cause of burnout, according to Sá,[14] includes personal factors such as the characteristics of employees, and professionals factors such as the working environment and organizational dynamics.

Maslach and Goldberg[15] report that burnout is a consequence of continued exposure to stressful events of a work origin, while Maslach and Leiter[10] maintain that burnout is not specifically a problem that is inherent to the person, but fundamentally results from the features of the organizational environment in which the person performs his professional functions.

Emotional, mental and spiritual exhaustion develops due to the decreased level of energy and enthusiasm when the workplace is viewed as hostile and excessively demanding, both economically and psychologically. The dedication and commitment to work, thus, wanes, and health professionals become cynical, distant and try not to be too greatly involved in the employment context.[6,11] Working with dying patients is, according to Pavelková and Bužgová,[8] considered to pose an even greater risk of burnout, and it was the situation of nurses in hospices that drew attention to burnout for the first time. Great demands are placed on health professionals in palliative care, since "they encounter suffering and the transience of life, seemingly futile battle, helplessness and grief".[8(p.218)] However, one should not confuse burnout with compassion fatigue. Compassion fatigue is often thought of as the caregiver's cost of caring and results when health professionals are exposed to repeated interactions requiring high levels of empathic engagement with distressed patients, although compassion fatigue can be a significant contributing factor in health professional burnout.[16,17]

Some studies have been carried out on the impact of working in palliative care on the level of burnout among health professionals. The level of burnout among professionals working in palliative care in these studies is lower than the level of burnout of professionals in other contexts.[18-20] In a previous review, burnout among health professionals working in palliative care was examined. This was, however, primarily limited to nurses and doctors, focusing on a survey of the research activity on the subject, an ethical perspective, a limited period of time and with no assessment of the methodological quality of the included studies.[5] Studies on the prevalence for burnout among health professionals working in palliative care have, however, not been systematically assessed. A precise estimate of the prevalence for burnout in this specific context can have immediate implications, such as vulnerable groups being identified and measures being taken to reduce the risk of burnout. There are also research implications, whereby interventions could be tested in high prevalence subgroups. This is important because of the relationship between a satisfied worker and a satisfied patient; high-quality care for patients is, thus, preceded by high-quality care for employees.[8]

An initial search of the *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Library, PROSPERO, PubMed and CINAHL found no existing systematic review on the epidemiology of burnout among health professionals working in palliative care. This review was guided by the methodology proposed for JBI for the conduct of the systematic review of prevalence and incidence data,[21] and examined the available evidence on the prevalence of burnout among health professionals working in palliative care. The objective, inclusion criteria and methods of analysis for this review were specified in advance and documented in a systematic review protocol.[22]

Review objective/questions

The objective of this review was to examine evidence on the prevalence of burnout among health professionals working in palliative care.

More specifically, the review focused on the following questions:
- What is the prevalence of burnout among health professionals working in palliative care?
- Is there a difference in the prevalence of burnout among different groups of health professionals working in palliative care?
- Is there a difference in the prevalence of burnout among health professionals working in different palliative care contexts?

Inclusion criteria
Types of participants
The current review included studies that encompassed all qualified health professionals (physicians, registered nurses, physiotherapists, psychologists, social workers and occupational therapists), caring for patients 18 years of age or older, working in palliative care.

Studies that included participants working in contexts other than palliative care were excluded unless the data were separated and analyzed in a study comparing palliative care with other areas of care.

Condition
The current review considered studies reporting on the point prevalence of "burnout" measured by any

burnout scale, such as, but not limited to, the Maslach Burnout Inventory, Burnout Measure and Copenhagen Burnout Inventory.

Context

The organization of palliative care across countries where it is developed distinguishes specialist from non-specialist palliative care. This review considered studies conducted in the context of specialist palliative care, more specifically, palliative care units, specialized palliative home care or hospices.

Types of studies

The current review considered observational study designs, including prospective and retrospective cohort, case-control and cross-sectional studies. Studies published in English, Spanish and Portuguese since 1975 were considered for inclusion. This year was chosen because publications related to burnout in healthcare began to appear in the literature after 1974.

Search strategy

A three-step search strategy was used in this review to find published and unpublished studies. The full search strategy is presented in Appendix I. A first initial limited search of MEDLINE (via PubMed) and CINAHL was undertaken, with an analysis of text words in the titles and abstracts and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all databases included in this review. Third, the reference list of all identified reports and articles was searched for additional studies.

The databases searched (on January 2, 2016) were: CINAHL Plus with Full Text, PubMed, Scopus and SciELO. The search for unpublished studies was undertaken in: DART-Europe, OpenGrey, RCAAP – Repositório Científico de Acesso Aberto de Portugal, ProQuest – Health and Medical Complete, and Banco de teses da CAPES. The initial search included the keywords: burnout, palliative, hospice, "home care," "end of life" and "health professionals."

The Mendeley software program was used to manage the list of all the articles retrieved and any duplication was removed. All identified studies were assessed for relevance based on title and abstract. Whenever the title and abstract lacked data on which to make a decision, the inclusion criteria described above were verified in full-text papers.

Methods of the review

Assessment of methodological quality

As originally outlined in the systematic review protocol,[22] papers selected for retrieval were assessed by two independent reviewers (VP and AC) for methodological validity prior to inclusion in the review using standardized critical appraisal instrument from the JBI – critical appraisal checklist for studies reporting prevalence data.[23] There were no disagreements between the reviewers relating to the inclusion or the critical appraisal of results.

Data extraction

Data from the included studies were extracted independently by the two reviewers, using a data extraction table, taking into account the review questions (Appendix II). The data extracted included specific details about the aim of the study, study design, measurement instrument, setting, sample characteristic and main results of significance to the review objective and specific questions. Authors of primary studies were contacted to provide missing or additional data.

Data synthesis

A meta-analysis was not performed due to significant differences between condition measures (clinical and methodological heterogeneity). The results are thus presented in a narrative form, including tables to aid data presentation.

Results

Description of studies

The stages of identification and retrieval of studies for inclusion are presented in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart (Fig. 1). A total 526 potentially relevant studies were identified for study selection and a total of 483 studies were excluded on evaluation of the title (420) and abstract (63). The full-text versions of the remaining 43 articles were read and eight were found to fulfil the inclusion criteria. A list of excluded studies after full-text eligibility assessment is presented in Appendix III. It is relevant to mention that two articles[24,25] were excluded because the authors did not provide information about the study context, and three further articles[26-28] were excluded due to not being able to obtain the full-text versions despite utilizing other research centers, databases and personal contact with the first author.
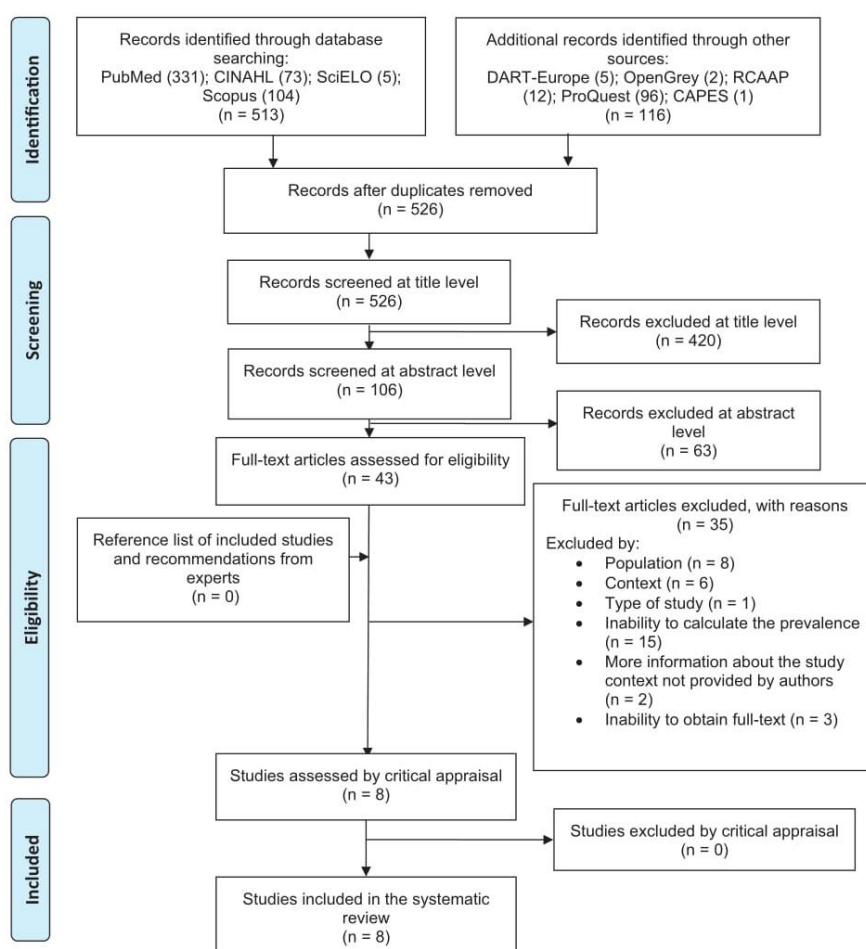
From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097

Figure 1: Flowchart of the study selection and inclusion process

Methodological quality

Eight articles meeting the inclusion criteria were assessed for methodological quality. The cutoff for inclusion/exclusion was not stated in the protocol, given that it was subsequently determined through consensus between the reviewers. The cutoff point for inclusion of a study in the review was a "yes" answer to at least five questions (more than 50%) in the standardized critical appraisal instrument from the JBI – critical appraisal checklist for studies reporting prevalence data.[23]

Two independent reviewers assessed the eight cross-sectional studies[8,12,13,29-33] and there was general agreement among the reviewers to include these (Table 1). One of the studies used a mixed-method approach, where the quantitative design of the research was a cross-sectional study.[32] Two studies attained five "yes" scores,[32,33] while the remaining studies had a minimum of six "yes" scores.

As described in Table 1, one of the nine questions in the standardized critical appraisal instrument for studies reporting prevalence data was accomplished by all cross-sectional studies. Questions 6 and 7, on validity of the burnout measurement instrument – with a significant impact on outcome assessment validity and how the measurement was conducted, that is with wrong interpretation of the instrument – were the questions that presented a greater risk for bias in the included studies. This entails that, in spite of the studies

individually justifying their options in a valid way when compared with one another, there was no coherence in relation to cutoffs and a definition of the presence of burnout. These aspects are discussed in greater detail in the "Discussion" section.

Characteristics of included studies
Details related to the study design, measurement instrument, setting and sample characteristics, main results and additional information or limitations reported are presented in Appendix II.

Study design
The current systematic review included eight cross-sectional studies.

Year of publication, country of publication and study setting
The included studies were published between 2007 and 2015; seven were published in English[8,12,13,29-32] and one in Spanish.[33] The year of publication, country where included studies were conducted and study setting are presented in Table 2.

Table 1: Critical appraisal results for included studies using the JBI prevalence critical appraisal checklist

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Asai et al.[29]	Y	Y	Y	Y	Y	N	Y	U	U
Dréano-Hartz et al.[12]	Y	Y	Y	Y	N	Y	N	Y	Y
Hunnibell et al.[30]	Y	U	N	Y	Y	Y	Y	Y	U
Koh et al.[13]	N	Y	Y	Y	Y	U	Y	Y	Y
Ostacoli et al.[31]	Y	N	U	Y	Y	Y	Y	Y	Y
Pavelková and Bužgová[8]	Y	Y	Y	Y	N	Y	Y	Y	U
Quinn-Lee et al.[32]	N	Y	U	Y	Y	N	N	Y	Y
Santamaría García et al.[33]	Y	U	U	Y	Y	N	Y	Y	N
Y%	75	63	50	100	75	50	75	88	50

N, no; U, unclear; Y, yes.

Table 2: Year of publication, country of publication and study setting of included studies

Reference	Year of publication	Country of publication	Setting
Asai et al.[29]	2007	Japan	Hospice or palliative care unit
Dréano-Hartz et al.[12]	2015	France	Palliative care unit and/or home care
Hunnibell et al.[30]	2008	USA	Hospice
Koh et al.[13]	2015	Singapore	Palliative care unit, home care and hospice
Ostacoli et al.[31]	2010	Italy	Hospice
Pavelková and Bužgová[8]	2015	Czech Republic	Hospice
Quinn-Lee et al.[32]	2014	USA	Hospice
Santamaría García et al.[33]	2008	Spain	Home care or palliative care unit

Study participants

Extracted data from the studies on sample, type of the sample, age and experience of palliative care are presented in Table 3. A total of 1406 health professionals from the eight studies were included in this review. Sample sizes ranged from 29 to 309 participants. The sample consisted of nurses, physicians and social workers. It is noteworthy that we also included physiotherapists, psychologists and occupational therapists in our review but none of the articles presented data about these categories of health professionals.

All the eight included studies presented data of the ages of the participants in the sample; however, some studies presented the mean with/without standard deviation and others presented the range and percentage. Similar variations could be found for experience in the field in the eight studies. However, the years of experience in palliative care was not presented in the article by Dréano-Hartz et al.[12] but rather the duration of the professional position held.

We decided to present these data since they provide a realistic representation of the sample.

Measurement instruments

Two different instruments, the Maslach Burnout Inventory and the Burnout Measure, were used to assess burnout in the included studies (Table 4).

Seven studies assessed the occurrence of burnout using the Maslach Burnout Inventory, but only one of these[13] presented the prevalence of burnout. The others did not present data about the presence or absence of burnout, but only about the sub-scales that made up the Maslach Burnout Inventory: Emotional Exhaustion, Depersonalization and Personal Accomplishment. Although the majority of the articles defined the presence of burnout, taking into account the sub-scales, they did this using different criteria. Even though the prevalence of the sub-scales was available in the included studies, the nature of the data was such that a calculation of the prevalence of burnout was not

Table 3: Characteristics of included studies (sample, type of sample, age and experience in palliative care)

Reference	Sample	Age in years	Experience in palliative care in years
Asai et al.[29]	Physicians (n = 87)	Mean ± SD: 43 ± 8.1	Mean ± SD: 12 ± 7.6 Range: 1.0–30
Dréano-Hartz et al.[12]	Physicians (n = 309)	Mean ± SD: 47.2 ± 9.2	Palliative care unit: 8.7 ± 7.0 Palliative care unit and home care – palliative care mobile team: 9.7 ± 6.8 Home care – palliative care mobile team: 8.9 ± 5.7
Hunnibell et al.[30]	Nurses (n = 244)	Mean ± SD: 48.10 ± 9.28 Age data include oncology nurses (56.6% of the sample), we could not obtain data exclusively for hospice nurses	Mean ± SD: 20.37 ± 10.66 Years of experience data include oncology nurses (56.6% of the sample), we could not obtain data exclusively for hospice nurses
Koh et al.[13]	Total (n = 273) Physicians (n = 74) Nurses (n = 156) Social workers (n = 37)	20–29 (n = 59) (21.6%); 30–39 (n = 99) (36.3%); 40–49 (n = 67) (24.5%); ≥50 (n = 44) (16.1%)	≤1 (n = 81) (29.7%); 1–2 (n = 41) (15.0%); 2–3 (n = 31) (11.4%); 3–5 (n = 41) (15.0%); 5–10 (n = 40) (14.7%); >10 (n = 30) (11.0%)
Ostacoli et al.[31]	Nurses (n = 33)	Mean ± SD: 37.27 ± 9.71	Mean ± SD: 3.38 ± 2.55
Pavelková and Bužgová[8]	Total (n = 141) Nurses (n = 139) Physicians (n = 2)	20–30 (n = 38) (15.8%); 31–40 (n = 78) (32.4%); 41–50 (n = 79) (32.8%); >50 (n = 46) (19.1%) Age data include attendant/orderly (41.5% of the sample); we could not obtain data exclusively for hospice nurses and physicians	≤5 (n = 126) (54.3%); 6–10 (n = 86) (37.1%); ≥11 (n = 20) (8.6%) Years of experience data include attendant/orderly (41.5% of the sample); we could not obtain data exclusively for hospice nurses and physicians
Quinn-Lee et al.[32]	Social workers (n = 290)	Mean: 44	Mean ± SD: 6.97 ± 5.31
Santamaría García et al.[33]	Total (n = 29) Physicians (n = 11) Nurses (n = 18)	20–30 (n = 10) (22.2%); 31–40 (n = 20) (44.4%); 41–50 (n = 13) (28.9%); 50–60 (n = 1) (2.2%); >60 (n = 1) (2.2%) Age data include nurses' auxiliaries (35.6% of the sample); we could not obtain data exclusively for physicians and/or nurses	<1 (n = 2) (4.4%); 1–5 (n = 25) (55.6%); 6–10 (n = 15) (33.3%); 11–20 (n = 3) (6.7%); >20 (n = 0) (0.0%) Years of experience data include nurses' auxiliaries (35.6% of the sample); we could not obtain data exclusively for physicians and/or nurses

SD, standard deviation.

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possible due to lack of information on whether the participants with severely abnormal levels of one of the sub-scales had the same ratings in the other sub-scales. Furthermore, it is worth mentioning that there were differences in the range used in the different sub-scales. The sub-scale Personal Accomplishment was interpreted incorrectly in two articles whereby the data were presented in one study as though it was a correct interpretation,[32] while in the other, there was no data presented at all.[12]

The Burnout Measure was used in the study by Pavelková and Bužgová[8] in which the prevalence of burnout was presented.

Findings of the review

It was impossible to perform a meta-analysis due to the differences in the range used for the sub-scales in the studies, and also the differences when classifying the prevalence of burnout. The findings of prevalence of burnout among health

Table 4: Results of included studies (measurement instruments of the condition)

Reference	Measurement instrument	Definition of the presence of burnout	Data on prevalence of burnout
Asai *et al.*[29]	Maslach Burnout Inventory	A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (score of ≥27), a high level of Depersonalization (score of ≥10) and a low level of Personal Accomplishment (score of ≤33) based on normative data from a sample of American health professionals	Calculation of the global prevalence of burnout not possible from data from the sub-scales
Dréano-Hartz *et al.*[12]	Maslach Burnout Inventory	Criteria for burnout syndrome was: at least one dimension with severely abnormal ratings MBI scores: High level of Emotional Exhaustion (score ≥30) High level of Depersonalization (score ≥12) Low level of Personal Accomplishment (score ≥40) – should be less than. We do not have the data of the correct interval	Taking into consideration the definition of burnout we could assume that the presence of high level scores for at least one of the sub-scales represented burnout
Hunnibell *et al.*[30]	Maslach Burnout Inventory Human Services Survey	A high level of burnout (presence of burnout) was defined as: High scores of Emotional Exhaustion and Depersonalization along with low scores for Personal Accomplishment The intervals were analyzed dividing the range in 3 (based on normative data)	Calculation of the global prevalence of burnout not possible from data from the sub-scales

Table 4. (*Continued*)

Reference	Measurement instrument	Definition of the presence of burnout	Data on prevalence of burnout
Koh et al.[13]	Maslach Burnout Inventory Human Services Survey	A high level of burnout (presence of burnout) was defined as: High scores for Emotional Exhaustion $\geq$27AND/OR high scores for Depersonalization $\geq$10 The sub-scale Personal Accomplishment has not been taken into consideration and with a high score for one of the other two sub-scales was enough to be considered as burnout	The article presented the prevalence of burnout
Ostacoli et al.[31]	Maslach Burnout Inventory	A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (upper third, score of $\geq$24), a high level of Depersonalization (upper third, score of $\geq$9) and a low level of Personal Accomplishment (lower third, score of $\leq$30)	Calculation of the global prevalence of burnout not possible from data from the sub-scales
Pavelková and Bužgová[8]	The Burnout Measure	Burnout was categorized into four levels: very good to good (less than 3), alarming (3 to 3.9), burnout (4 to 5) and acute crisis (more than 5)	The article presented the prevalence of burnout
Quinn-Lee et al.[32]	Maslach Burnout Inventory Human Services Survey	Presence of burnout was defined as: A score in the sub-scales of $\geq$27 for Emotional Exhaustion, a score for $\geq$13 on Depersonalization, AND/OR a score of $\geq$39 on Personal Accomplishment Personal Accomplishment sub-scale is reversed so in reality the score should be $\leq$31, taking in consideration the intervals mentioned – we have the correct data from the article and we will present those	Calculation of the global prevalence of burnout not possible from data from the sub-scales

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Table 4. (*Continued*)

Reference	Measurement instrument	Definition of the presence of burnout	Data on prevalence of burnout
Santamaría García et al.[33]	Maslach Burnout Inventory	A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (score of ≥27), a high level of Depersonalization (score of ≥10) and a low level of Personal Accomplishment (score of ≤33) based on normative data from a sample of American health professionals	Calculation of the global prevalence of burnout not possible from data from the sub-scales

professionals working in palliative care are, therefore, presented in a narrative summary and in tables.

We used the following formula to calculate the point prevalence:

$$\text{Prevalence} = \frac{\text{Number of people with disease at a given point in time}}{\text{Total number of people in the population}}$$

Since only three studies presented data on the prevalence of burnout, we have also presented the prevalence of the three sub-scales of the Maslach Burnout Inventory.

Prevalence of burnout among health professionals working in palliative care

The results of studies included in this systematic review on the prevalence of burnout among health professionals working in palliative care are presented in Table 5.

Prevalence of burnout

Only three studies presented values of the global prevalence of burnout. However, as mentioned previously, two studies presented different interpretations of the definition of burnout using the Maslach Burnout Inventory,[12,13] while the third used a different instrument to calculate the prevalence of burnout.[8] Our findings reveal a prevalence of burnout of 17.3%.

Prevalence in the three sub-scales of the Maslach Burnout Inventory

When calculating the prevalence in the sub-scales of the Maslach Burnout Inventory, the article by Pavelková and Bužová[8] was excluded since they used a different instrument and the article by Quinn-Lee et al.[32] was also excluded for the calculation of the sub-scale of Personal Accomplishment because the study presented an incorrectly analyzed value for the specific sub-scale.

The findings reveal that the sub-scale of Personal Accomplishment had the highest prevalence (19.5%), followed by Emotional Exhaustion (17.5%) and then Depersonalization (6.5%).

Differences in the prevalence of burnout in different subgroups of health professionals working in palliative care

The results of studies included in this systematic review on the differences in the prevalence of burnout in different subgroups of health professionals working in palliative care are presented in Table 6.

Prevalence of burnout

The prevalence of burnout was highest among social workers (27%), but it should be noted that these data were only from one study with a low number of participants.[28] The prevalence for nurses was 18.6% while physicians had the lowest, with 15.1%.

Prevalence in the three sub-scales of the Maslach Burnout Inventory

The findings show that nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%) and physicians had lower levels of Personal Accomplishment (41.2%) compared with the other subgroups.

Differences in the prevalence of burnout among health professionals working in different contexts of palliative care

The results of studies included in this systematic review on the differences in the prevalence of

Table 5: Results of included studies (prevalence of burnout among health professionals working in palliative care)

Reference	Sample size	Prevalence in the sub-scales of the Maslach Burnout Inventory			Prevalence of burnout
		High level of Emotional Exhaustion	High level of Depersonalization	Low level of Personal Accomplishment	
Asai et al.[29]	(n = 87)	(n = 13) (15%)	(n = 7) (8%)	(n = 46) (53%)	Calculation not possible from data
Dréano-Hartz et al.[12]	(n = 309)	(n = 27) (9%)	(n = 12) (4%)	Wrong value stated in the article	(n = 27) (9%)
Hunnibell et al.[30]	(n = 244)	(n = 44) (18%)	(n = 11) (4.5%)	(n = 7) (2.9%)	Calculation not possible from data
Koh et al.[13]	(n = 273)	(n = 72) (26.4%)	(n = 43) (15.8%)	(n = 111) (40.7%)	(n = 91) (33.3%)
Ostacoli et al.[31]	(n = 33)	(n = 1) (3%)	(n = 1) (3%)	(n = 1) (3%)	Calculation not possible from data
Quinn-Lee et al.[32]	(n = 290)	(n = 44) (15%)	(n = 4) (1.3%)	(n = 17) (6%) Revised value	Calculation not possible from data
Santamaría García et al.[33]	(n = 29)	(n = 5) (17.2%)	(n = 4) (13.8%)	(n = 4) (13.8%)	Calculation not possible from data
Pavelková and Bužgová[8]	(n = 141)	Other instrument used – the Burnout Measure			(n = 7) (5%)
Total	(n = 1406)	221/1265 = 17.5%*	82/1265 = 6.5%*	186/956 = 19.5%†	125/723 = 17.3%‡

*This result did not included the article by Pavelková and Bužgová.[8]
†This result did not included the articles by Pavelková and Bužgová[8] and Dréano-Hartz et al.[12]
‡Data from the articles by Pavelková and Bužgová,[8] Dréano-Hartz et al.[12] and Koh et al.[13]

burnout among health professionals working in different contexts of palliative care are presented in Table 7.

Prevalence of burnout
The three studies[8,12,13] which presented the global prevalence of burnout had samples from different contexts in palliative care. One study included palliative care units, home care and hospices,[13] while another included palliative care units and home care[12] compared to the third which only included hospice.[8] The prevalence of burnout for each palliative care context is thus calculated on the basis of only two studies for each context.

The findings show that the highest prevalence of burnout existed in health professionals working in

Table 6: Results of included studies (differences in the prevalence of burnout in different subgroups of health professionals working in palliative care)

Reference	Type of Sample	Prevalence in the sub-scales of the Maslach Burnout Inventory			Prevalence of burnout
		High level of Emotional Exhaustion	High level of Depersonalization	Low level of Personal Accomplishment	
Asai *et al.*[29]	Physicians ($n = 87$)	($n = 13$) (15%)	($n = 7$) (8%)	($n = 46$) (53%)	Calculation not possible from data in the article
Dréano-Hartz *et al.*[12]	Physicians ($n = 309$)	($n = 27$) (9%)	($n = 12$) (4%)	Wrong value stated in the article	($n = 27$) (9%)
Hunnibell *et al.*[30]	Nurses ($n = 244$)	($n = 44$) (18%)	($n = 11$) (4.5%)	($n = 7$) (2.9%)	Calculation not possible from data in the article
Koh *et al.*[13]	Physicians ($n = 74$) Nurses ($n = 156$) Social workers ($n = 37$)	($n = 23$) (31.1%) ($n = 40$) (26.0%) ($n = 8$) (22.2%)	($n = 15$) (20.3%) ($n = 22$) (14.3%) ($n = 5$) (13.9%)	($n = 22$) (29.7%) ($n = 69$) (44.8%) ($n = 16$) (44.4%)	($n = 31$) (41.9%) ($n = 48$) (31.2%) ($n = 10$) (27.8%)
Ostacoli *et al.*[31]	Nurses ($n = 33$)	($n = 1$) (3%)	($n = 1$) (3%)	($n = 1$) (3%)	Calculation not possible from data in the article
Quinn-Lee *et al.*[32]	Social workers ($n = 290$)	($n = 44$) (15%)	($n = 4$) (1.3%)	($n = 17$) (6%) Revised value	Calculation not possible from data in the article
Santamaría García *et al.*[33]	Physicians ($n = 11$) Nurses ($n = 18$)	($n = 2$) (18.2%) ($n = 3$) (16.7%)	($n = 1$) (9.1%) ($n = 3$) (16.7%)	($n = 3$) (27.3%) ($n = 1$) (5.6%)	Calculation not possible from data in the article
Pavelková and Bužgová[8]	Nurses ($n = 139$) Physician ($n = 2$)	Other instrument used – the Burnout Measure			($n = 7$) (5%) ($n = 0$)
Total	Physicians ($n = 483$) Nurses ($n = 590$) Social workers ($n = 327$)	62/481 = 12.9%* 88/451 = 19.5%* 52/327 = 15.9%	35/481 = 7.2%* 37/451 = 8.2%* 9/327 = 2.8%	71/172 = 41.2%† 78/451 = 17.3%* 33/327 = 10.1%	58/385 = 15.1%‡ 55/295 = 18.6%§ 10/37 = 27%‖

*This result did not include the article by Pavelková and Bužgová.[8]
†This result did not include the articles by Pavelková and Bužgová[8] and Dréano-Hartz *et al.*[12]
‡Data from articles by Dréano-Hartz *et al.*[12] and Koh *et al.*[13]
§Data from articles by Pavelková and Bužgová,[8] and Koh *et al.*[13]
‖Data from article by Koh *et al.*[13]

palliative home care context (19.6%). The lowest prevalence was found in the hospice context (14.2%).

Prevalence in the three sub-scales of the Maslach Burnout Inventory

Most of the included studies reported prevalence in the sub-scales of the Maslach Burnout Inventory from different palliative care contexts simultaneously, which made the data impossible to calculate. Dréano-Hartz *et al.*[12] was the only study that had information about the context of palliative care units and home care in the sub-scales for Emotional Exhaustion and Depersonalization. The sub-scale

Personal Accomplishment had incorrectly analyzed values and these data thus cannot be presented.

Discussion

The objective of this systematic review was to examine the evidence on the prevalence of burnout among health professionals working in palliative care. This is the first review investigating the prevalence of burnout in professionals working in this emotionally demanding context. Following an extensive search, eight cross-sectional studies were included in this review.

Seven of the eight included studies assessed the occurrence of burnout using the Maslach Burnout

Table 7: Results of included studies (differences in the prevalence of burnout among health professionals working in different contexts of palliative care)

Reference	Setting	Prevalence in the sub-scales of the Maslach Burnout Inventory			Prevalence of burnout
		High level of Emotional Exhaustion	High level of Depersonalization	Low level of Personal Accomplishment	
Asai et al.[29]	Hospices or palliative care units ($n = 87$)	($n = 13$) (15%)	($n = 7$) (8%)	($n = 46$) (53%)	Calculation not possible from data from the article
Dréano-Hartz et al.[12]	Palliative care units ($n = 77$) Home care ($n = 159$)	($n = 3$) (4%) ($n = 20$) (13%)	($n = 2$) (3%) ($n = 6$) (4%)	Wrong value stated in the article	($n = 3$) (4%) ($n = 20$) (13%)
Hunnibell et al.[30]	Hospice ($n = 244$)	($n = 44$) (18%)	($n = 11$) (4.5%)	($n = 7$) (2.9%)	Calculation not possible from data from the article
Koh et al.[13]	Palliative care units ($n = 80$) Home care ($n = 65$) Hospice ($n = 100$)	($n = 72$) (26.4%)	($n = 43$) (15.8%)	($n = 111$) (40.7%)	($n = 25$) (31.3%) ($n = 24$) (36.9%) ($n = 27$) (27.8%)
Ostacoli et al.[31]	Hospice ($n = 33$)	($n = 1$) (3%)	($n = 1$) (3%)	($n = 1$) (3%)	Calculation not possible from data from the article
Quinn-Lee et al.[32]	Hospice ($n = 290$)	($n = 44$) (15%)	($n = 4$) (1.3%)	($n = 17$) (6%) Revised value	Calculation not possible from data from the article
Santamaría García et al.[33]	Home care or palliative care units ($n = 29$)	($n = 5$) (17.2%)	($n = 4$) (13.8%)	($n = 4$) (13.8%)	Calculation not possible from data from the article

Table 7. (Continued)

Reference	Setting	Prevalence in the sub-scales of the Maslach Burnout Inventory			Prevalence of burnout
		High level of Emotional Exhaustion	High level of Depersonali-zation	Low level of Personal Accom-plishment	
Pavelková and Bužgová[8]	Hospice ($n = 139$)	Other instrument used – the Burnout Measure			($n = 7$) (5%)
Total	Palliative care units ($n = 157$)	3/77 = 4%[*]	2/77 = 3%[*]	-	28/157 = 17.8%[†]
	Hospice ($n = 806$)	89/667 = 13.3%[‡]	16/667 = 2.4%[‡]	25/667 = 3.7%[‡]	34/239 = 14.2%[§]
	Home care ($n = 224$)	20/159 = 13%[*]	6/159 = 4%[*]	-	44/224 = 19.6%[†]

[*]Data from article by Dréano-Hartz *et al.*[12]
[†]Data from articles by Dréano-Hartz *et al.*[12] and Koh *et al.*[13]
[‡]Data from articles by Hunnibell *et al.*,[30] Ostacoli *et al.*[31] and Quinn-Lee *et al.*[32]
[§]Data from articles by Pavelková and Bužgová,[8] and Koh *et al.*[13]

Inventory, and in only the article by Pavelková and Bužgová[8] a different measurement instrument was used, the Burnout Measure. We have, thus, decided to use the sub-scales of the Maslach Burnout Inventory when presenting the results as they enable a better comprehension of the realities captured in the studies. This decision is strengthened by the lack of a total score for the prevalence of burnout in five studies using this instrument,[29-33] in which only the results from the different sub-scales were presented. Attaining a total score of the prevalence of burnout was not possible due to an absence of information on whether the participants with severely abnormal levels in one of the sub-scales had the same scores in the other sub-scales. Prevalence in the various sub-scales was the only information available, and, thus, the total score of the prevalence of burnout using the instrument in these studies could not be presented.

In the seven studies using the Maslach Burnout Inventory, an interpretation of the definition of the presence of burnout in the instrument was made. Despite using the existing literature to justify the options, this interpretation and definition were, however, not the same in all studies. Furthermore the range for the different sub-scales was not equal in the seven studies.

In the study by Koh *et al.*,[13] the presence of burnout was assigned a high score for Emotional Exhaustion AND/OR a high score for Depersonalization, which means that the sub-scale Personal Accomplishment was not taken into consideration and, together with a high score in one of the other two sub-scales, was sufficient to be considered as burnout. This interpretation of the instrument, which was rationalized by references to the literature by the authors, differs from that in the other five studies named above, which took all the three sub-scales into account for the definition of the presence of burnout – a high level of Emotional Exhaustion, a high level of Depersonalization and a low level of Personal Accomplishment.

The same occurred in the study by Dréano-Hartz *et al.*[12] where burnout was determined if at least one of the dimensions was severely abnormal. Based on this definition of burnout, we could assume that at least that having participants with a high level in one of the sub-scales constitutes burnout.

In addition to the differences in the range for the sub-scales in the studies and the varying interpretation of the instrument for the existence of burnout, it is noteworthy that the sub-scale Personal Accomplishment was interpreted incorrectly in two articles – one article presented data from which we were able

to make a correct interpretation[32] and the other did not present any data at all.[12]

The adoption of different ranges, different interpretations of the instrument and even the incorrect interpretation in two studies[12,32] had important repercussions for the present review. The presence of these divergences affected the results of the individual articles as well as prevented the performance of a meta-analysis. We have, thus, only presented a narrative synthesis, as recommended.[21,34]

The inability to perform meta-analysis relates not only to the statistical heterogeneity of the studies but also to the clinical heterogeneity (in terms of differences in the characteristics of study populations and measurements). In the studies by Santamaría García et al.,[33] Hunnibell et al.[30] and Pavelková and Bužgová,[8] data about the age and experience in palliative care were not only from the participants included in the review but also from other participants; however, we decided to present these results since they provide a realistic representation of the included studies. To minimize this bias, the percentage of the non-representative sample was provided to enable the interpretation. Furthermore, in relation to palliative care experience, the largest number of participants in the study by Koh et al.[13] had less than one year of experience compared with the other ranges in the study and with the other studies. It is, thus, possible that this heterogeneity has influenced the presented results, and they should be interpreted with caution, taking these considerations into account.

Based on the analysis of the primary studies, the prevalence of burnout among health professionals is 17.3%. This has been calculated from three primary studies, two of them with different interpretations of the definition of burnout using the Maslach Burnout Inventory,[12,13] while the other used a different instrument to calculate the prevalence of burnout.[8] The highest prevalence (19.5%) is for the Personal Accomplishment sub-scale of the Maslach Burnout Inventory; however, as stated previously, these results should be interpreted with caution because the range used in the sub-scales was not always the same.

The practice of palliative care generates a wide range of feelings, from sadness and grief for the death of patients to feelings of gratification, enrichment and Personal Accomplishment for the work done, which helps to avoid physical and Emotional Exhaustion.[35,36] However, Dréano-Hartz et al.[12] alerts us to the following: one physician declared that he did not want to take part in the study because he was suffering from burnout. This situation is a potential bias, as the health professionals who did not participate in the studies could possibly be those mainly suffering from the studied condition and those participants may have already left palliative care.

The study by Koh et al.[13] presented ratings of the prevalence of the different sub-scales of the Maslach Burnout Inventory that were more extreme than in the other studies, and as stated previously, this could be explained by there being many participants having little experience of palliative care. It would be appropriate in the future to develop research on the relationship between professional experience and burnout.

In terms of the difference in the prevalence of burnout in different subgroups of health professionals, nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%), which might be due to their spending the greatest amount of time with the patient in the end-of-life phase.[37] Physicians have lower levels of Personal Accomplishment (41.2%) compared with the other subgroups. The prevalence of burnout is, however, greater among social workers (27%) but it is important to mention that this rating has been obtained from a single study.[13] Qualitative studies would be valuable for understanding these differences between subgroups of health professionals.

It is noteworthy that the included studies were published between 2007 and 2015 and are representative of the changes in the global landscape resulting from the broadened definition of palliative care by the World Health Organization in 2002.[2] This led to changes in the area of operation and together with a global crisis in the world's population, which began in 2007, many Health Systems were forced to face structural reform with the aim of providing them with solvency and viability as well as strengthening cohesive measures to make them sustainable over time.

None of the studies analyzed in this systematic review were carried out with a full range of professional categories. Although we used the term health professionals, as our study was centered upon multidisciplinary teams, data in the studies

exclusively concerned nurses, physicians and social workers. We did not find data about physiotherapists, psychologists or occupational therapists. The absence of other health professionals may be explained by is the possibility that these professionals would not be solely working in palliative care units, hospices or specialized palliative home care. They would likely be attached to palliative care as part of their role. It cannot be assumed that similar findings would emerge with a different sample. This, thus, limits any possible generalization. Our results suggest that it would be positive to incorporate data from other team members concerning the prevalence of burnout to inform about their work and to provide input into the development of multidisciplinary team planning.

Finally, the findings indicated the highest prevalence of burnout in the specialized palliative home care context (19.6%). This might be due to those in home care having responsibility for a larger number of patients, less support, less control and fewer acute care resources in patient care compared to those available at an inpatient hospice or hospital setting.[13] More studies should be undertaken to gain a greater understanding of this phenomenon.

In spite of the review's limitations in terms of only including articles published in English, Portuguese and Spanish and the inability to perform meta-analysis, the presented results are relevant for clinical practice and highly relevant for studies in the field.

Conclusion

The current systematic review contributes to the generation of a body of empirical knowledge that facilitates the professional growth of palliative care teams as it identifies the prevalence of burnout among health professionals in different subgroups and different palliative care contexts.

Results reveal a prevalence of burnout among health professionals of 17.3%, with the sub-scale Personal Accomplishment in the Maslach Burnout Inventory registering the highest prevalence. Nurses have higher levels of Emotional Exhaustion and Depersonalization, and physicians have lower levels of Personal Accomplishment. The prevalence of burnout is higher among social workers and the highest prevalence of burnout is in the home care context.

Each of the included studies provide useful information about the condition of burnout, nevertheless the range used in the sub-scales of the Maslach Burnout Inventory and the interpretation of this instrument of the existence of burnout were not always the same. Furthermore two of the studies interpreted the sub-scale Personal Accomplishment incorrectly, and five studies using this instrument have only presented the results from the different sub-scales. All these factors should be taken into consideration when developing future research on the burnout syndrome, and the use of a standard instrument that will allow a comparison of data with previous evidence.

Implications for practice

The current review reveals that the syndrome of burnout is present among nurses, physicians and social workers, and more common in the context of home care, supporting the basis for the development and implementation of interventions aimed at reducing the level of burnout in these professional groups and in this specific context (JBI Grades of Recommendation = B).

Reviews of prevalence concern an understanding of and an establishment of the nature or "size" of a problem, and in this case it is about the problems health professionals are experiencing and will have implications for health professionals and workforce management. Managers and healthcare professionals should be aware of the prevalence of burnout in palliative care, and be able to recognize it and be prepared to respond to it. This response should be at the individual level (for the wellbeing of the worker) and also at the service (i.e. the site and service provision) and system levels (JBI Grades of Recommendation = B).

Implications for research

Studies in this area need to be more robust, with a standard instrument that allows a common interpretation of the results of the scale and/or sub-scales to indicate the presence of burnout. These studies are required either to confirm or refute our findings on the prevalence of burnout among health professionals working in palliative care. Furthermore, a review comparing the burnout levels among health professionals in palliative care and in other areas of care should be undertaken to understand if there are significant differences among them.

Research on the perspectives of other health professionals in the multidisciplinary teams, for example, physiotherapists and psychologists, is also needed, since they have an important role in the provision of care. Their perspective is absent in the studies included in this systematic review.

In addition, a clear understanding of the factors that affect health professionals and contribute to burnout, and how these factors are managed in daily care, requires evaluation.

Finally, studies on interventions that focus on reducing the pressure felt by health professionals in terms of physical, psychological, social and spiritual aspects – which will have a direct impact on the levels of Emotional Exhaustion, Depersonalization and Personal Accomplishment – are required to gain clarity about the burnout syndrome. Concurrent evaluation of the needs of health professionals and their capacity to provide care at the end of life is important for supporting caregiving activities.

In spite of the limitations of this systematic review, the burnout syndrome is present among all professionals and in all palliative care contexts, thus further studies finding the best strategies and theories on how to provide this care in the most efficient manner possible avoiding burnout symptoms remain a high priority.

Acknowledgements

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Appendix I: Search strategy

PubMed – searched on January 2, 2016

Search ID#	Search terms	Results
S12	Filters: (English[lang] OR Portuguese[lang] OR Spanish[lang])	331
S11	S7 AND S10	365
S10	S8 OR S9	10385
S9	burnout[Title/Abstract]	5948
S8	professional burnout[MeSH Terms]	8271
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	108789
S6	hospice[MeSH Terms]	9355
S5	palliative care[MeSH Terms]	44407
S4	end of life care[MeSH Terms]	43737
S3	"end of life"[Title/Abstract]	14743
S2	palliative*[Title/Abstract]	46426
S1	hospice*[Title/Abstract]	9494

CINAHL Plus – searched on January 2, 2016

Search ID#	Search terms	Results
S11	Limiters: English; Portuguese; Spanish EXCLUDE Medline	73
S10	S6 AND S9	215
S9	S7 OR S8	6661
S8	ABTI "burnout"	
S7	MH "burnout, professional"	
S6	S1 OR S2 OR S3 OR S4 OR S5	42649
S5	ABTI "palliative"	
S4	MH "palliative care"	
S3	ABTI "end of life"	
S2	ABTI "hospice"	
S1	MH "hospice care"	

Scopus – searched on January 2, 2016

Search ID#	Search terms	Results
S7	Filters: AND (English[lang] OR Portuguese[lang] OR Spanish[lang]) Medline	104
S6	S4 AND S5	233
S5	ABTI "burnout"	13387
S4	S1 OR S2 OR S3	79696
S3	ABTI "palliative"	
S2	ABTI "end of life"	
S1	ABTI "hospice"	

Banco de teses da CAPES – searched on January 2, 2016

Search ID#	Search terms	Results
S12	S5 + S6 + S7 No Filters:	1
S11	AB (burnout AND hospice)	0
S10	AB (burnout AND "end of life")	0
S9	AB (burnout AND palliative)	1
S8	AB burnout	56
S7	AB hospice	0
S6	AB "end of life"	1
S5	AB palliative	5
S4	TI burnout	0
S3	TI hospice	0
S2	TI "end of life"	0
S1	TI palliative	0

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DART-Europe – searched on January 2, 2016

Search ID#	Search terms	Results
S9	Filters: English; Portuguese; Spanish	5
S8	S5 + S6 + S7	5
S7	(burnout AND hospice)	0
S6	(burnout AND palliative)	1
S5	(burnout AND "end of life")	4
S4	burnout	343
S3	"end of life"	207
S2	hospice	33
S1	palliative	365

OpenGrey – searched on January 2, 2016

Search ID#	Search terms	Results
S7	Filters: English; Portuguese; Spanish	2
S6	(hospice OR palliative OR "end of life") AND burnout	4
S5	burnout	176
S4	(hospice OR palliative OR "end of life")	662
S3	hospice	114
S2	"end of life"	177
S1	palliative	493

RCAAP – Repositório Científico de Acesso Aberto de Portugal – searched on January 2, 2016

Search ID#	Search terms	Results
S7	Filters: None	12
S6	AB (burnout AND hospice)	0
S5	AB (burnout AND "end of life")	2
S4	AB (burnout AND palliative)	10
S3	TI (burnout AND hospice)	0
S2	TI (burnout AND "end of life")	0
S1	TI (burnout AND palliative)	0

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ProQuest – Health and Medical Complete – searched on January 2, 2016

Search ID#	Search terms	Results
S4	Filters: English; Portuguese; Spanish	96
S3	S1 AND S2	96
S2	ti(burnout) OR ab(burnout)	4464
S1	ti(palliative OR "end of life" OR hospice) OR ab(palliative OR "end of life" OR hospice)	38,232

SciELO – searched on January 2, 2016

Search ID#	Search terms	Results
S4	Filters: Language: English; Portuguese; Spanish	5
S3	((ti:(("palliative" or "end of life" or "hospice"))) OR (ab:(("palliative" or "end of life" or "hospice")))) AND ((ti:(burnout)) OR (ab:(burnout)))	5
S2	(ti:(("palliative" or "end of life" or "hospice"))) OR (ab:(("palliative" or "end of life" or "hospice")))	855
S1	(ti:(burnout)) OR (ab:(burnout))	513

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Appendix II: Extraction instrument

Author/year/ country	Aims	Study design/ measurement instrument	Setting	Sample characteristic	Main results Prevalence *n/n* (%):proportion of health professionals with burnout; Proportion of health professionals with burnout in different contexts	Additional information/limitations
Asai et al.[29] 2007 Japan	To determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients	Cross-sectional study; Maslach Burnout Inventory (MBI)	Hospices or palliative care units (PCUs)	Physicians (*n* = 87)	High level of Emotional Exhaustion (*n* = 13) (15%) High level of Depersonalization (*n* = 7) (8%) Low level of Personal Accomplishment (*n* = 46) (53%)	A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (score of ≥27), a high level of Depersonalization (score of ≥10) and a low level of Personal Accomplishment (score of ≤33) based on normative data from a sample of American health professionals Data from the sub-scales did not permit a calculation of the global prevalence of burnout
Dréano-Hartz et al.[12] 2015 France	To define how clinical settings can have an influence on burnout among palliative care physicians	Cross-sectional study; MBI	PCU and/or Home care – palliative care mobile team (PCMT)	Physicians (*n* = 309) PCU (*n* = 77) PCMT/PCU (*n* = 73) PCMT (*n* = 159)	Total (*n* = 309) High level of Emotional Exhaustion (*n* = 27) (9%) High level of Depersonalization (*n* = 12) (4%) Low level of Personal Accomplishment (*n* = 71) (23%) – Wrong value PCU (*n* = 77) High level of Emotional Exhaustion (*n* = 3) (4%) High level of Depersonalization (*n* = 2) (3%) Low level of Personal Accomplishment (*n* = 22) (29%) – Wrong value PCMT/PCU (*n* = 73) High level of Emotional Exhaustion (*n* = 4) (6%) High level of Depersonalization (*n* = 4) (6%) Low level of Personal Accomplishment (*n* = 13) (18%) – Wrong value PCMT (*n* = 159) High level of Emotional Exhaustion (*n* = 20) (13%) High level of Depersonalization (*n* = 6) (4%) Low level of Personal Accomplishment (*n* = 36) (23%) – Wrong value	It was considered to be Burnout syndrome if at least one of the dimensions was severely abnormal MBI scores: High level of Emotional Exhaustion (score ≥30) High level of Depersonalization (score ≥12) Low level of Personal Accomplishment (score ≥40) – should be less than. We do not have the data for the correct intervals Taking into consideration the definition of burnout we could assume that at least the participant with one of the sub-scales with high level represented burnout One physician mentioned in an E-mail that he did not want to take part in the study because he was suffering from burnout. This could be a bias, since the physicians who did not take part could mainly be those suffering from the studied condition

(Continued)

Author/year/country	Aims	Study design/measurement instrument	Setting	Sample characteristic	Main results Prevalence *n/n* (%):proportion of health professionals with burnout; Proportion of health professionals with burnout in different contexts	Additional information/limitations
Hunnibell *et al.*[30] 2008 USA	To determine the relationship between self-transcendence and burnout and compare the differences in self-transcendence and burnout between hospice and oncology nurses	Cross-sectional study: descriptive comparative; Maslach Burnout Inventory-Human Services Survey (MBI-HSS)	Hospice	Nurses (*n* = 244)	High level of Emotional Exhaustion (*n* = 44) (18%) High level of Depersonalization (*n* = 11) (4.5%) Low level of Personal Accomplishment (*n* = 7) (2.9%)	A high level of burnout (presence of burnout) was defined as: High scores for Emotional Exhaustion and Depersonalization along with low scores for Personal Accomplishment The intervals were analyzed dividing the range in 3 (based on normative data) Data from the sub-scales did not permit a calculation of the global prevalence of burnout Reported only the percentage in the sub-scales, we calculated the number of participants taking into account that we know the size of the sample The demographic information includes hospice and oncology nurses They analyzed the intervals dividing the range in 3 (based on normative data) They used a convenience sample of members of professional organizations that may not be representative of the population of working hospice

(Continued)

Author/year/ country	Aims	Study design/ measurement instrument	Setting	Sample characteristic	Main results Prevalence n/n (%):proportion of health professionals with burnout; Proportion of health professionals with burnout in different contexts	Additional information/limitations
Koh et al.[13] 2015 Singapore	To evaluate the prevalence of burnout and its impact upon the psychological health among PCP (physicians, nurses and social workers) within the public healthcare sector in Singapore	Multi-center, prospective, cross-sectional study; MBI-HSS	Acute hospital PCUs, Palliative home care services Inpatient hospices	($n = 273$) Physicians ($n = 74$) (27.1%) Nurses ($n = 156$) (57.1%) Social workers ($n = 37$) (13.6%)	The prevalence of burnout in the study for healthcare professionals was 91 out of 273 (33.3%) **Participants** **Total:** Burnout: ($n = 91$) (33.3%) High level of Emotional Exhaustion ($n = 72$) (26.4%) High level of Depersonalization ($n = 43$) (15.8%) Low level of Personal Accomplishment ($n = 111$) (40.7%) **Physicians:** Burnout: ($n = 31$) (41.9%) High level of Emotional Exhaustion ($n = 23$) (31.1%) High level of Depersonalization ($n = 15$) (20.3%) Low level of Personal Accomplishment ($n = 22$) (29.7%) **Nurse:** Burnout: ($n = 48$) (31.2%) High level of Emotional Exhaustion ($n = 40$) (26.0%) High level of Depersonalization ($n = 22$) (14.3%) Low level of Personal Accomplishment ($n = 69$) (44.8%) **Social worker:** Burnout: ($n = 10$) (27.8%) High level of Emotional Exhaustion ($n = 8$) (22.2%) High level of Depersonalization ($n = 5$) (13.9%) Low level of Personal Accomplishment ($n = 16$) (44.4%) **Settings** **Palliative care units** ($n = 80$) (29.3%) Burnout: ($n = 25$) (31.3%) **Home care** ($n = 65$) (23.8%) Burnout: ($n = 24$) (36.9%) **Hospice** ($n = 100$) (36.6%) Burnout: ($n = 27$) (27.8%) **Multiple places** ($n = 22$) (8.1%) Burnout: ($n = 12$) (54.6%)	A high level of burnout (presence of burnout) was defined as: High scores for Emotional Exhaustion ≥ 27 AND/OR high scores for Depersonalization ≥ 10 The sub-scale Personal Accomplishment has not been taken in consideration and with a high score for one of the other two sub-scales was enough to be considered as burnout The article mentioned that this is in line with other similar studies in palliative care that have adopted the same method of measuring burnout based on high Emotional Exhaustion and/or Depersonalization scores The study presented the number of participants with low PA, but did not mention the corresponding score interval Provides us with only the vision of the public healthcare sector (may not be representative) Survival bias may also influence the results as those who may be burnt out may have already left palliative care.
Ostacoli et al.[31] 2010 Italy	To clarify the differential contributions of situational and individual factors to burnout symptoms e	Cross-sectional study; Italian versions of the MBI	Hospices	Nurses ($n = 33$)	High level of Emotional Exhaustion ($n = 1$) (3%) High level of Depersonalization ($n = 1$) (3%) Low level of Personal Accomplishment ($n = 1$) (3%)	Burnout is conceptualized as a continuous variable indicating the presence of low, moderate or high levels of symptoms; in this study they report the classification of the MBI validated values in the Italian version of the tool A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (upper third, score of ≥ 24), a high level of Depersonalization (upper third, score of ≥ 9) and a low level of Personal Accomplishment (lower third, score of ≤ 30) Data from the sub-scales did not permit a calculation of the global prevalence of burnout

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(Continued)						
Author/year/ country	Aims	Study design/ measurement instrument	Setting	Sample character-istic	Main results Prevalence *n/n* (%):pro-portion of health pro-fessionals with burnout; Proportion of health pro-fessionals with burnout in different contexts	Additional information/limitations
Pavelková and Bužgová[8] 2015 Czech Republic	To determine the degree of burnout among healthcare workers caring for patients in hospices	A cross-sectional study; the Burnout Measure	Hospices	($n = 141$) Nurses ($n = 139$) Physician ($n = 2$)	**Nurses** Burnout: ($n = 7$) (5%) Alarming levels: ($n = 40$) (29%) **Physician** Burnout: ($n = 0$) Alarming levels: ($n = 1$) (50%)	Burnout was categorized into four levels: very good to good (less than 3), alarming (3 to 3.9), burnout (4 to 5), acute crisis (more than 5) Demographic information included Attendant/orderly
Quinn-Lee et al.[32] 2014 USA	To determine the prevalence of burnout and death anxiety among hospice social workers	Mixed-methods (cross-sectional study; grounded theory study; MBI-HSS	Hospice	Social workers ($n = 290$)	High level of Emotional Exhaustion ($n = 44$) (15%) High level of Depersonaliza-tion ($n = 4$) (1.3%) Low level of Personal Accomplishment ($n = 17$) (6%) – revised value	Presence of burnout was defined as: A score in the sub-scales of ≥ 27 for Emotional Exhaustions, a score of ≥ 13 for Depersonalization, AND/OR a score of ≥ 39 for Personal Accomplishment Personal Accomplishment sub-scale is reversed so in reality the score should be ≤ 31, taking in consider-ation the intervals mentioned – we have the correct dates from the article and we present those Data from the sub-scales did not permit a calculation of the global prevalence of burnout
Santamaría García et al.[33] 2008 Spain	To study the prevalence of burnout syndrome in health pro-fessionals working in palliative care units	Cross-sectional descriptive study; MBI	Home care or pal-liative care units	($n = 29$) Physicians ($n = 11$) Nurses ($n = 18$)	**Physicians:** High level of Emotional Exhaustion ($n = 2$) (18,2%) High level of Depersonaliza-tion ($n = 1$) (9,1%) Low level of Personal Accomplishment ($n = 3$) (27,3%) **Nurses:** High level of Emotional Exhaustion ($n = 3$) (16,7%) High level of Depersonaliza-tion ($n = 3$) (16,7%) Low level of Personal Accomplishment ($n = 1$) (5.6%)	A high level of burnout (presence of burnout) was defined as: High level of Emotional Exhaustion (score of ≥ 27), a high level of Depersonalization (score of ≥ 10) and a low level of Personal Accom-plishment (score of ≤ 33) based on normative data from a sample of American health professionals Data from the sub-scales did not permit a calculation of the global prevalence of burnout Reported only the percentage in the sub-scales, we calculated the number of participants taking into account we know the size of the sample We cannot use any demographic information because they include nurses' auxiliaries (35.6%) in those dates

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Appendix III: List of excluded studies after full-text eligibility assessment

Cruz BSP da. Burnout e fadiga por compaixão em enfermeiros portugueses. Dissertação de mestrado em Psicologia Clínica e da Saúde (Intervenções Cognitivo-Comportamentais nas Perturbações Psicológicas e da Saúde), apresentada à Faculdade de Psicologia e Ciências da Educação da Universidade de Coimbra; 2014.
Reason for exclusion: This study did not meet the inclusion criteria (context)

Simões SCA. Burnout em cuidados paliativos. Instituto Politécnico de Castelo Branco. Escola Superior de Saúde Dr. Lopes Dias; 2013.
Reason for exclusion: This study did not meet the inclusion criteria (context).

Pereira S, Teixeira C, Ribeiro O, Hernández-Marrero P, Fonseca A, Carvalho A. Burnout in physicians and nurses: a multicentre quantitative study in palliative care units in Portugal. Rev Enferm Ref. Escola Superior de Enfermagem de Coimbra – Unidade de Investigação em Ciências da Saúde – Enfermagem; 2014 Dec;IV Série(3):55−64.
Reason for exclusion: This study did not meet the inclusion criteria (context).

Kamal AH, Bull JH, Wolf SP, Swetz KM, Shanafelt TD, Ast K, *et al.* Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S. J Pain Symptom Manage. 2016;51(4):690−6.
Reason for exclusion: This study did not meet the inclusion criteria (context).

Hernandez-Marrero P, Pereira SM, Carvalho AS. Ethical decisions in palliative care: interprofessional relations as a burnout protective factor? Results from a mixed-methods multicenter study in Portugal. Am J Hosp Palliat Care. 2015
Reason for exclusion: This study did not meet the inclusion criteria (context).

Fonseca A, Pereira S, Carvalho AS. Burnout in nurses working in Portuguese palliative care teams: a mixed methods study. Int J Palliat Nurs. 2012;18(8):373−81.
Reason for exclusion: This study did not meet the inclusion criteria (context).

Plante A, Bouchard L. Occupational stress, burnout, and professional support in nurses working with dying patients. Omega. 1996;32(2):93−109.
Reason for exclusion: This study did not meet the inclusion criteria (does not report the prevalence of "burnout" or data to calculate it).

Bridgeman CA. Caregiver burnout and job satisfaction among palliative and non-palliative nurses: a mixed-methods study. University of Phoenix; 2013.
Reason for exclusion: This study did not meet the inclusion criteria (does not report the prevalence of "burnout" or data to calculate it).

Jackson F. Measuring the burnout of Michigan hospice nurses. Wayne State University; 1988.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Etxeburu IS, Mier O. A descriptive study of death anxiety and stressors in the various practitioners of a palliative care unit. Med Paliativa. 2006;13(1):18−24.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Boyd I. Role conflict and role ambiguity as predictors of burnout among hospice nurses and social workers. University of Florida; 1995.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Kalicinska M, Chylinska J, Wilczek-Rozyczka E. Professional burnout and social support in the workplace among hospice nurses and midwives in Poland. Int J Nurs Pract. 2012;18(6):595–603.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Mallett K, Price JH, Jurs SG, Slenker S. Relationships among burnout, death anxiety, and social support in hospice and critical care nurses. Psychol Rep. 1991;68(3 Pt 2):1347–59.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Patrão CNR, Ribeiro, Olivério Paiva O. Burnout nos enfermeiros de cuidados paliativos. Instituto Politécnico de Viseu, Escola Superior de Saúde de Viseu; 2012.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Sherman DW. Nurses' stress & burnout. How to care for yourself when caring for patients and their families experiencing life-threatening illness. Am J Nurs. 2004;104(5):48–56.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Slocum-Gori S, Hemsworth D, Chan WWY, Carson A, Kazanjian A. Understanding compassion satisfaction, compassion fatigue and burnout: a survey of the hospice palliative care workforce. Palliat Med. 2013;27(2):172–8.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Mor V, Laliberte L. Burnout among hospice staff. Health Soc Work. 1984;9(4):274–83.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Tay WY, Earnest A, Tan SY, Ng MJM. Prevalence of burnout among nurses in a community hospital in Singapore: a cross-sectional study. Proc Singapore Healthc 2014;23(2):93–9.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Gama G, Barbosa F, Vieira M. Personal determinants of nurses' burnout in end of life care. Eur J Oncol Nurs. 2014;18(5):527–33.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Casado Moragón A, Muñoz Durán G, Ortega González N, Castellanos Asenjo A. Burnout in professionals belonging to palliative, intensive care and emergency services in a general hospital. Med cli?nica. 2005;124(14):554–5.
Reason for exclusion: This study did not meet the inclusion criteria (did not report the prevalence of "burnout" or data to calculate it).

Alkema K, Linton JM, Davies R. A study of the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among hospice professionals. J Soc Work End Life Palliat Care. 2008;4(2):101–19.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Baxendale L. An investigation of compassion fatigue, compassion satisfaction, burnout and coping strategies in hospice workers. University of Southampton; 2015.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Cavaleiro RMD. Burnout nos profissionais de saúde dos serviços de psiquiatria, paliativos, dermatologia. 2010.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Holland JM, Neimeyer RA. Reducing the risk of burnout in end-of-life care settings: the role of daily spiritual experiences and training. Palliat Support Care. 2005;3(3):173–81.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Melo CG, Oliver D. Can addressing death anxiety reduce health care workers' burnout and improve patient care?. J Palliat Care. 27(4):287–95.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Turnipseed DLJ. Burnout among hospice nurses: an empirical assessment. Hosp J. 1987;3(2–3):105–19.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Whitebird RR, Asche SE, Thompson GL, Rossom R, Heinrich R. Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota. J Palliat Med. 2013;16(12):1534–9.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Payne N. Occupational stressors and coping as determinants of burnout in female hospice nurses. J Adv Nurs. 2001;33(3):396–405.
Reason for exclusion: This study did not meet the inclusion criteria (type of population).

Ascensão DS de. Burnout nos enfermeiros em cuidados paliativos. Escola Superior de Saúde Dr. Lopes Dias do Instituto Politécnico de Castelo Branco; 2013.
Reason for exclusion: This study did not meet the inclusion criteria (type of study).

Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM, Leaning MS, *et al*. Burnout and psychiatric disorder among cancer clinicians. Br J Cancer. 1995;71(6):1263–9.
Reason for exclusion: This study did not meet the inclusion criteria (the authors did not provide more information about the study context – we contacted the authors, Gregory WM and Leaning MS; we received no response).

Dunwoodie DA, Auret K. Psychological morbidity and burnout in palliative care doctors in Western Australia. Intern Med J. 2007;37(10):693–8.
Reason for exclusion: This study did not meet the inclusion criteria (the authors did not provide more information about the study context – we contacted the author, Dunwoodie DA, we received no response).

Bram PJ, Katz LF. A study of burnout in nurses working in hospice and hospital oncology settings. Oncol Nurs Forum. 1989;16(4):555–60.
Reason for exclusion: We could not check the inclusion criteria (we were unable to obtain the full-text from other research centers and the databases available, and although we contacted the author, Bram PJ; we received no response).

Ortega Ruiz C, López Ríos F, Gómez Martín S. Psychological intervention for professional burnout in the Palliative Care Unit at Gregorio Marañón University Hospital. Med Paliativa. 2008;15(2):93–7.
Reason for exclusion: We could not check the inclusion criteria (we were unable to obtain the full-text from other research centers and the databases available, and although we contact the author, Ortega Ruiz C, we received no response).

Pereira SM. Burnout em cuidados paliativos: uma perspectiva bioética. Universidade Católica Portuguesa; 2011.
Reason for exclusion: We could not check the inclusion criteria (we were unable to obtain the full-text from other research centers and the databases available, and although we contact the author, Pereira SM, we received no response).

4.4. Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review

Feature Article

Burnout in Palliative Care Settings Compared With Other Settings

A Systematic Review

Vitor Parola, RN, MSc ○ Adriana Coelho, RN, MSc ○ Daniela Cardoso, RN ○ Anna Sandgren, PhD, RN ○ João Apóstolo, PhD, RN

A systematic review, using the guideline of the Joanna Briggs Institute, was conducted to explore the effect of working in palliative care settings, compared with other settings, on burnout among health care professionals. Multiple databases were searched—CINAHL, PubMed, Scopus, and SciELO—as well as gray literature for studies published since 1975 that compared health professionals caring for patients older than 18 years in specialized palliative care settings (palliative care units, home care, or hospices) with health professionals working in other settings. Of the 539 studies retrieved, 7 cross-sectional studies were included in this review. Of these, six were conducted with nurses, and six used the Maslach Burnout Inventory. Working in palliative care (palliative care unit or hospices) was associated with lower levels of emotional exhaustion and depersonalization, as well as higher levels of personal accomplishment, compared with working in other settings. Evidence indicates that burnout levels seem to be lower among professionals working in palliative care compared with professionals working in other settings. Further research is needed to explore the strategies used by nurses working in palliative care that help them deal with burnout and to apply these same strategies to professionals working in other settings.

KEY WORDS

burnout, end-of-life care, hospice care, palliative care, systematic review

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Life expectancy is increasing because of advances in science and technology.[1] The aging of the population that will occur in this society where death is being increasingly delayed allows us to predict a gradual increase in the prevalence of degenerative and disabling diseases.[2] It also means that the palliative care needs of these patients will increase. Palliative care aims to improve patients and their families' quality of life in the face of a serious or life-threatening illness.[3] However, providing such care can include multiple stressful and demanding challenges for the health care professionals, including applying relevant scientific and technical knowledge to their care; establishing intense interpersonal relationships; addressing the multiple complex needs of patients and caregivers often in crisis during this period; making significant ethical end-of-life decisions; and being in constant contact with people's suffering, end of life, and death.[4,5] These challenges can lead to physical, psychological, emotional, and moral distress, as well as work-related stress, all of which in turn can increase the risk of burnout.[6-8]

The concept of burnout was first mentioned by Herbert Freudenberg[9] in the 1970s. This author conceptualized burnout as a series of unspecified physical and psychosocial symptoms, produced by excessive energy requirements in work, which usually emerges in professions involved in a helping relationship. Maslach and Leiter[10-12] later defined burnout as a syndrome comprising 3 dimensions—emotional exhaustion, depersonalization, and a lack of personal accomplishment in the workplace— that arises when stress-coping strategies fail. Burnout is believed to be the result of continued exposure to work-related

stressful events.[13,14] When a workplace is seen as extremely demanding, emotional, mental, and spiritual exhaustion can arise because of a concomitant decrease in people's level of energy and enthusiasm.[13,15] Ultimately, workers' enthusiasm, organizational commitment, and dedication to their work disappear, which influences not only health professionals' job performance and quality of care but also their job satisfaction and personal health.[7,16] Although working in a palliative care setting[8,16] (palliative care units, home care, or hospices) shares characteristics with working in other health care settings[17] (internal medicine, oncology, hematology), such as the need to balance distress across multiple diseases and domains, which is known to put professionals at risk of burnout, researchers have pointed out that the constant contact with the end of life is considered to pose a higher risk of burnout for professionals in palliative care.[8,16,17]

Several studies have been conducted to investigate the influence of working in palliative care on the burnout of health care professionals. These studies have revealed that the burnout level of health professionals in palliative care tends to be lower than that of health professionals working in other settings (internal medicine, oncology, hematology, intensive care).[17-20] However, no previous systematic review has been made on the burnout level among health care professionals working in palliative care and how this compares with that among health care professionals working in other settings.

Considering the potentially negative effects of burnout among health care professionals,[16,21] a greater understanding of the level of burnout among those in palliative care settings, and how this compares with the level among professionals in other settings, has immediate implications. In particular, it would highlight the vulnerable populations (type of health professional) and settings of care at which measures to alleviate or prevent burnout should be directed. This line of study would have implications for research as well because it would identify the directions for research on stress management strategies (eg, effective coping mechanisms) and preventative measures used by those with lower burnout. Ensuring that health care professionals are happy and fulfilled is important because it can lead to high-quality palliative care.[8]

Overall, the purpose of this systematic review is to review the literature on the effect of working in palliative care settings, compared with other settings, on burnout among health care professionals.

METHODS

This review follows the methodology proposed by the Joanna Briggs Institute (JBI) for the conduct of systematic reviews[22] and complies with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.[23] This review was registered in the PROSPERO international prospective register of systematic reviews (registration number CRD42016045791).

Search Strategy

The search strategy aimed to identify both published and unpublished studies. The databases of published studies that we searched included CINAHL Plus with Full Text, PubMed, Scopus, and SciELO. We searched for unpublished studies in DART-Europe, OpenGrey, Repositório Científico de Acesso Aberto de Portugal, and ProQuest-Health & Medical Complete.

The primary inclusion criteria were as follows: (1) articles written in English, Portuguese, or Spanish; (2) observational study designs, including prospective and retrospective cohort studies, case-control studies, and cross-sectional studies; (3) articles comparing health care professionals working in specialized palliative care settings (palliative care units, home care, and/or hospices) with health care professionals working in other settings; and (4) studies written/published between 1975 and 2015. We chose 1975 as the start date because studies related to burnout in health professionals began to appear in the literature after 1974. Other inclusion criteria were studies wherein (1) the study population was qualified health care professionals (physicians, registered nurses, physiotherapists, psychologists, social workers, occupational therapists), (2) the professionals were caring for patients 18 years or older, and (3) the outcome was "burnout," as measured by any burnout scale (eg, the Maslach Burnout Inventory, Burnout Measure, and Copenhagen Burnout Inventory).

The search terms included "palliative," "end of life," and "hospice" because they are related and often used interchangeably when discussing palliative care. We also used the search terms "burnout" and "professional burnout."

A 3-step search strategy was undertaken: (1) An initial limited search of CINAHL and MEDLINE was completed, followed by (2) an extensive search using all identified keywords and index terms across all included databases and then (3) a hand search of the reference lists and bibliographies of included articles. The process was documented in detail to enable replication by others (Table 1).

Quality Assessment and Data Analysis

Mendeley version 1.17.6 was used to manage the list of articles retrieved; any duplications were removed. All identified articles were assessed for relevance according to the title and abstract. Whenever the title and abstract lacked data to make a decision, we verified the inclusion criteria described previously by reading the full-text articles.

Articles selected for retrieval were assessed by 2 independent reviewers for methodological validity before their inclusion in the review using standardized critical appraisal instruments from the JBI Critical Appraisal Checklist

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TABLE 1	Search Strategy

PubMed, searched on June 1, 2016: 336 results
(((((((((hospice*[Title/Abstract]) OR palliative*[Title/Abstract]) OR ''end of life''[Title/Abstract]) OR end of life care[MeSH Terms]) OR palliative care[MeSH Terms]) OR hospice[MeSH Terms])) AND ((professional burnout[MeSH Terms]) OR burnout[Title/Abstract])) AND ((English[lang] OR Portuguese[lang] OR Spanish[lang]))

CINAHL Plus, searched on June 1, 2016: 77 results
(TI (''end of life'' OR ''hospice'' OR ''palliative'') OR AB (''end of life'' OR ''hospice'' OR ''palliative'') OR MH (''palliative care'' OR ''hospice care'')) AND (MH burnout, professional) OR (TI burnout OR AB burnout)
Filters: English, Portuguese, Spanish AND EXCLUDE Medline

Scopus, searched on June 1, 2016: 119 results
((TITLE-ABS(''hospice'')) OR (TITLE-ABS(''end of life'')) OR (TITLE-ABS(''palliative''))) AND (TITLE-ABS(''burnout'')) AND NOT (PMID (1*) OR PMID (2*)) AND (LIMIT-TO (LANGUAGE, ''English'') OR LIMIT-TO(LANGUAGE,''Spanish'') OR LIMIT-TO(LANGUAGE,''Portuguese''))

DART-Europe, searched on June 1, 2016: 6 results
(burnout AND palliative) = 5; (burnout AND hospice) = 1; (burnout AND ''end of life'') = 0
Filters: English, Portuguese, Spanish

Open Grey, searched on June 1, 2016: 2 results
(hospice OR palliative OR ''end of life'') AND burnout
Filters: English, Portuguese, Spanish

RCAAP, Repositório Científico de Acesso Aberto de Portugal, searched on June 1, 2016: 17 results
TI (burnout AND palliative) = 3; TI (burnout AND ''end of life'') = 0; TI (burnout AND hospice) = 0; AB (burnout AND palliative) = 12; AB (burnout AND ''end of life'') = 2; AB (burnout AND hospice) = 0

ProQuest-Health & Medical Complete, searched on June 1, 2016: 98 results
(ti(palliative OR ''end of life'' OR hospice) OR ab(palliative OR ''end of life'' OR hospice)) AND (ti(burnout) OR ab(burnout))
Filters: English, Portuguese, Spanish

SciELO, searched on June 1, 2016: 6 results
((ti:((''palliative'' or ''end of life'' or ''hospice''))) OR (ab:((''palliative'' or ''end of life'' or ''hospice'')))) AND ((ti:(burnout)) OR (ab:(burnout)))
Filters: English, Portuguese, Spanish

for Analytical Cross Sectional Studies.[24] The cutoff point for inclusion of a study in the review was receiving a ''yes'' answer to at least 4 questions (>50%) on the standardized critical appraisal instrument. Two independent reviewers assessed all studies. Any disagreements that arose between the reviewers were resolved through discussion or consultation with a third reviewer.

The data were extracted from the articles included in the review independently by 2 reviewers, using a data extraction table, by taking into account the review questions. The data extracted included specific details about the study aims, design, measurement instrument, and setting; the sample characteristic; and the main results of significance to the aims of this review (Table 2). The authors of the primary studies were contacted to obtain missing or additional data. Any disagreements arising between the reviewers regarding what data were relevant for extraction were resolved through discussion or consultation with a third reviewer.

A narrative synthesis was used for the data analysis of the included studies. Therefore, the findings hereinafter are presented in narrative form along with tables to aid in data presentation.[22]

RESULTS

A total of 539 abstracts were reviewed, and 43 articles met the inclusion criteria and were reviewed in their entirety. Subsequently, 8 articles fulfilling all of our inclusion criteria underwent a methodological quality assessment using the JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies.[24] One dissertation[28] and 1 article[28] reported the same results from 1 study and were therefore pooled. There was general agreement among the reviewers to include 7 cross-sectional studies. The stages of the systematic review process can be seen in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (Figure).

Study Characteristics, Settings, and Sample

The included studies were published between 1996 and 2014. Two of the studies were conducted in the United States, whereas the others were conducted in Canada, Italy, Japan, Poland, and Portugal. The study settings were hospice or palliative care units versus medical cancer centers and internal medicine, oncology, hematology, critical care, or maternity wards. None of the included studies had home palliative care as a setting.

The sample sizes of the included studies ranged from 76 to 647 participants, for a total of 2231 health professionals. Although physiotherapists, psychologists, social workers, and occupational therapists were populations that could be included in our review, none of the articles present data on these groups. Six studies presented data on participants' age (mean range, 30.5-48.1 years), whereas 1 study[27] did not present any data on age or work experience. Five of the remaining studies presented data on work experience (mean range, 3.38-20.37 years), whereas 1 study presented only ''years in current post''; in that study, 52 of all participants (68.4%) had worked for less than 6 years in their actual unit.[30]

Measurement Instruments in the Studies

Six studies assessed the occurrence of burnout using the Maslach Burnout Inventory. However, these studies did

TABLE 2 Data Presentation Over the Included Studies in the Systematic Review

| Author(s), Year, Country	Aims	Study Design; Measurement Instrument	Setting	Sample Characteristic	Main Results
Asai et al,[25] 2007, Japan	To determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for patients with cancer.	Cross-sectional study; Maslach Burnout Inventory (MBI)	Hospices and palliative care units Medical centers for cancer and adult disease	Physicians (N = 647): (n = 87) (n = 560)	Palliative care physicians: High level of emotional exhaustion (n = 13, 15%) High level of depersonalization (n = 7, 8%) Low level of personal accomplishment (n = 46, 53%) Clinical oncologists/physicians: High level of emotional exhaustion (n = 129, 23%) High level of depersonalization (n = 56, 10%) Low level of personal accomplishment (n = 364, 65%)
Gama et al,[17] 2014, Portugal	To identify sociodemographic, professional exposure to dying, training degree, and personal factors relevant to burnout dimensions in nurses coping with death issues.	Cross-sectional study; MBI	Palliative care units Internal medicine Oncology Hematology	Nurses (N = 360): (n = 59, 14.2%) (n = 184, 52.8%) (n = 48, 13.6%) (n = 69, 19.4%)	Palliative care unit nurses (mean): High level of emotional exhaustion, 13.03 High level of depersonalization, 3.42 Low level of personal accomplishment, 38.63 Internal medicine nurses: High level of emotional exhaustion, 16.42 High level of depersonalization, 6.3 Low level of personal accomplishment, 38.11 Oncology nurses: High level of emotional exhaustion, 18.40 High level of depersonalization, 5.83 Low level of personal accomplishment, 36.06 Hematology nurses: High level of emotional exhaustion, 18.03 High level of depersonalization, 4.54 Low level of personal accomplishment, 36.29.
Hunnibell et al,[26] 2008, United States	To determine the relationship between self-transcendence and burnout and compare the differences in self-transcendence and burnout between hospice and oncology nurses.	Cross-sectional study; MBI Human Services Survey	Hospice Oncology	Nurses (N = 563): (n = 244) (n = 319)	Hospice nurses: High level of emotional exhaustion (n = 44, 18%) High level of depersonalization (n = 11, 4.5%) Low level of personal accomplishment (n = 7, 2.9%) Oncology nurses: High level of emotional exhaustion (n = 78, 24.5%) High level of depersonalization (n = 36, 11.3%) Low level of personal accomplishment (n = 35, 11%)

(continues)

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TABLE 2 Data Presentation Over the Included Studies in the Systematic Review, *Continued*

Author(s), Year, Country	Aims	Study Design; Measurement Instrument	Setting	Sample Characteristic	Main Results
Kalicinska et al,[27] 2012, Poland	To explore the relationship between burnout and social support at work received from coworkers and superiors among the hospice nurses and the midwives.	Cross-sectional study; MBI	Hospices Maternity ward	Nurses (N = 117): (n = 58) (n = 59)	Hospice nurses (mean [SD]): High level of emotional exhaustion, 16.83 (9.78) High level of depersonalization, 4.29 (4.04) Low level of personal accomplishment, 21.64 (12.78) Midwives (mean [SD]): High level of emotional exhaustion, 23.59(11.03) High level of depersonalization, 7.10 (5.74) Low level of personal accomplishment, 21.15 (11.10)
Mallett et al,[28] 1991, United States	To compare hospice nurses from critical care nurses in relation to the incidence of symptoms of burnout	Cross-sectional study; modified version of the MBI	Hospice Critical care	Nurses (N = 376): (n = 209) (n = 167)	Hospice nurses (mean [SD]): Total, 34.2 (16) High level of emotional exhaustion, 18.5 (9.5) High level of depersonalization, 5.5 (5.4) Low level of personal accomplishment, 61.7 (7.5) Critical nurses (mean [SD]): Total, 48.6 (19.9) High level of emotional exhaustion, 22.2 (9.6) High level of depersonalization, 10.6 (8.3) Low level of personal accomplishment, 56.4 (9.5)
Ostacoli et al,[29] 2010, Italy	To clarify the differential contributions of situational and individual factors to burnout symptoms experienced by 2 independent groups	Cross-sectional study; Italian versions of the MBI	Hospices Hospital (internal medicine, oncology day hospital, pulmonary oncology day hospital, pneumology)	Nurses (N = 92): (n = 33) (n = 59)	Hospice nurses (mean [SD]): High level of emotional exhaustion, 11.28 (6.69) High level of depersonalization, 1.76 (2.25) Low level of personal accomplishment, 40.88 (4.87) Hospital nurses (mean [SD]): High level of emotional exhaustion, 19.65 (9.91) High level of depersonalization, 5.15 (4.54) Low level of personal accomplishment, 34.58 (4.19)
Plante & Bouchard,[30] 1996, Canada	To examine the relationship among occupational stress, burnout, and professional support in nurses.	Cross-sectional study; Jones Staff Burnout Scale for Health Professionals	Palliative care units Medical oncology units	Nurses (N = 76): (n = 31) (n = 45)	Palliative care nurses' burnout, mean (SD), 48.02 (13.20) Medical oncology nurses' burnout, mean (SD), 55.95 (14.10)
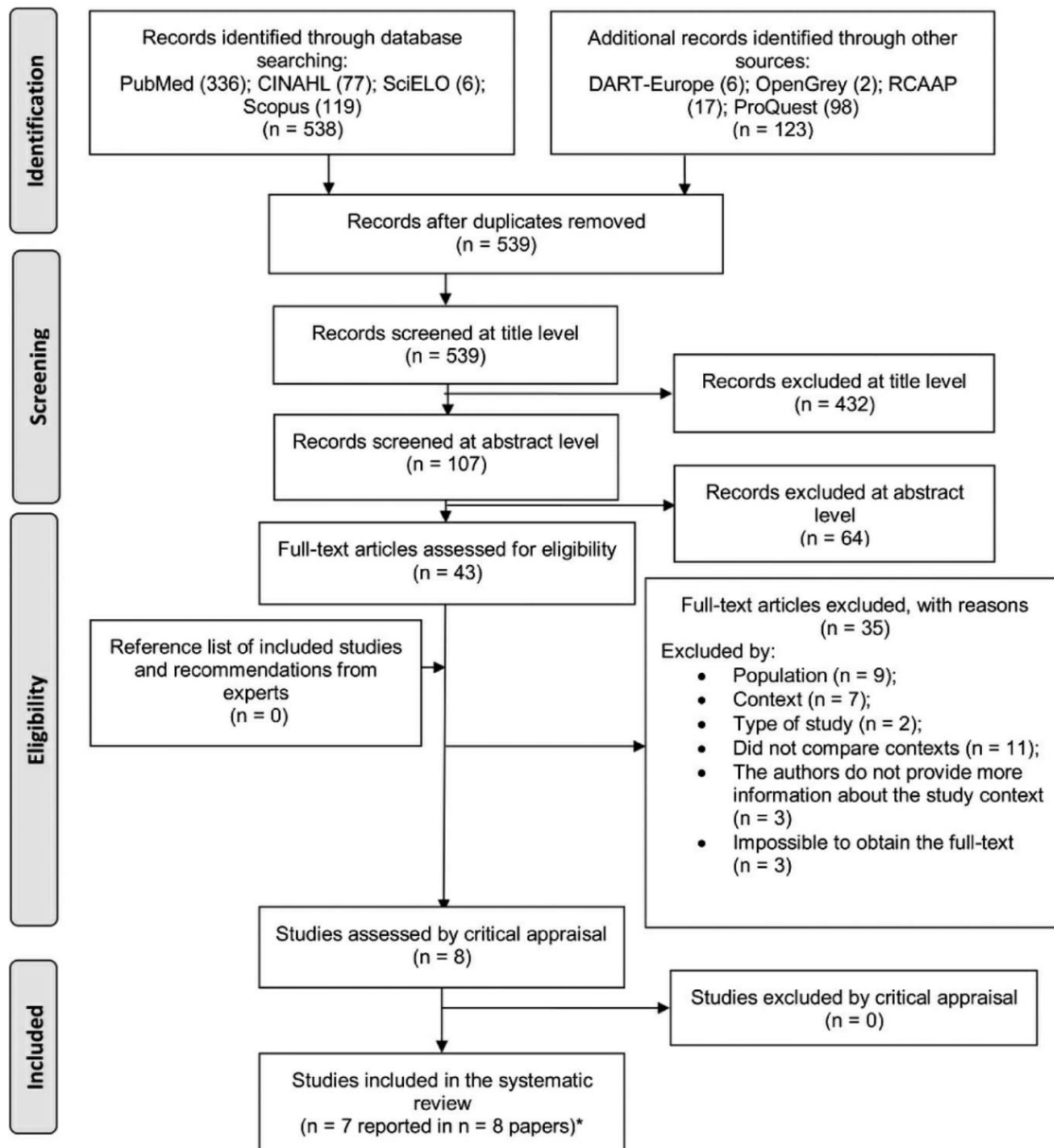
* A dissertation (Mallett, 1988) and one article (Mallett, Price, Jurs, & Slenker, 1991) reported the same results from one study and were therefore pooled.

FIGURE. PRISMA flow diagram of the systematic review process.

not examine the presence or absence of burnout; they only presented data on the subscale scores of the Maslach Burnout Inventory (emotional exhaustion, depersonaliza- tion, and personal accomplishment). Two studies[25,26] presented the level of burnout according to the Maslach Burnout Inventory—in other words, they provided the

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number of health professionals with high levels of emotional exhaustion and depersonalization and low levels of personal accomplishment, which they deemed to represent a higher risk of burnout. The remaining 4 articles that used the Maslach Burnout Inventory[17,27-29] presented the means (SDs) of the subscale scores, whereby a higher mean of emotional exhaustion and depersonalization and a lower mean of personal accomplishment indicated a high level of burnout. Although the articles only presented the subscales, it is possible to compare the settings in terms of the mean scores or the number of health professionals that had abnormal values on these subscales. The study by Plante and Bouchard[30] was the only study to use a different measurement instrument to assess the level of burnout: the Jones Staff Burnout Scale for Health Professionals.

Differences in the Level of Burnout Among Health Professionals Working in Palliative Care Compared With Those Working in Other Settings

Concerning the differences in the level of burnout among health professionals working in palliative care and other settings, the data from the included studies revealed that the level of burnout was lower in palliative care settings than in other settings. This means that those working in palliative care tend to have lower levels of emotional exhaustion and depersonalization and higher levels of personal accomplishment than those working in other settings.

All of the included studies showed these results consistently; in particular, compared with health professionals working in palliative care settings (palliative care units or hospices), burnout levels were higher in professionals working in cancer centers,[17,25,26,30] internal medicine and hematology wards,[17] maternity wards,[27] critical care wards,[28] and general hospitals.[29]

However, these data must be interpreted with caution. In Hunnibell et al,[26] there was no mention of whether the differences in the level of burnout between the different settings (hospice vs oncology ward) were statistically significant. Furthermore, in Kalicinska et al,[27] there was no significant difference between the hospice and maternity ward settings for the personal accomplishment subscale ($P > .05$). Finally, in the study by Gama et al,[17] although there were statistically significant differences between palliative care units and oncology settings for all subscales, there was no significant difference in the personal accomplishment subscale ($P > .05$) when comparing palliative care units with internal medicine. The same was true for the depersonalization subscale when comparing palliative care units with hematology wards ($P > .05$). Table 3 presents the results of the studies' comparison of the level of burnout among health professionals working in palliative care with those working in different settings.

DISCUSSION

The provision of palliative care involves multiple, stressful, difficult, and unique challenges that can lead to burnout among health care professionals. The purpose of this systematic review is therefore to examine the current literature on the effect of working in palliative care settings, compared with other health care settings, on the level of burnout among health professionals.

Seven original articles were included in this review, all published after 1991. Our analysis of the publication years of the included studies showed that there has been an increase in publications on the subject since 2007. This might be due to increasing recognition of the peculiar characteristics of working in palliative care (eg, the daily contact with suffering, dying, and death) and a greater awareness of the fact that health professionals also have self-care needs.[31,32]

Working in palliative care exposes professionals to numerous stress factors, such as communication of bad news, repeated exposure to the death of persons with whom they have established a relationship, involvement in emotional conflicts, adaptation to the failure of medical cures, and absorption of the anger and grief expressed by the patient and family caregivers.[4,33,34] However, this review has demonstrated that there is evidence that working in palliative care is associated with lower levels of emotional exhaustion and depersonalization and higher levels of personal accomplishment when compared with working in other settings.

This result calls for reflection on whether the rewards of working in the palliative care setting serve as factors that decrease the risk of burnout. Such rewards include feelings of usefulness,[17] the opportunity to relieve patients' symptoms, personal development,[28] belonging to a multidisciplinary team with the same vision,[17] and working in a setting where holistic care is provided and where professionals can be inspired by patients and their families. There is also the possible benefit of working in this setting by choice.[17] Furthermore, despite the fact that palliative care exposes health professionals to numerous stress factors and painful experiences, they are also given many opportunities for spiritual and personal growth, such as facing their own mortality and their personal and professional limitations, as well as learning to be with patients rather than only doing something for them.[4,35]

In the palliative care setting, it seems relevant to highlight the importance of implementing strategies that help preserve the emotional and physical health of health professionals and thereby avoid burnout. Such strategies can be implemented by institutions or by the professionals themselves. It would be important to investigate in future studies which strategies are used by palliative care professionals and their actual effectiveness because the same

TABLE 3 Results of the Studies' Comparison of the Level of Burnout Among Health Professionals Working in Palliative Care With Those Working in Different Settings

Study	Setting, Sample	Level of Burnout in the Subscales of the Maslach Burnout Inventory					
		High Level of Emotional Exhaustion, n (%)	P^a	High Level of Depersonalization, n (%)	P^a	Low Level of Personal Accomplishment, n (%)	P^a
Asai et al,[25] 2007	Hospices or palliative care units (N = 87)	13 (15)		7 (8)		46 (53)	
	Medical cancer centers (N = 560)	129 (23)	.09	56 (10)	0.66	64 (65)	.05
Hunnibell et al,[26] 2008	Hospice (N = 244) Oncology (N = 319)	44 (18) 78 (24.5)	No data	11 (4.5) 36 (11.3)	No data	7 (2.9) 35 (11)	No data

Study	Setting, Sample	Level of Burnout in the Subscales of the Maslach Burnout Inventory					
		Emotional Exhaustion		Depersonalization		Personal Accomplishment	
		Mean or Mean (SD)	P^a	Mean or Mean (SD)	P^a	Mean or Mean (SD)	P^a
Gama et al,[17] 2014	Palliative care units (N = 59)	13.03		3.42		38.63	
	Oncology (N = 48) Internal medicine (N = 184)	18.40 16.42	<.008 <.009	5.83 6.3	<.003 <.0001	36.06 38.11	<.027 >.05
	Hematology (N = 69)	18.03	<.001	4.54	>.05	36.29	<.047
Kalicinska et al,[27] 2012	Hospices (N = 58) Maternity ward (N = 59)	16.83 (9.78) 23.59 (11.03)	<.01	4.29 (4.04) 7.10 (5.74)	<.01	21.64 (12.78) 21.15 (11.10)	>.05
Mallett et al,[28] 1991	Hospice (N = 209) Critical care (N = 167)	18.5 (9.5) 22.2 (9.6)	.01	5.5 (5.4) 10.6 (8.3)	.01	61.7 (7.5) 56.4 (9.5)	.01
Ostacoli et al,[29] 2010	Hospice (N = 33) Hospital units (N = 59)	11.28 (6.69) 19.65 (9.91)	<.01	1.76 (2.25) 5.15 (4.54)	<.01	40.88 (4.87) 34.58 (4.19)	<.01

Study	Setting, Sample	Jones Staff Burnout Scale, Mean (SD)	P^a
Plante & Bouchard,[30] , 1996	Palliative care units (N = 31) Medical oncology units (N = 45)	48.02 (13.20) 55.95 (14.10)	<.001

^{a}Differences between palliative care setting and the other setting.

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strategies could perhaps be applied to professionals experiencing burnout in other settings.

Most of the studies involved professionals working in hospice services, only 3 studies were conducted in palliative care units, and none were conducted in home care. The professionals who provide palliative care in the home care setting are likely confronted with challenges specific to that setting; as such, the lack of studies addressing this setting limits our ability to determine the specific effects of working in palliative care on burnout in comparison with other settings.

Notably, 6 of the 7 articles focused on nurses, and only 1 article investigated physicians. Pavelková and Bužgová[8] argue that nurses' situation in hospices is the main reason that so much attention has been given to burnout in hospice setting, which is likely why nurses were the main study population. Nurses are also the health professionals with the closest relationships with patients at the end of life. On the one hand, this may suggest that their risk of burnout is higher, but on the other hand, as mentioned previously, it may also increase their degree of personal fulfilment, thus reducing the risk of experiencing burnout. However, once again, the lack of studies on burnout among the other professionals of the multidisciplinary team in palliative care limits the determination of the effects of working in palliative care (vs other settings) on burnout among health professionals in general.

Another limitation was the fact that we only included articles written in English, Portuguese, or Spanish. Thus, articles written in other languages were not included, even if they would have been relevant to this review. Finally, a meta-analysis was not performed because of significant differences in condition measures (ie, clinical and methodological heterogeneity).

CONCLUSIONS

Despite the limitations, this systematic review has provided evidence that burnout among professionals (6 studies about nurses and 1 study about physicians) working in palliative care is lower than that of professionals working in other health care settings (medical cancer center, oncology, internal medicine, hematology, maternity, critical care, hospital units, medical oncology units). Thus, more studies should be conducted on this topic, in particular, in other palliative care settings (beyond hospices) and other professionals (beyond nurses). It is, in particular, important to acknowledge the role of teamwork in the provision of palliative care and how burnout in one of the professional groups in this team influences burnout among the other groups.

Clinical Implications

This review has provided evidence that working in palliative care is associated with lower levels of emotional exhaustion and depersonalization and higher levels of personal accomplishment than working in other health care settings (medical cancer center, oncology, internal medicine, hematology, maternity, critical care, hospital units, medical oncology units). These data are quite important for clinical practice. In particular, given the direct relationship reported in the literature between "happy work" and the provision of quality care,[8] the data from this review emphasize the need for professionals working in settings other than palliative care to implement strategies to reduce burnout and therefore improve their clinical practice. Further research should be undertaken to extend our understanding of the strategies used by these nurses and how they might be implemented by nurses working in other settings, such as critical care, oncology, and internal medicine wards.

Acknowledgment

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CHAPTER V

PHASE III: UNDERSTANDING THE PHENOMENON

This chapter addresses the Phase III of the study, and is divided into two sub-heading.

The first sub-heading presents the Phenomenology as a methodological option.

The second sub-heading presents the article: Caring in palliative care - a phenomenological study of nurses' lived experiences.

The literature reveals that care in PC leads to feelings of intense emotions, and all these emotions and challenges if not treated in time, put the HCPs at risk of burnout.

Simultaneously, the accomplishment of the previous studies allowed concluding that the prevalence of burnout among HCPs working in PC was 17.3%, and nurses had higher level of Emotional Exhaustion and Depersonalization in comparison with physicians and social workers. This reminds us of the fact that although the caring in PC is based on interdisciplinary team work, care for the person is essentially a nursing concern, since the nurse deals closely and for longer with the suffering of the patient. However, compared to other contexts, the second systematic review reveals that, nurses working in PC have lower levels of emotional exhaustion and depersonalization, while having higher levels of personal accomplishment. This ambiguity makes it difficult to understand how nurses live the experience of caring in PC. From the Scoping Review it seems important to mention also that data about nurses were found in 20 out of the 22 articles included.

The accomplishment of this phase allowed understanding this phenomenon, revealing that five themes reflect the essence of the lived experience by nurses caring in PC: (1) experience centered on the relationship with the other; (2) experience centered on the relationship with one's own self; (3) exhausting experience; (4) rewarding experience; and (5) the team as a pillar. This study provided visibility to the experiences of the nurses caring in PC and provided valuable contributions for designing interventions that focus on reducing the risk of burnout among nurses.

5.1. Phenomenology as a methodological option

After the previous Phases were performed (map the existing literature and identify the best scientific evidence) the need to develop a qualitative study was identified, since this methodology provides the development of the understanding of the experiences of each person, in addition to considering the totality of the experiences in the particular contexts in which the investigation takes place (A. Giorgi, 2005; Janice M. Morse & Field, 1996; Streubert & Carpenter, 2002).

Thus, an analysis of the literature related to the different qualitative methods was carried out. Each of these methods is a specific path to the study of reality, being the selection of one or the other method, defined by the research objectives that are intended to be carried out (Íñiguez, 1999). Quoting Giorgi (2014, p. 550), "methods are geared to answer specific questions, and that is why there are so many of them".

After this analysis, the phenomenological method, compared to other methods of qualitative research, proved to be ideal for the present study, since "the phenomenological tradition seeks to understand the lived experience of individuals"(Janice M. Morse & Field, 1996, p. 20).

It was our objective to understand the experiences of nurses who provide care in a PCU and, in fact, phenomenology represents a tendency within subjective idealism, recognizing the importance of the subject in the process of knowledge construction (Triviños, 1987).

The word phenomenology comes from the Greek and is composed of two terms: "fenomenon" - which means to show your-self, to bring out the light of day, to make it visible - and "logos" - which means word, thought, speech, science. According to the antecedents of the word, phenomenology is the science that deals with how to reveal and make visible the realities, or how to access the polysemy that comes with all reality (Solano, 2006). Its center of inquiry, is the subjective experience of the participants (J. Morse, 1994).

Several authors, as Streubert and Carpenter (2002) and Morse (1994) distinguish two schools of thought: the eidetic or descriptive and the hermeneutic or interpretative. Husserl is considered as the father of the Phenomenology and Heidegger as his disciple.

The eidetic phenomenology, proposed by Edmundo Husserl, retains the concept of cartesian subject-object dualism (De la Cuesta, 1997). This approach emphasizes the intention to clarify the experience as it is lived and constitutes consciousness, that is, it aims to describe the meaning of an experience (object) based on the vision of those who have had this experience (subject) (De la Cuesta, 2006; Triviños, 1987).

As explained by Cibanal (1997), according to Husserl, the essence of things resides in the sense we attribute to them (in the same way that there is an "essence of a circle" in the warped circle that a child paints). In order to achieve the extraction of the essence of the experience of the subject, Husserl believes that the researcher should be devoid of presuppositions. This is what he calls the Epoché (or eidetic reduction) which means putting aside the researcher's preconceptions and judgments (Oliveira & Botelho, 2010).

The essential thing is that the descriptions relating to the lived experience are collected and recorded as they appear to the consciousness. According to Husserl, only by this means will a rigorous and exhaustive description be achieved, without pretending to explain or find causality, aspiring only the approach to the essence of the lived phenomenon (Oliveira & Botelho, 2010).

The phenomenological reduction, the description, and the search of essences constitute the three stages of Husserl's phenomenological philosophical method.

The hermeneutical phenomenology is carried out by Martin Heidegger, student and critic of Husserl. The aim of Heidegger's approach is to explore and understand the different possibilities that a text can present (Escalante, 2011).

Heidegger proposes an approach that makes it possible to analyze the human being as being incorporated into the world, existing in the world. Thus, to understand the human being, it is necessary to understand his world and the entities of his world (people, things, places) (Flood, 2010).

According to Coltro (2000), the hermeneutical phenomenology is not satisfied with the description or with knowledge, for that reason it tries, by means of an exhaustive exploration, the interpretation of the phenomenon. This method requires the researcher use "the 'fore-knowledge' of the phenomenon that one has in order to determine a proper perspective with which to approach the phenomenon" (A Giorgi & Giorgi, 2008, p. 167). With his proposal, Heidegger moves from the paradigm of consciousness, based on perception, to the hermeneutic paradigm, based on interpretation.

Phenomenological method according to Giorgi

In this study (Phase III - understanding the phenomenon) we used the theoretical-methodological orientations of the phenomenological method defined by Giorgi, which has its roots in descriptive phenomenology (Amedeo Giorgi, 1997, 2000, 2006, 2014)

According to Giorgi (2005, p. 169), "Husserl articulated a philosophical phenomenological method, but at the level of scientific practice, one could not follow his steps exactly because such a strict following of Husserl would result in a philosophical analysis rat her than a scientific, psychological one." And add, "Husserl in his philosophy introduced a method for a more adequate approach to the achievements of consciousness and when properly modified the phenomenological method can serve as the basis for the human sciences, including nursing. The use of such a method can make the qualitative analysis of phenomena rigorous and scientific" (A. Giorgi, 2005, p. 75).

Giorgi (1997, 2000, 2006) believes that the phenomenological method allows researchers to study, in a scientific way, the complex process of the phenomenon of human experience, since it is oriented to the experience and to the meaning that it has towards the person who has experienced it. Mentioning also: "that caring is a genuinely experiential phenomenon, both on the side of the recipient and the giver. This means that the care given has to be responsive to the other's entire situation in the world and not just to the medical and technical aspects of the person's body.(...)that phenomenology practiced from within a human science perspective can help us gain accurate knowledge about experiential processes" (A. Giorgi, 2005, p. 82).

His method is constituted by four stages (Amedeo Giorgi, 1997, 2000, 2006, 2014):

1) The first step consists of a reading of transcripts, several times, to get a sense of the whole experience. The phenomenological approach focuses on the total context of the lived experience, and as such the researcher should start by reading the whole transcribed interview ("empirical evidence"). Giorgi recommends that at this stage the researcher has an attitude of phenomenological reduction (which means putting aside the researcher's theoretical, cultural and experiential presuppositions), read all the descriptions to get the overall meaning. At this stage, the objective is to grasp the meaning of the whole, and does not involve a systematic analysis, but rather reflects a general idea of each participant's experience.

2) The second step, consists of performing a subsequent readings of the transcripts with the purpose of identify the meaning units (sections of the collected data that could reveals potentials aspects of the phenomenon under investigation). Each meaning unit is delimited by a change in the thematic content. Thus, the investigator returns to the transcribed interviews, and re-reads them in a delayed way, and each time the researcher identifies a transition of meaning in the transcripts, these are marked with a forward slash (/).At the end of this step, we obtain a series of units of meaning, still expressed in the common language of the participants.

According to Giorgi (2009), how or where the meaning units are delineated is not absolute. Different researchers may delineate the meaning units in different places in the same data. Thus in the present study to ensure rigour, the first and second authors performed individual analyses. Every step of analysis were compared and discussed to strengthen the validity of analysis

Additionally, distinguishing meaning unit can be a self-correcting process in which the researcher discovers that meaning units are too long or too short in their delineation. It is acceptable to combine or divide meaning units as one's familiarity with the data provides clarity about better places for their distinctions. Overall, the researcher does not have to commit to the initial delineations and battle through them as an inviolable rule (Amedeo Giorgi, 2009).

3) In third step the delineated meaning units identified in the previous step are transformed in appropriate language to the phenomenon under study and grouped into common themes and sub-themes that represent the essence of the phenomenal structure of the of caring in PC.

It is in this third step that the first change is made to the data in the analytical process. The meaning units are re-expressed but remaining faithful to the meanings expressed by the participant.

The transformations are formulations of the essential meanings of each meaning unit. Because the researcher is still in the phenomenological attitude, each transformation describes what the meaning unit expresses without any interpretation or positing about its "truth."

In this step, the researcher performs imaginative variation, that is, it transforms the daily language expressed by the participants into a language more rigorous for scientific discourse according to the disciplinary context. The imaginative variation allows determining the essence of the phenomenal structure of the experience.

4) Finally, in fourth analysis step, based upon the transformed meaning units that have been derived, a general structure of the experience of the phenomenon is articulated. That is, the structure is gained by going over the last transformations of meaning units and attempts to determine what constituents are typically essential in order to account for the concrete experiences reported.

Finally, the description of each structure is communicated to other researchers with the purpose of being evaluated critically for confirmation.

5.2. Caring in palliative care - a phenomenological study of nurses' lived experiences

Feature Article

Caring in Palliative Care

A Phenomenological Study of Nurses' Lived Experiences

Vitor Parola, RN   ○   Adriana Coelho, RN   ○   Anna Sandgren, PhD, RN   ○
Olga Fernandes, PhD, RN   ○   João Apóstolo, PhD, RN

Providing palliative care involves serious challenges for nurses, such as end-of-life decisions, contact with people's suffering and dying, and increased risk of burnout. However, studies have revealed that the burnout level of health professionals working in palliative care is lower than that of health professionals working in other settings. This study aimed to describe the lived experiences of nurses caring in a palliative care unit. A phenomenological descriptive study was undertaken. Nine nurses were recruited from a palliative care unit in Portugal. Data were collected using individual interviews and analyzed following the method of Giorgi. Five themes reflect the essence of the lived experience: (1) experience centered on the relationship with the other (ie, the patient and the family), (2) experience centered on the relationship with one's own self, (3) exhausting experience, (4) rewarding experience, and (5) the team as a pillar. These findings can be valuable for understanding the challenges and strategies experienced by nurses caring in palliative care and for designing interventions that focus on reducing the risk of burnout among nurses—not only those working in palliative care but also those working in other contexts who experience regular contact with suffering and death.

KEY WORDS

As a result of medical advances, life expectancy is gradually increasing. Consequently, the number of people living with a chronic degenerative and disabling disease has increased.[1] This has contributed to a growing need for palliative care. According to the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problems 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."[2(p84)]

Specifically, in Portugal, palliative care units are designed to provide comprehensive care for patients with more complex palliative needs, in situations of clinical decompensation or social emergency, such as severe caregiver exhaustion.[3] It is estimated that each year more than 40 million people need palliative care, including 20 million who are at the end of their life. Therefore, more health care professionals than before are needed to provide this care at the end of life.[1]

The literature reveals that working in palliative care causes intense emotions that could lead to multiple stressful and demanding challenges, including establishing intense interpersonal relationships, addressing the multiple complex needs of patients and caregivers, making significant ethical end-of-life decisions, and being in constant contact with people's suffering.[4,5] These challenges, if not treated in time, put the health care professionals at risk of burnout.[6,7] According to Pavelková and Bužgová,[7] working with dying patients is considered to pose an even higher risk of burnout than working in other areas of health care.

A systematic review of the prevalence of burnout among health care professionals working in palliative care revealed a burnout prevalence of 17.3%.[8] Although palliative care is based on interdisciplinary teamwork,

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nurses are often the ones who are in closest proximity to, and who spend the most time with, the suffering of the patient.[9] This might be one of the reasons why nurses had higher levels of emotional exhaustion (19.5%) and depersonalization (8.2%) than physicians and social workers did.[8] However, compared with nurses in other contexts, nurses working in palliative care have lower levels of emotional exhaustion and depersonalization, as well as higher levels of personal accomplishment.[10] These data demonstrate that nursing practice is a complex endeavor and that more information is needed to understand how nurses experience caring in palliative care.

Earlier research has primarily focused on specific topics when describing the experiences of nurses in palliative care, such as ethical dilemmas,[11] grief and loss,[12] palliative sedation,[13] and challenges.[14] These studies are important to understand parts of the phenomenon, but they do not provide an understanding of the phenomenon in depth and breadth and as a whole.

The purpose of this study was therefore to describe the lived experiences of nurses caring in palliative care.

METHODS

This study was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing (reference no. P371-11/2016) and the Ethics Committee of the Hospital Arcebispo João Crisóstomo (November 9, 2016) before commencement. This study also conforms to the Consolidated Criteria for Reporting Qualitative Research guidelines.

A phenomenological methodology was chosen in order to capture the structure of the complex phenomenon—the meaning of the lived experiences of nurses caring in palliative care.

Data were collected between December 2016 and March 2017. Participants were recruited from a Portuguese palliative care unit. To be included, nurses had to have been working in the palliative care unit for at least 1 year. The nurses who met the recruitment requirements were identified with the help of the chief nurse. One of the authors then contacted the nurses meeting the criteria and informed them both orally and in writing about the objectives and the procedure of the study. From a total of 13 nurses working in the palliative care unit, 3 nurses did not meet the inclusion criteria and were excluded. In all, 10 nurses were asked to participate. Of these, 9 nurses gave their informed consent to participate, and 1 nurse declined participation (Table).

Data were collected by nonstructured interviews because this technique facilitates a personal narrative by the nurses.[9] Interviews were conducted individually, lasting approximately 44 minutes (range, 29-53 minutes), and were performed in a private room in the palliative care unit. All the interviews started with the following question: "I

know you've been caring in palliative care for some time. How do you experience this?" In order to deepen the understanding of the participants' experience, follow-up questions were asked: "Could you describe this experience in more detail? What did this experience mean to you?" Data collection was made by one of the authors (V.P.). The results were considered saturated after 8 interviews; however, we decided to conduct 1 more interview. All the interviews were audio recorded and transcribed verbatim. Transcripts were made by the interviewer (V.P.). To manage the data, the QSR NVivo version 10 software (QSR International Pty Ltd, Melbourne, Australia) was used.

Data analysis was performed according to Giorgi's[15] phenomenological descriptive method, which involved 4 steps. The first step required reading the entire transcripts several times to get a sense of the whole experience. This was done without a critical reflection on the experience. In the next step, a second reading of the transcripts was done with the intention of determining the meaning units. Each meaning unit was delimited by a change in the thematic content. In the third step, the delineated meaning units identified in the previous step were transformed in appropriate language to the phenomenon under study and grouped into common themes and subthemes that represented the experiences of caring. The fourth step was to synthesize all the transformed meaning units into a consistent and descriptive statement regarding the participants' experiences of caring in palliative care.

This study adhered to credibility, dependability, transferability, and confirmability for sustaining rigor.[16] In order to achieve credibility, during the interviews, cross-checks were performed to clarify and confirm the information mentioned by the participants. The interviewer was a doctor-of-philosophy student with more than 10 years' experience as a nurse who is trained and experienced in qualitative research. In order not to influence the results, he tried to avoid referring to his own experiences and notions and instead let the participants express their own thoughts and feelings.

To achieve the dependability of the study, the characteristics of the participants, their selection process, and a detailed description of all steps and results of the research were described. As a guarantee of rigor, the second author also conducted individual analysis. All the steps of the analysis were compared and discussed to reinforce their validity. Furthermore, the last author (J.A.) reviewed all the data, including transcriptions, data coding, and theme formulation, again, in order to achieve dependability.

Related to transferability, so that readers/researchers can determine that the results obtained can be transferred to another context or persons, a detailed description of the characteristics of the study participants and the context of the study was provided.

Finally, to achieve confirmability, the interviews were conducted by the first author (V.P.), who is not a member of

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TABLE Demographic Characteristics of the Participants (n = 9)		
Gender, n	Male	3
	Female	6
Age, y		Range, 24-58
		Mean, 40.7
Marital status, n	Single	3
	Married	5
	Divorced	1
Postgraduate education in PC, n	Yes	0
	No	9
Years of experience before working in PC		Range, 1-29
		Mean, 12.2
Years of experience in PC		Range, 2-11
		Mean, 6.7

the staff at this hospital and shared no relationship (personal or professional) with the participants. Confirmability was also achieved through an audit trial of data and procedures.

FINDINGS

Five themes reflect the essence of the lived experience for nurses caring in palliative care: experience centered on the relationship with the other, experience centered on the relationship with one's own self, exhausting experience, rewarding experience, and the team as a pillar. These 5 themes and their subthemes are presented as a comprehensive scheme organized in an interactive structure in the Figure.

Theme 1: Experience Centered on the Relationship With the Other

Nurses working in palliative care experience a relationship that focuses on the patients and their respective family. With each patient, a singular relationship is established, where nurses experience involvement. This relationship is based on the provision of a differentiated care. With the family, not only a partner relationship but also a supportive relationship is established.

Differentiated Care

Nurses (because they have already provided care in other services) mention that providing palliative care is different from providing other kinds of care. Palliative care emphasizes making the patient feel good about himself/herself. A nurse described it this way: "I think that the way we

see care here is truly different… to have a well-cared-for patient, with a shaved beard, feeling good, with a well-preserved self-esteem, enjoying seeing himself or herself, than perhaps other aspect…." Although nurses recognize that going beyond physical comfort should be a goal of
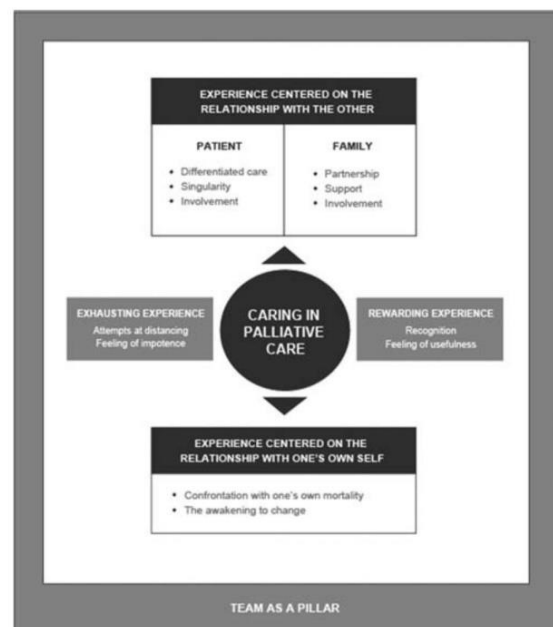

FIGURE. Conceptual representation of the themes and subthemes based on the findings.

nursing in all contexts, they point out that this is a particularity of palliative care, distinguishing palliative care units from other units. A nurse commented, "Unfortunately, there are areas of nursing where we are more practical… here we always want to go further. Being able to give a little more, feel, try to make the person feel the best possible… is not only the control of pain or the control of dyspnea, but it is a set of things that we try to give, and therefore we are different from a normal hospitalization."

Singularity

In this regard, each patient is unique, so the nurses described how they provided personalized and singular care tailored to the preferences, wishes, and needs of each patient. A nurse explained, "I always value what he wants to do. If he wants to take a shower, he does. If he doesn't want to, he doesn't. If he wants to eat, he eats. If he doesn't, he doesn't. If he wants to eat what he feels like, wishes to get up, to go there, do that… that is, my care at that moment is focused on what the patient wants, not what I try to do routinely."

Involvement

The particularity of the patient's end-of-life situation leads to a reciprocal emotional and spiritual involvement between the patient and the nurse. A nurse said, "This experience, in sentimental terms, requires a greater involvement on our part; people are usually in a critical phase and get more involved with us… and I also end up becoming more involved in a conscious way…."

Partnership

Between the family and nurses, a partner relationship is established in which, when the patient is unable to express himself, the family speaks for the patient, promoting personalized care. For example, "It is very important for the family to inform us when the patient cannot say or verbalize what is really important to him, what it is he values… for example, if he likes to listen music or not."

Support

Nonetheless, a supportive relationship is also established: "People end up giving themselves more, opening up more with us; we often end up being their place of shelter, and it is, ultimately, with us that they open up, exposing the difficulties they are feeling." Sometimes it is necessary to provide support in the transition process, redirecting hope. This support was described as one of the great difficulties, causing them suffering and distress: "There are families who are already aware what the diagnosis of the patient is and accept better the situation. There are others who are not aware of anything and think that here is where they are going to get healed, here they will be rehabilitated, here they are going to do the impossible, well… and they react differently, and changing these latter families' opinion is

very complicated… both of them need support to pass through those moments."

Theme 2: Experience Centered on the Relationship With One's Own Self

Notwithstanding the above, nurses also have an experience centered on their relationship with themselves. From this emerges the confrontation with one's own mortality and the awakening to change.

Confrontation With One's Own Mortality

Caring for the other, in such a singular moment in the human experience, paves the way to the confrontation with one's own mortality: "There is always a time when we face our own death."

The Awakening to Change

The confrontation with one's own mortality makes one conscious of the ephemeral nature of life, inviting reflection, personal development, and the incorporation of changes in the way of thinking, being, and living life. Personal problems become relative: "It changed the way I often face life in the face of a problem, and I think: This, it's just this! If I was like one of my patients, I'd be much worse…." Furthermore, interpersonal relationships acquire a new meaning, a new value: "The way I see life today is different from the way I saw it a while ago. I now try to enjoy other things and value things that I did not before… now I try to be with the people who are close to me; we do not know what is going to happen tomorrow." Thinking more of the present and less of the future: "Before working here, I did not think so much about today, about what is happening today… and that has changed. Now I think more about today!" It can even stoke the aspiration to adopt a healthier lifestyle: "I have already changed my behavior and ways of living… for example, I used to smoke and quit as a result of this experience… because… hey man… life is already so short."

Theme 3: Exhausting Experience

During this journey that oscillates between the experience centered in the other and the experience centered in oneself, the nurses experience an emotional, exhausting experience either through attempts at distancing or by the feeling of impotence.

Attempts at Distancing

The nurses mention making attempts at emotional distancing as a protection strategy. However, this is a difficult task because of the link they establish with patients and families. As 1 nurse described it: "What turns out to be more difficult for us is to be able to work and create this barrier, this wall, is it not?! Because at the same time we have to be more predisposed, but on the other hand, we

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also have to defend ourselves a bit." Another nurse said, "Sometimes it's a little difficult… we have patients who move us more than others, and the younger they are, the harder it is, and if we have children, the harder it is, and if we know the family, which is almost always the case… it is even harder."

Feeling of Impotence

The feeling of impotence to relieve the physical, emotional, and existential suffering of the other is described as a source of distress. The anguish continues even after the nurse takes off the uniform and goes home. One nurse said, "There have been situations that, unfortunately, were not so peaceful, and then yes, we go home, and we are disturbed by them… but there you go! We have given everything, we have done everything, but it is not having an effect… then it becomes a moment of anguish."

Theme 4: Rewarding Experience

Nevertheless, emotional exhaustion is counterbalanced by recognition and the feeling of usefulness. Nurses said that caring in palliative care is a highly rewarding experience that offers a sense of personal fulfillment and personalization (mediated by the uniqueness of the care provided in the person-to-person relationship), which overlaps with the emotional drain experienced.

Recognition

The nurses highlight the good feeling that comes from the recognition of their work by the other (patient and family). This recognition is revealed through their appreciation/thanks. A nurse said, "It's good to work here… the patients notice what care we give them, the patients thank us; although they have their head in a noose, they thank us for all the care, which is very good."

Feeling of Usefulness

Nurses mention experiencing a sense of usefulness that enriches them and compensates for all setbacks. A nurse commented, "It is above all this feeling of usefulness; it is no economic reward, but it is the feeling that people feel good with us, with our care, and that makes a difference… it makes us feel good that others pass away well… to be able to ensure that in the last phase of their life, on their last days, in their last moments, that the person is well… that is enriching… and brings me… compensates for everything else."

Theme 5: The Team as a Pillar of the Experience

The multidisciplinary team is described as a pillar of the experience in palliative care, by providing shared feelings, opinions, doubts, and relaxing moments. These moments of sharing did more than promote individual well-being;

they contributed to strengthening the team. For example, "We have a shift change that… also relieves a lot of stress for us, yes, relieves this most difficult part regarding feelings. I think that is a good thing." Another nurse stated, "There are always situations that raise doubts in me and that I sometimes cannot solve by myself, and I turn to the team. And there are things that are sometimes hard to accept; we need to speak to each other." Another nurse pointed out, "We have some moments of our own, not necessarily on duty, and even in the ward we play a little bit, which sometimes allows for the release of energies. And as I always say, there are 3 or 4 moments during the year when we get together outside work, to talk about other things… this is key."

DISCUSSION

This study describes the experiences of nurses who provide palliative care, revealing that caring in palliative care favors an experience centered in the relationship with the other but also in relation with the self. It is an experience both exhausting and rewarding. The team represents the pillar of all the experience.

When caring in palliative care, nurses are living an experience that focuses on the relationship with the other. In fact, according to Joice Travelbee's Human-to-Human Relationship Model,[17] the purpose of nursing is achieved only through the establishment of a person-to-person relationship because nursing is an interpersonal process, this relationship can be effective only when there is involvement.[17,18] Sekse et al[9] conclude in their qualitative meta-synthesis that nurses are the professionals most attuned with patients, which may justify the reciprocal involvement experienced by the participants in the present study.

In palliative care, "the other" represents not only the patient but also the family. In addition to the World Health Organization,[2] whose definition of palliative care addresses the family, several studies emphasize the care of the family as a key aspect of palliative care and stress that working with families is a significant challenge.[14,19] In fact, the findings of this study, in addition to supporting these data, reinforce the idea that a support relationship is established between nurses and the family, revealing that this experience is difficult for the nurses. Tsaloukidis[20] finds that families deny the reality and severity of the illness as a primary coping mechanism. According to Seed and Walton,[14] it is a complex and demanding process to help families to understand that their loved one has died or is dying, because of the denial of the terminal stage of their family members' illness.

Actually, as human beings, the nurses recognize and value the humanity of the patient/family, and in turn, the nurses' humanity is recognized by the patient.[17,18] Thus, the nurses also focus on themselves because as a human

being the nurse cannot be indifferent to the suffering of the other, to the death of the other, as it forces them to confront their own mortality. In Davies and Oberle's[21] model, which describes the attributes of nurses in the practice of palliative care, it is found in the dimension of "preserving one's own integrity," insofar as the nurse is regarded not only as a professional but also as a person.

A previous study has indicated that caring in palliative care may contribute to emotional drain, resulting from experiencing the death of many patients in a short period or being involved with a specific patient over a long period.[22] Nurses working in palliative care interact regularly and meaningfully with people who face some of the most demanding and emotional moments of their lives: illness and acceptance of death.[9]

However, this study provides a new understanding by revealing the power of caring in palliative care to transform the nurse as a human being. The results suggest that this awareness of vulnerability is an opportunity for personal development and the incorporation of changes in one's personal life.

Although the findings of the present study demonstrate an involvement between the nurse and the patient, they also demonstrate attempts at distancing, as a defense mechanism and preservation of nurses' emotional well-being. This is in line with Breen et al,[23] who identified detachment as a coping strategy to avoid emotional exhaustion and the fatigue of compassion. Nevertheless, this study's results are not fully supported by the results of Perry[24] and Caro et al,[25] who discovered that the connection with the other generates professional satisfaction, and Breen et al[23] and Strang et al,[26] who determined that the establishment of a deep relationship leads to mutual acceptance of suffering and death. However, the findings can be regarded as contradictory; the involvement with the other favors providing differentiated, singular partnership and supportive care, as at the same time it generates emotional drain.

The findings showed that emotional exhaustion is counterbalanced by recognition and a sense of usefulness. Echoing Perry's[24] study, the professional satisfaction experienced by palliative care nurses is related to recognition. That is, when patients are comforted and their needs are met, patients and families express gratitude. This gratitude is quite significant, as it represents acknowledgment and is a source of motivation to continue to provide high-quality care that effectively addresses the needs of patients. In addition to feeling appreciated, the participants also mention feeling a sense of usefulness that compensates for emotional exhaustion. These findings can be compared with those of Källström Karlsson et al,[27] who find that when the care provided makes a difference in the quality of life of patients and relatives emotional tension can be thwarted.

The findings suggest that the team is the pillar of the experience of caring in palliative care. The role of the team in the context of palliative care is described in the literature, highlighting, in particular, the importance of team meetings and the existence of a safe environment where concerns, doubts, and feelings can be expressed.[14,28] Nevertheless, this study reveals that humor and relaxed moments experienced as a team, inside and outside the palliative care unit, are of importance for the nurses' self-care. Self-care is crucial when caring for end-of-life patients[14] and is possible only with the team's support. In Davies and Oberle's[21] models and according to Newton and McVicar,[29] one of the strategies nurses use for "preserving one's own integrity" is humor. However, this study suggests that humor and relaxed moments as a team, rather than an individual strategy to preserve the integrity of the self, contribute to the good functioning of the team, strengthening it, which, in turn, ends up improving individual well-being.

CONCLUSIONS

This study shows that nurses' caring in palliative care favor living an experience centered not only in a relationship with the other, the recipient of the nurse's care, but also in a relation with oneself, opening space for personal development. On the one hand, it is an exhausting experience because of the nurses' frustrated attempts to distance themselves and because of their feeling of powerlessness in light of the suffering of the other. On the other hand, the enriching experience is mediated by the recognition received from the other and by feeling useful. The team represents the pillar of all the experience, when there is a relationship of not only sharing concerns and doubts but also good moments inside and outside the service.

In the future, more and more nurses will come in contact with the suffering and death of patients in various contexts. Therefore, acknowledging these experiences is crucial because it forces nurses, other health care professionals, and managers in palliative care and other areas to reflect on the challenges experienced by these nurses, their strategies of self-care, and the team as a pillar that supports the (demanding) experiences.

Future research should focus on nurses' experiences in a palliative home care context and should design interventions that focus on reducing the exhausting experience among nurses in palliative care, as well as in other contexts where nurses have regular contact with suffering and death.

Feature Article

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OVERVIEW AND FUTURE DIRECTIONS

In this final section we proceed to a systematization of the most relevant results by objective, in an integrated perspective, in order to discuss the relevance and implications of the studies presented in this thesis. Figure 4 presents Key Statements about the study.

In the **Phase I**, with the purpose of map the literature on the elements contributing to the construction of the HCP in the context of PC, we perform a scoping review. It is known that as the population continues to age and PC becomes more present in health care practice, having an understanding of the necessary elements of HCPs, who effectively manage care in PC is essential, since they are working daily with people who are dying and are exposed to intense emotional reactions.

This scoping review identifies five key elements around the construction of the HCP concept in the context of PC: Construction and application of the concept of care; Psychosocial effects that daily care produces; Working conditions that influence the caregiving provided; Knowledge mobilized in the provision of care; Strategies adopted by HCP to build relationships.

This scoping review revealed that the close contact provided by the daily care with patients in PC, could cause suffering and distress for the HCPs themselves. Since, when HCPs are focused on the needs of the dying patient they may forget to care for themselves. In this sense, this scoping review evidences the need of emotional support to team members. Furthermore none of the included articles clearly explains the strategies HCPs adopt, or should adopt to help them in the daily care.

From the findings of the scoping review it seems necessary to understand whether the impact of care in PC are ever compensated by the satisfaction, sense of commitment and purpose of the work HCP provide, and whether the lower levels of burnout reported by PC professionals are specific to a context of care or they could be generalized. As Maslach and colleagues indicated burnout research had its roots in professions involving human interactions, especially when the cared person is in need of assistance and support, as it is the primary concern in nursing profession (Maslach, 2003; Maslach & Leiter, 2000; Maslach et al., 2001). In this sense, we developed the systematics reviews of the literature focused on burnout.

Refer that most of the studies analysed in this scoping review were not carried out taking into account all team members of the multidisciplinary team. For instance, in eighteen articles data were only gathered retrospectively on nurses' views. Even if we use the term HCPs, since this scoping review was made taking into account the multidisciplinary team, most of the data relate to nurses. Therefore, this limits any possible generalisation among other HCPs involved in the care in PC.

Overall, this scoping review contributes to the generation of a solid body of empirical knowledge that facilitates the professional growth of PC teams, since it identifies key elements in the concept of the HCP construction, revealing the importance of developing specialized training programs and adding new elements to define strategies of action, showing the necessity of promoting interpersonal skills and emotional management mechanisms.

In the **Phase II**, two reviews were performed. In the first systematic review, taking into consideration the results from the scoping review, we performed a Systematic Review of Prevalence, to examine the evidence on the prevalence of burnout among HCPs working in PC. Results reveal a prevalence of burnout among HCPs of 17.3%. Nurses have higher levels of Emotional Exhaustion and Depersonalization and physicians have lower levels of Personal Accomplishment. The prevalence of burnout is higher among social workers and the highest prevalence of burnout is in the home care context. From this study it is important also to mention that two of the studies interpreted the sub-scale Personal Accomplishment incorrectly; five studies using the Maslach Burnout Inventory instrument have only presented the results from the different sub-scales, and did not provide a global result; the ranges used in the sub-scales of the Maslach Burnout Inventory and the interpretation of this instrument, the existence of burnout, were not always the same. All these factors should be taken into consideration when developing future research about the burnout syndrome, and the use of a standard instrument that allow a comparison of data with previous evidence.

Moreover, managers and HCPs should be aware of the prevalence of burnout in PC and be able to recognize it and be prepared to respond to it. This response should be at the individual level (for the wellbeing of the worker) and also at the service (i.e. the site and service provision) and system levels. From the findings of the present systematic review it seems to us even more relevant to perform the systematic review comparing the burnout levels among HCPs in PC and in other areas of care to understand if there are significant differences among them.

In addition, a clear understanding of the factors that affect HCPs which will have a direct impact on the levels of Emotional Exhaustion, Depersonalization and Personal Accomplishment generating burnout among them, and how these factors are managed in daily care requires understanding.

Overall, this systematic review contributes to the generation of a body of empirical knowledge that facilitates the professional growth of PC teams, since it identifies the prevalence of burnout among HCPs, in the different subgroups and in different PC contexts.

In the second study, a systematic review comparing the burnout levels among HCPs in PC

and in other areas of care was performed, in order to understand if there are significant differences among them. This systematic review provided evidence that burnout among HCPs (six studies included about nurses and one about physicians) working in PC is lower than is that of HCPs working in other health care settings. These data are quite important for clinical practice given the direct relationship reported in the literature between "happy work" and the provision of quality care.

The data from this systematic review emphasize the need for professionals working in settings other than PC to implement strategies to reduce burnout and therefore improve their clinical practice. We develop the qualitative study, to extend our understanding, and provide new relevant data, of the strategies used by these nurses in PC, that might be able to be implemented by nurses working in other settings, such as critical care, oncology wards, internal medicine.

Although, from the results of the systematics reviews nurses in PC are the professional group with higher levels of Emotional Exhaustion and Depersonalization, despite when comparing with other contexts of care then PC, the levels of burnout were lower, which is relevant too. Additionally, in the Portuguese contexts is in the PCUs that nurses have the daily contact with death and suffering and where the philosophy of PC are more develop, so it seems important for us to develop this final study in one of this units.

In **Phase III**, the development of the phenomenological qualitative study allowed us to understand that Caring in PC favours the living of an experience centred in the relationship with the other, the aim of the nurse's care, but also in the relation with the self, opening space for personal development. If, on the one hand, it is an exhausting experience because of the frustrated attempt to distance oneself, and by the feeling of powerlessness in the light of the suffering of the other, on the other, the experience of an enriching experience is mediated by the recognition received by the other and by feeling useful. The team represents the pillar of all the experience when there is a relationship of sharing concerns, doubts but also of good moments inside and outside the service.

As mentioned before despite being in the PCUs that nurses have the daily contact with death and suffering, death occurs less and less at home and more at the hospital (Cohen et al., 2008; Gomes, Sarmento, Ferreira, & Higginson, 2013; Observatório Português de Cuidados Paliativos, 2017). Thus, more and more nurses, from the most diverse areas, come into contact with the suffering and death of the patients who are the object of their care. Therefore, documenting these experiences was crucial, since it asks nurses, researchers and managers in the area of PC and others, to reflect on the challenges experienced by these nurses, their strategies of self-care, and the team as a pillar that supports the

(demanding) experiences.

From the point of view of scalability, it is expected that the development of the present thesis allow stakeholders to take a holistic view in order to understand all the elements of providing care to patients in PC context, since this will have an impact on the care provided. Managers and HCPs should be aware of the prevalence of burnout in PC, be able to recognize it and be prepared to respond to it. Our results revealed that burnout syndrome is present among all professionals and in all PC contexts, so further studies finding the best strategies and theories on how to provide this care in the most efficient manner possible avoiding burnout symptoms and studies on interventions that focus on reducing HCPs' physical, psychological, social, and spiritual needs, that can have a direct impact on the level of Emotional Exhaustion, Depersonalization and Personal Accomplishment, remain a high priority in order to gain greater knowledge about the burnout syndrome.

The state of the science on HCPs' concerns and needs is evolving. Research evidence requires further research in these areas to find the best strategies and theories on how to provide this care in the most possibly efficient manner. Our intentional focus on understanding the experience of care helps to improve not only the welfare of the HCP but also the care provided to the patient in PC. This assumes a role of significant relevance for the HCP and the patient, who receives care at this singular moment.

Mention that methodological issues and limitations presents in our studies have been openly discussed in the corresponding chapters. Regarding the thesis in its overall, we recognize as limitation the absence of a specific intervention to deal with burnout. However, we are convinced that all the work done (mapping the evidence about the subject, realization of two systematic reviews, and understanding the phenomenon of caring in palliative care, through a phenomenological study) is central for those future studies with the aim of develop interventions. Any future intervention designed in this area with the aim of preventing or alleviating burnout will benefit from the work we have done.

It is our believe that the research developed in this thesis produce evidence to support a paradigm change in the prevention and management of burnout in the context of PC and hopefully in other contexts, and also to provide incentives for future research promoting the well-being of HCPs. As Maslach and Leiter (2015) points out, once the levels of burnout are known, it is important to move towards interventions that mitigate it. Having the approval for publication in scientific journals with impact factor, reveals that this subject has international relevance.

The existence of many studies about burnout in PC, revealed by the performance of the systematics reviews, the recent creation of the National Commission of PC in Portugal

revealing the growing relevance of PC in our country, and the multiples references to the importance of research about this subject, are aspects that put in evidence the opportunity and potential reach proposed herein.

However, this thesis is not confined to questions related to burnout. In this thesis we went further and with the accomplishment of the qualitative study we understand that although caring in PC constitutes an exhausting experience (which can effectively culminate in the state of burnout, which is why interventions should be designed and implemented), it is also a rewarding experience.

As Travellbee points out, "engagement" is an act of courage. When the nurses are sympathetic, when they care about the other, when they get involved with the other, there is the risk to effectively help the patient and feel enriched or be unable to help and feel frustrated. The nurses Caring in PC decide to take that risk, dare to get involved and say it's worth it.

The work developed in this thesis, gives visibility to Caring in CP, a care guided by a nurse-patient-family relationship in which one human being relates to another, and which is characterized by the compassion and sympathy, that lie in the very heart of nursing.

What is already known about the topic?

- The increased number of people living with a chronic degenerative and disabling disease contributed to a growing need for PC;

- More nurses will provide this singular care;

- Caring in PC causes intense emotions which could lead to multiple stressful and demanding challenges for nurses;

- These challenges can cause physical, psychological and emotional distress as well as work-related stress, and if not treated in time, there is a risk of burnout.

What does this study add?

- Phase I: Provide a map of the key elements of the construction of the HCP and identifies a number of gaps in the literature;

- Phase II: Revealed a prevalence of burnout of 17.3% among HCPs in PC. Nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%), and physicians had lower levels of Personal Accomplishment (41.2%). Also provided evidence that burnout among HCPs working in PC (6 studies about nurses and 1 study about physicians) is lower than that of HCPs working in other health care contexts;

- Phase III: Revealed that five themes reflect the essence of the lived experience by nurses caring in PC: (1) experience centered on the relationship with the Other; (2) experience centered on the relationship with one's own self; (3) exhausting experience; (4) rewarding experience; and (5) the team as a pillar.

Implications for practice, theory or policy.

- Phase I: Put in evidence that future research should be addressed with the intention to explore the emotional exhaustion, depersonalization, and the personal accomplishment among HCPs in PC;

- Phase II: Managers and nurses should be aware of the prevalence of burnout in PC identified, in order to be able to respond to it, at the individual level, and also at the service and system levels;

 This phase also emphasizes that research should be undertaken to extend the understanding of the strategies used by PC nurses/managers and how they could be implemented by nurses/managers working in other contexts, as well, the need to develop / implement interventions that lead to a reduction in burnout levels;

- Phase III: Provided visibility to the experiences of the nurses caring in PC and provided valuable contributions for designing interventions that focus on reducing the risk of burnout among nurses — not only those working in PC but also those working in other contexts who experience regular contact with suffering and death.

Figure 4: Key Statements about the study

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Specific references of the scientific papers are provided at the end of each paper. The references are in accordance with the journal guidelines. The remaining references are presented in this section.

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APPENDICES

Appendix 1

Data Collection Instrument of the study: *Caring in palliative care — a phenomenological study of nurses' lived experiences.*

Instrumento de Recolha de Dados do estudo:

Cuidar em Unidades de Cuidados Paliativos:Vivência dos enfermeiros

---

Dados socio demográficos

Género:
Idade:
Estado Civil:
Habilitações académicas:
Tempo de experiência profissional em Cuidados Paliativos:

GUIÃO DA ENTREVISTA

Sei que exerce funções em Cuidados paliativos há algum tempo.

Como tem vivido esta experiência?

Appendix 2

Informed consent of the study: *Caring in palliative care — a phenomenological study of nurses' lived experiences.*

CONSENTIMENTO INFORMADO

Cuidar em Unidades de Cuidados Paliativos:Vivência dos enfermeiros

Título do estudo: Cuidar em Unidades de Cuidados Paliativos:Vivência dos enfermeiros

Investigador: Vítor Sérgio de Oliveira Parola. Assistente Convidado na Escola Superior de Enfermagem de Coimbra.

Âmbito: Doutoramento em Ciências de Enfermagem - Instituto de Ciências Biomédicas Abel Salazar.

Com o desenvolvimento e implementação das Unidades de Cuidados Paliativos, os enfermeiros vivenciam cada vez mais o Cuidar do ser humano em situação de fim de vida. Cuidar neste contexto tão peculiar onde o contacto com a morte é vivido de forma constante, constitui um desafio profissional e pessoal.
Assim, este estudo de investigação visa descrever e compreender as vivências dos enfermeiros que prestam cuidados em Unidades de Cuidados Paliativos.

Por esse motivo, solicito a sua participação no estudo, agradecendo desde já a sua colaboração.
Para a recolha de informação, será utilizada uma entrevista que decorrerá em espaço adequado e tempo possível.

A entrevista será gravada em suporte áudio, de forma a facilitar a sua posterior análise. O seu nome nunca será publicado, tendo apenas os investigadores acesso à gravação (as entrevistas serão codificadas). Todos os dados recolhidos são confidenciais.

Para esclarecimento de dúvidas poderá contactar-me através do número de telemóvel:

 96 3432 067 – Vítor Parola

O Sr.(a).Enfermeiro(a)_____ aceita participar livre e voluntariamente no estudo, declarando ter compreendido o objetivo, procedimentos do mesmo, e tendo-lhe sido dada a oportunidade de esclarecer as dúvidas existentes, ficando clara a possibilidade de poder abandonar a investigação a qualquer momento.

Data __/__/____

Assinatura do Participante   Assinatura do Investigador

Appendix 3

Ethics Committee authorization of the Health Sciences Research Unit: Nursing to perform the study:

Caring in palliative care — a phenomenological study of nurses' lived experiences.

COMISSÃO DE ÉTICA

da **Unidade Investigação em Ciências da Saúde: Enfermagem** (UICISA: E)
da **Escola Superior de Enfermagem de Coimbra** (ESEnfC)

Parecer Nº P371-11/2016

Título do Projecto: Cuidar em unidades de cuidados paliativos: vivência dos enfermeiros

Identificação do Proponente
Nome(s): Vitor Sérgio de Oliveira Parola
Filiação Institucional: Instituto de Ciências Biomédicas Abel Salazar, UP
Orientador: Prof. Doutor João Apóstolo

Relator: José Carlos Amado Martins

Parecer

O investigador pretende desenvolver estudo de tipo qualitativo, fenomenológico, com o objectivo de descrever e compreender as vivências dos enfermeiros que prestam cuidados numa unidade de cuidados paliativos".

A informação será colhida junto de enfermeiros a desempenhar funções na unidade de cuidados paliativos do hospital Arcebispo João Crisóstomo, sendo a sua acepção efectuada com apoio do enfermeiro chefe da unidade. São definidos os critérios de inclusão e exclusão.

A colheita de informação acontecerá entre dezembro de 2016 e maio de 2017.

Como estratégia para a colheita de informação será utilizada a entrevista "pouco estruturada". As entrevistas serão áudio-gravadas. O investigador garante a guarda do material áudio e a sua destruição após a transcrição e análise das entrevistas.

A participação dos enfermeiros é voluntária, não existindo qualquer ascendente hierárquico que coloque os mesmos em posição de vulnerabilidade.

Não são previstos danos ou ganhos diretos para os participantes.

É garantida a **confidencialidade** e anonimato da informação.

É referido

Face ao exposto, esta Comissão de Ética emite parecer favorável.
O presente parecer não dispensa a autorização da Instituição onde decorre o estudo.

O relator:

Data: 30/11/2016   A Presidente da Comissão de Ética:

FCT Fundação para a Ciência e a Tecnologia

Appendix 4

Ethics Committee authorization of the Hospital Arcebispo João Crisóstomo to perform the study:

Caring in palliative care — a phenomenological study of nurses' lived experiences.

Exm⁰ Senhor
Dr. Vitor Sérgio de Oliveira Parola

Conforme requerido vimos confirmar a aprovação pela Comissão de Ética do H.A.J.C. na sua reunião de 9 de novembro de 2016 do estudo "Cuidar em Unidades de Cuidados Paliativos: Vivência dos Enfermeiros".

Hospital Arcebispo João Crisóstomo, 11 de janeiro de 2017

A Presidente da Comissão de Ética para a Saúde

(Drª Maria de Lurdes Sá Tenreiro)

R. Padre Américo · 3060-186 Cantanhede · Tlf. 231 419 210 · Fax 231 419 219
geral@hdcantanhede.min-saude.pt · www.hdcantanhede.min-saude.pt

Appendix 5

Permission to reproduce the papers:

The prevalence of burnout in health professionals working in palliative care: a systematic review protocol and

Prevalence of burnout in health professionals working in palliative care: a systematic review.

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22nd November 2017

Vitor Oliveira Parola
PhD student, MSc, RN
Guest Assistant at the Nursing School of Coimbra (EsenfC).
Research Collaborator at the Portugal Centre for Evidence-Based Practice (PCEBP): a Collaborating
Centre of the Joanna Briggs Institute - Health Sciences Research Unit: Nursing (UICISA: E).

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Editor-in-Chief, *JBI Database of Systematic Reviews and Implementation Reports*
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Appendix 6

Permission to reproduce the papers:

Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review and

Caring in palliative care — a phenomenological study of nurses' lived experiences.

VP Vitor Oliveira Parola
sex 17-11-2017 11:12
Para: bferrell@coh.org »

↩ Responder | ⌄

> Esta mensagem foi marcada como Confidencial.

Dear Dr. Betty Ferrell,

My name is Vitor Parola and last October I published an article in The Journal of Hospice and Palliative Nursing entitled "Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review". Also I have an accepted article entitled: "Caring in palliative care — a phenomenological study of nurses' lived experiences".

These studies were part of my PhD in nursing science, which I intend to finish next December.

I want to ask your permission (and also, Lippincott Williams & Wilkins permission) to reproduce this article - "Burnout in Palliative Care Settings Compared with Other Settings: A Systematic Review" - and the final peer-reviewed manuscript of the - "Caring in palliative care — a phenomenological study of nurses' lived experiences" - in my doctoral thesis.

I appreciate your support and look forward to your authorizations.

Regards,

Vitor Oliveira Parola

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sex 17-11-2017 12:02
Para: Vitor Oliveira Parola (vitor.parola@hotmail.com) »

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