Spiritual care in Portuguese palliative care settings: a cross-sectional study

Rita Sampaio dos Santos, Tiago Domingues, Manuel Luís Capelas and Sílvia Caldeira

Abstract

Background: Spirituality is a core dimension of palliative care. However, Portuguese palliative care teams do not have many spiritual care resources. **Methods:** Cross-sectional and observational survey studies were used to characterise spiritual care resources in Portuguese palliative care teams based on a non-probabilistic convenience sampling. An electronic questionnaire was used for data collection. **Results:** A total of 150 responses were obtained. In 68.7% of the teams, there was no specific professional dedicated to spiritual care, although 68% of the participants considered that a spiritual assessment or intervention was a part of their role; 47.3% considered that their colleagues were reasonably prepared to develop a spiritual assessment or follow-up; for a patient, and 54.7% were considered to be reasonably involved. However, 50.0% did not consider themseleves to be competent at providing spiritual care. Most referred to not using any specific assessment tool or document (67.3%); 49.3% dedicated less than 10% of their time to specific education or training about spirituality. **Conclusion:** This study involved different professionals from multidisciplinary teams. Most recognised the importance of attending to the patient's spirituality and spiritual care. Results suggest that there is a need for specific training, resources and techniques to meet a patient's spiritual care needs at the end of life. This need may be similar in all teams, not just palliative care teams, to facilitate comparing indicators and promote the implementation of holistic care in palliative care.

Key words: cross-sectional studies ● palliative care ● patient care team ● spirituality

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Palliative care is based on optimising the quality of life of patients and families, including the prevention and treatment of physical, psychological, social and spiritual needs (Puchalski et al, 2009). This holistic approach highlights that all human dimensions should be considered among the healthcare team (Rainbird et al, 2009; Yardley et al, 2009). The World Health Organization (WHO, 2002) describes palliative care as a holistic approach that improves the quality of life of patients and families facing life-threatening illnesses, through the prevention and relief of suffering based on early assessment and treatment of pain and other physical, psychosocial and spiritual symptoms (World Health Organization, 2002). This definition and approach to palliative care is used globally, and the Portuguese Palliative Care Association (PPCA) was established in 1995 (PPCA, 2020).

Assessing spiritual needs and spiritual interventions in palliative care have been considered major indicators of good care (Dalva Yukie Matsumoto, 2009). Most patients want to share spiritual needs with healthcare teams and expect these needs to be met, particularly at the end of life (Ott et al, 1999; Hefti and Esperandio, 2016). Research on spirituality in health and nursing is now an emerging topic (Cockell and McSherry, 2012). For example, research on the prevalence of spiritual distress at the end of life has been considered a priority in palliative care (Selman et al, 2011; Selman et al, 2014). Despite the importance of spiritual care, this concept still entails ambiguities and further research is needed to deepen and consolidate knowledge that could inform clinical practice (Balboni et al, 2017).

In 2018, 102 452 patients in Portugal required palliative care (Capelas et al, 2019). In 2012, palliative care was defined in Portugal as active, coordinated and comprehensive care provided by specific units and teams, in the hospital or at home, to patients suffering from incurable or severe illness, at an advanced and progressive stage. The main objective of palliative care is to promote the patient's quality of life through the prevention and relief of physical, psychological, social and spiritual suffering, based on the early

identification and rigorous treatment of pain and other physical symptoms, and also psychosocial and spiritual difficulties.

In 2018, a total of 103 palliative care teams were listed in the Portuguese public health system, but this seems insufficient (Capelas et al, 2019). The integration of the assessment of spirituality in palliative care has been widely recommended, but at the same time, this is a dimension which is often neglected in healthcare (Selman et al, 2014). The 2019 fall Report of the Portuguese Observatory of Palliative care describes the three main instruments that are used in assessing spirituality, as follows: FACIT-Spiritual Well-Being Scale, Herth Hope Index, and Patient Dignity Inventory. But, only five teams (7.3%) usually use it (Capelas et al, 2019). This reality needs further study and broad understanding, as palliative care, based on a holistic approach, refuses to attend to patients purely as biological or physical entities (Dalva Yukie Matsumoto, 2009). Additionally, spiritual care is a core aspect of patient and family care within this holistic care paradigm (Caldeira, 2012). Spiritual needs are critical in palliative care, as the experience and perception of the proximity of death leads to people at the end of life having spiritual questions and uncertainty (Dones Sánchez et al, 2016). This is an opportunity for healthcare professionals to support patients spiritually (Dones Sánchez et al, 2016) and provide spiritual care. In particular, research on spirituality in healthcare in Portugal has been increasing in psychology and nursing, but palliative care is the second most frequent context where studies are conducted (Romeiro et al, 2018). In a literature review aiming to synthesise the state of the art of research in palliative care in Portugal, 49 papers have been analysed, and the authors concluded that most studies are quantitative and relate to nurses' needs and decisions (Pinto et al, 2014).

The implementation of spirituality in care is often considered difficult, and no systematic approach is known concerning the spiritual needs of palliative care patients, nor tools of measuring and evaluating these needs, which could be impeding a rigorous and evidence-based development (Branco and Vieira, 2011). Not a lot of evidence is available regarding the resources that are effectively used by palliative care teams in providing spiritual care, and this discloses a need to explore that topic aiming to improve palliative care and to implement spirituality in clinical practice, education and future research. As so, this study aims to characterise the resources for spiritual care in Portuguese palliative care teams.

Research design

This is an observational and cross-sectional survey study.

Participants

A non-probabilistic convenience sampling technique was used. All healthcare members of the Portuguese palliative care teams, as listed in the Portuguese Association of Palliative Care, were invited to participate in this study by e-mail. First, all coordinators were e-mailed, informed about the study and invited to participate. Then, those who consented to participate were asked to forward the e-mail to all healthcare members.

Data collection and analysis

The e-mail comprised the information about the study, participants' informed consent, and the link to an online survey, which was open from January to June 2018. The survey has been adapted from Dones Sánchez et al (2013), and was translated and adapted for the present study. The survey comprised 22 questions listed in four sections. The first three sections were composed of closed questions and the last section had an open-ended question. The questions addressed the themes: self-perception, commitment and competence for spiritual care, models in use, and at the end, the open-ended question concerning the concept of spirituality, if possible, was described in a single word. Data treatment was based on descriptive statistics and the open-ended question with content analysis. The questionnaire was designed in Survio, and was later imported into Excel. The tests Kruslkall-wallis, Chi-square (Monte Carlo correction) and Spearman correlation were used. The results were considered statistically significant if the p value was lower than 0.05.

The survey was tested in a palliative care team that was not included in the study. The content analysis included organising the data into data units, coding and naming the units according to the content they represent, and grouping the answers into shared concepts.

Ethical approval

This project has been approved by the ethics committee of the Institute of Health Sciences of the Universidade Católica Portuguesa.

Results

Sample characteristics

A total of 150 answers was obtained from different members of the palliative care teams. Most were women (80.7%), aged between 22 to 66 years old, with 4 years of experience in

palliative care. The palliative care teams included in this study were comprised of an average of 13 members. Participants of the survey were: nurses (55.7%), physicians (25.5%), psychologists (10.1%), social assistants (5.4%), sociocultural animators (1.3%), spiritual assistants, physiotherapists and nutritionists (0.7%). Most were working in Lisbon (34.7%), Porto (17.3%), and Bragança (10%). The majority (44.6%) were involved with palliative care within a hospital, 27.1% were associated with a palliative care unit, 24.9% with community support teams, and 3.4 % to other contexts.

Self-perception, commitment and competence

More than half of the participants (68.7%; n=103) reported that there was not a specific team member associated with spiritual care; 50% perceived themselves as being not very competent at providing spiritual care, 42.0% felt reasonably competent, 5.3% were not competent, and 2.7% felt very competent. Nevertheless, 68.0% confirmed that spiritual care was considered part of their role, but 24.7% felt that they should provide spiritual care if no other professional was available, or capable of that role.

Additionally, 67.3% (n=101) of participants stated that they did not have the resources available for a spiritual needs assessment or any specific document in the religious/spiritual sphere. Also, 76.0% (n=114) affirmed that they were not following any specific scale of assessment of suffering/emotional stress or need/spiritual resources.

From all Portuguese districts, Braga had the best resources for the providing spiritual care to patients at the end of life (*Table 1*).

Regarding the presence or not of a specific professional in the team dedicated to spiritual care, the PISS (Private Institution of Social Solidarity) were institutions that had a dedicated healthcare member for spiritual care (*Table 2*).

Definition of spirituality

The open-ended question ('use one word to describe the essence of spirituality') had different answers (*Table 3*).

Models used to provide spiritual care

No specific models used for spiritual care were identified, but some healthcare members were recognised as competent at providing spiritual care.

Discussion

This study aimed to characterise the resources that provided spiritual care to Portuguese healthcare teams.

Self-perception

Most participants seemed to define spirituality as the meaning of life, peace and transcendence. Defining spirituality in healthcare is challenging, as finding common language for this aspect of human experience is subjective. For instance, words such as 'transcendence', 'infinity', 'deep connection' may be found in Portuguese literature (Branco and Vieira, 2011). The different perception of the same concept may hinder implementation in clinical practice, and therefore, it is necessary for professionals to be able to understand the different forms of expressions of faith, spiritual interventions, as well as the limitations of professionals and a continuous reflection on their spirituality (Hefti and Esperandio, 2016). Although defined in a different way, healthcare providers should be aware of their own spiritual beliefs, as well as the obstacles to including spirituality in care, aiming to enable the development of competencies and facilitate the implementation of spiritual care in practice (Caldeira and Timmins, 2017).

From a personal point of view, half (50.0%) of the professionals did not feel very competent at providing spiritual care and 42.0% felt reasonably competent. They believed thatvmost of their teammates considered spiritual care very necessary (48.7%) and reasonably necessary (46.0%). Previous studies suggested that nurses believe spiritual care is important; however, they do not have confidence and do not receive training in this area (Mcsherry and Jamieson, 2011). Considering the complexity of the topic, the practice of spiritual care and the determination when patients are experiencing spiritual distress can be challenging at a professional and personal level. The existence of several perspectives within religions and populations drives increasing personalised and selective approaches to spirituality, with new and alternative "spiritualties" and emerging beliefs. As such, healthcare professionals may not have specific guidance on the spiritual care they should provide, perhaps justifying their lack of competence.

Commitment and competencies

The study sample consisted mainly of nurses (55.7%) and physicians (25.5%), which should be considered when analysing the results. No professional category was identified as mainly responsible or the most competent in providing spiritual care. The lack of clarity in

Table 1. Resources for spiritual care by Portuguese districts

District	Yes	
	n	%
Braga (n=8)	6	75.0%
Castelo Branco (n=2)	1	50.0%
Viana do Castelo (n=2)	1	50.0%
Viseu (n=2)	1	50.0%
Bragança (n=15)	7	46.7%
Lisbon (n=52)	22	42.3%
Setúbal (n=13)	4	30.8%
Autonomous Region of the Azores (n=5)	1	20.0%
Porto (n=26)	5	19.2%
Faro (n=6)	1	16.7%
Aveiro (n=7)	0	0.0%
Coimbra (n=1)	0	0.0%
Guarda (n=6)	0	0.0%
Portalegre (n=1)	0	0.0%
Santarém (n=4)	0	0.0%

Table 2. Resources for spiritual care by type of institution

Institution	Yes	
	n	%
Private Institution of Social Solidarity (n=10)	8	80.0%
Public Private Partnership (n=14)	7	43.8%
Corporate Public Organization (n=91)	30	33.0%
Private (n=16)	2	14.3%
Community health centres (n=14)	0	0.0%
Mercy institutions (n=2)	0	0.0%
Other (n=3)	0	0.0%
Total (n= 150)	47	31.3%

the responsibility for spiritual care can influence the level of motivation for the healthcare professional for training. The scarcity of training and knowledge on how spiritual care is provided opens space for uncertainty about the role of each element in the multidisciplinary team of PC teams. It is known that one of the challenges of spiritual care is to form and have a properly prepared multidisciplinary team, in which each professional needs to develop basic skills, such as understanding the model of spiritual care and assessing the patients' beliefs, spiritual needs and spiritual resources. It is necessary for the team to be aware of the different forms of faith expression, of the spiritual interventions, of their own limitations, and of the importance of ongoing reflection about their own spirituality (Hefti and Esperandio, 2016).

The difficulty in identifying a specific professional in the team, particularly devoted to spiritual care, may be related to the association or reductionistic perspective of the concepts of religion and spirituality, which promotes the lack of clear indications on how to provide spiritual care. Thus, nurses seem to tend to consider that it is the chaplain's role and responsibility to attend to those needs. If all healthcare providers are expected to provide holistic care, then all should be trained to identify spiritual needs and be able to refer to a team member who can guarantee support in spiritual distress (Cummings and Pargament, 2010). Nurses should understand the importance of referring patients to the chaplain or another spiritual leader (Timmins and Caldeira, 2017), but should be aware that this referral of the patient does not erase their responsibility. Interestingly, 80% of the patients included in Hefti and Esperandio's study were

not willing to talk to a chaplain (Hefti and Esperandio, 2016).

One of the main requirements for an effective provision of spiritual care is multidisciplinary training. In this sense, it is necessary for each professional on the team to develop basic skills, such as understanding the model of spiritual care, understanding pastoral/spiritual counsellor collaboration, and finally, understanding the evaluation of beliefs, needs and spiritual resources (Hefti and Esperandio, 2016). The scarcity of education for spiritual care is illustrated by a study involving 339 physicians and nurses caring for patients with advanced cancer, in which only 12% of nurses and 14% of physicians reported receiving any spiritual care training (Otis-Green et al, 2012). The need for more education and training in providing spiritual care as part of palliative care, and the need to identify the role of palliative healthcare members in implementing spiritual care, has been described in literature (Balboni et al, 2013; Caldeira et al, 2016; Balboni et al, 2017). Even though, 46.0% of participants of the present study reported that they always paid attention to religious and spiritual needs. Nurses are recognised as being in a privileged position to meet the spiritual needsof their patients, however, despite their recognition of the importance of the topic, Portuguese nurses reported a lack of training to achieve this (Romeiro et al, 2018).

Furthermore, studies have shown that nurses perceive that there is a lack of preparation and training for spiritual care, mentioning that the topic is poorly developed in undergraduate courses in Portugal and Brazil, which does not allow for the adequate development of competencies (Caldeira et al, 2016).

Concerning the provision of spiritual care, the ambivalence of the results seems to corroborate the gap and the emerging need to clarify concepts and methodology. Professionals from palliative care teams in Portugal recognise the importance of this dimension of care (68% believe that spiritual care is part of their role, and 46.0% always consider the religious or patients' spiritual needs). However, only 31.3% sometimes address religious/spiritual needs in multidisciplinary

Table 3. Answers to the opened question

Answers	Frequency
Meaning of life	26
Peace	19
Transcendence	17
Wellness	13
Faith	9
Life, tranquility	7
Belief	4
Fullness, self-knowledge, belief, compassion	3
Essence, meaning, love, existence, inner	2
Religiosity, harmony, entirety, person, affection, connection, confidence, pillar, soul, growth, totality, self-esteem, universe, protection, forwarding, mental health, resilience, relationship, respect for difference, respect, union, inner strength, fundamental, involvement, values, balance, meeting, dimension, humanity, contagia	1

meetings, 29.3% often consider religious aspects independently of spiritual needs and 25.3% sometimes. Furthermore, most Portuguese healthcare team members admitted that there are no resources for assessing spiritual needs or any specific document (67.3%), and that they do not use any specific scale (76%). A study conducted in Brazil reported that 53% of healthcare professionals acknowledge that their patients would like to discuss their spiritual dimensions with them, but around 18% frequently report doing so (Esperandio, 2014; Hefti and Esperandio, 2016).

It seems critical to keep the research on spirituality in palliative care within the domains of spirituality assessment and spiritual wellbeing, chaplaincy, interventions and education. These topics are foundational to achieving evidence-based methods to integrate spirituality into palliative care and to promote integrated care for the physical, emotional, social and spiritual wellbeing of patients and families. Participants described spirituality as an essential and critical dimension in palliative care. Still, no specific models in use for spiritual care were identified as a systematic, regular and standard approach among all healthcare teams. These results open new paths for research to understand the reasons, conditions and expectations for adopting specific models to provide spiritual care and, if implemented, monitor and measure the related outcomes (in patients, families and team/organisation).

This study uncovered some needs (for training and organisation of staff and care) that are important to consider in the future. It is essential to highlight the importance of including spiritual care recognised by professionals, which may facilitate future work, with a view to the continued development and sedimentation of palliative care in Portuguese teams.

Conclusion

This study described the needs of palliative care teams concerning resources for spiritual care. No clear resources have been described in Portugal, particularly regarding the concepts of spirituality and the methodology for implementing spiritual care. Participants recognise the importance of spiritual care and its positive impact on patients' health and life, but self-perception of competencies and commitment discloses that more training is needed.

Participants described not having the training nor resources and/or skills to apply spiritual care and feeling that they were not competent at providing spiritual care. However, caution is needed when reading the results of this study, as the sample does not represent all healthcare professionals. Further studies should involve more participants and study the validity and reliability of the instrument used. Nonetheless, this study discloses the need to improve the training and education on spiritual care for patients at the end of life for healthcare professionals. *IJPN*

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CPD reflective questions

- What spiritual care needs do patients have at the end of life?
- Why does a nurse's responsibility to provide spiritual care not end following the patient's referral to a chaplain?
- How could healthcare providers be better prepared to meet the spiritual care needs of patients at the end of life?

Key points

- Spiritual care is important for patients at the end of life, however no clear resources have been described in Portugal on implementing spiritual care for healthcare providers
- Healthcare providers have insufficient training and resources to provide adequate spiritual care for patients
- The practice of spiritual care can be challenging at a professional and personal level.

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