



## Spirituality in palliative care: experiences of an interdisciplinary team\*

Espiritualidade nos cuidados paliativos: experiência vivida de uma equipe interdisciplinar  
Espiritualidad en los cuidados paliativos: experiencia vivida de un equipo multidisciplinario

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### ABSTRACT

**Objective:** To understand the experience of spirituality in the daily routine of a palliative care interdisciplinary team. **Method:** A qualitative study was conducted with an oncological palliative care team in southern Brazil. The data was collected through phenomenological interviews in 2014, and interpreted using a hermeneutic phenomenological approach. **Results:** Six professionals participated in the study. Spiritually-related activities, such as prayer and providing comprehensive care, were useful therapeutic resources for offering comfort, survival with dignity and humanization of death, in addition to helping the team and patients understand the end-of-life process and search for meaning in the suffering caused by illness. **Conclusion:** Spirituality on the part of professionals with patients imparted meaning to their palliative care work and facilitated the formation of bonds between teams, patients, and family members.

### DESCRIPTORS

Spirituality; Palliative Care; Holistic Nursing; Patient Care Team; Existencialism; Professional-Family Relations.

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## INTRODUCTION

Palliative care involves improving the quality of life of people and their families who are facing life-threatening conditions, through early diagnosis and treatment of physical, psychosocial and spiritual symptoms<sup>(1)</sup>. This type of care requires multiprofessional teams in order to cover the multiplicity of aspects related to the disease process, and thereby care for human beings in their wholeness, from the start of palliative care up to the family grieving process<sup>(2)</sup>.

From this perspective, health professionals play an important role in assisting patients during the course of a life-threatening illness and the search for meaning in their lives. It is also recommended that teams provide assurance of care to the person and caregivers, imparting meaning to this time of their lives, even when healing is no longer possible<sup>(3)</sup>.

Studies on human beings coping with diseases frequently demonstrate that spiritual beliefs influence this process, making it increasingly necessary to understand the spiritual care needs of these individuals. Therefore, it is important for health teams to prepare a spiritual anamnesis for patients with chronic conditions and document it, as is done with respect to biopsychosocial aspects. Once data is collected from the medical record, the professional can endeavor to support the beliefs of the individual receiving palliative care by providing an environment that permits religious rituals that are important to the individual and manifesting a welcoming attitude toward the patient's community of faith. These are avenues through which professionals can integrate spirituality into health care<sup>(4)</sup>.

It is important to distinguish between the concepts of spirituality and religion in health care. Religion is defined as a system of beliefs and practices of a specific community, supported by rituals and values<sup>(4)</sup>. Spirituality may be related to religion or not, and is understood as the search for meaning in life, in dimensions that transcend the palpable human experience<sup>(5)</sup>, which is the concept adopted in the present study.

Spirituality is significant in palliative care in that it can alleviate suffering regardless of the stage of the disease<sup>(6)</sup>. It also has an influence on the way in which patients cope with their health problems, and provides well-being, not only in the face of death<sup>(7)</sup>.

Besides the relevance of building a spiritual record, it is possible, through understanding the meaning of this dimension for human beings, to develop better care practices for palliative care patients, for whom spiritual aspects tend to assume greater importance in their end-of-life condition. When reflecting on the integral nature of human beings and the spiritual care given during the final stages of life, it is necessary to consider the person who is ill, and not the illness itself, with a focus on well-being, quality of life and comfort. Therefore, comprehensive care is understood as a set of actions strategically and jointly coordinated by all the members of the health team, to ensure a humanized and holistic care model that contemplates well-being in the multiple dimensions of human beings, who should be viewed as both biopsychosocial and spiritual beings<sup>(8)</sup>.

However, just like physical, social and emotional pain, there may also be spiritual pain related to lack of meaning in life and death, fear of the afterlife, feelings of guilt before God, and the search for faith and spiritual comfort<sup>(2)</sup>. In the present study, based on the theoretical framework of Viktor Frankl, which is inspired by the principles of existentialism and phenomenology, it is understood that human beings feel compelled to find meaning for their lives, and that this desire is the main driving force. Life has meaning as a whole; therefore, inevitable suffering also has meaning and is part of life. For this reason, in situations such as the stages of a terminal disease, there are few possibilities open to individuals, such as taking a dignified stand before life. And, when they ask themselves about the meaning of life, they are expressing their innermost human essence<sup>(9)</sup>.

Therefore, the exercise of spirituality in situations that dictate the end of an individual's life becomes essential for palliative care patients to carry on with life, where spirituality is considered a driving force for responding to the circumstances of these people in relation to their own existence. The exercise of spirituality is also viewed as an agent for transforming and regulating emotions, representing an effective tool for reducing levels of depression and anxiety among people suffering from cancer<sup>(10)</sup>.

With respect to palliative care for people with cancer, spirituality is also recognized as a promoter of quality of life, and faith is the most important component for translating it. Faith has been cited as a factor that helps improve the physical and psychological symptoms of patients, giving them better quality of life. And in palliative care, it affirms a human being's existence in its plurality, and transcends care focused solely on the biological body<sup>(11)</sup>.

As for the spirituality of palliative care professionals, this is known to be very important and assists them in carrying out their work, as well as contributing to the quality of care provided. As professionals become more sensitive to the needs of patients, the exercise of spirituality enables a more comprehensive and humanized care model. Furthermore, when there is a broad spectrum of spirituality and spiritual support within the health team, the spiritual needs of the families of patients, who are also debilitated before the finitude of life, are also included<sup>(12)</sup>.

However, there is little in the literature on this topic, and most of the studies involving spirituality in palliative care treat patients as the object of the study. In view of this, when considering spirituality and putting it into practice in health care, this requires a foundation of scientific knowledge, which is the basis for providing care to human beings throughout the life cycle. The present study explores the spiritual dimension that tends to emerge in the end-of-life process. Therefore, its goal is to understand the experience of spirituality in the daily routine of a palliative care interdisciplinary team.

## METHOD

This was a qualitative phenomenological study conducted in southern Brazil, in the Interdisciplinary Oncological Home Care Program linked to the Teaching Hospital of

the Universidade Federal de Pelotas. This program was implemented in April 2005 and expanded to two teams in 2011. It received new patients from other oncological services in the city, providing comprehensive care in the diagnosis, treatment and palliative care of people who have no possibility of healing.

The ethical principles set forth in Resolution No. 466, of December 12, 2012<sup>(13)</sup> were respected during the investigation, and the study was approved by the Ethics and Research Committee of the School of Medicine of the Universidade Federal de Pelotas, under Opinion No. 668.915, on May 29, 2014. The anonymity of the participants was ensured through their identification by the letter "P", for professional, followed by a number, according to the chronological order in which the interviews were held, i.e., P1 (Professional 1) and so on.

In this study, six different professionals who worked in the Interdisciplinary Oncological Home Care Program met the selection criterion for participants: be part of the team for at least one year. With respect to religion, two workers said they were spiritists and four said they were Catholics. The information was collected from June to October 2014, via scheduled phenomenological interviews: four were conducted in rooms set aside by the hospital and two at the homes of the professionals, by their preference. These interviews contained the following questions: one which was general – *What meaning does spirituality have for you as a professional in treating palliative care patients?*<sup>20</sup>; and two guiding questions – *Tell me about your experience interacting with these patients* and *What influence do you feel your spirituality has on your work process?* The information was recorded and transcribed in the days following the interviews.

To operationalize this information, a Ricoeurian hermeneutic phenomenological interpretation was performed, which started off by preparing a text produced from the descriptions in the information collected through the interviews with professionals from the palliative care team<sup>(14)</sup>. The first contact with the text looked for the meaning of the experiences lived by the participants, in order to understand them existentially. At that time, the principle of phenomenology *back to the same things* was considered, through which the meanings that emerge beyond the realm of words were identified. Following this, the texts were carefully reread, with no need to explain them, but rather to highlight the meanings contained therein, based on what was expressed by the participants in an existential moment.

Afterwards, the text was interpreted in order to establish meaning units in interrelated excerpts, pointing out distinguishable moments in the totality of the text of the description. The last stage of the hermeneutic was comprehension, also referred to as manifest sensibility. In this stage, there is an emanation of the unknown through the synthesis of the meanings revealed by the participants, and the search for relevant constituents indicated in the description of the lived experience, individually validated in the phenomenological reduction with each participant, after which the categories emerged.

## RESULTS

The following categories were formulated to understand the experience of spirituality in the daily routine of the interdisciplinary palliative care team.

### MEANING IN THE WORK OF PALLIATIVE CARE PROFESSIONALS

Spirituality gives meaning to the work of palliative care professionals, starting with their strengthening as individuals, which is reflected in their professional work. Spirituality was also considered the true meaning of palliative care, resulting in peace and understanding of the objective of this form of health care, and assignment of new meaning to the actions of these professionals.

*Spirituality strengthens me as a person and as a professional. (...) without spirituality, much of what we do would have no meaning. (...) it enriches us a lot as professionals and greatly enhances the care (P1).*

*I've noticed that spirituality has an influence on my work as a facilitator and harmonizer. It helps me understand the 'why' aspect and reveals the essence of the person and their values, principles, dreams and desires, something that is internal (P3).*

*My spirituality brings me peace. I'm no longer afraid of suffering and death (P4).*

*Spirituality strengthens me because I am able to comfort and support patients and be at their side (P5).*

*Before starting to work in palliative care, I had no idea that spirituality needed to go hand-in-hand with the work of health professionals. I have to explain this to people, because they comment that our work must be very frustrating. I tell them it's not so because we are able to help people die more peacefully, in a more dignified way because, besides the clinical part, the spiritual side is also necessary (P6).*

### SPIRITUALITY AS A THERAPEUTIC RESOURCE FOR THE HUMANIZATION OF CARE

The professionals mentioned that it is possible to comfort patients through spirituality. They also noted the relevance and power of positive thinking in the act of transcending, i.e., finding something outside oneself which, according to the participants, has beneficial results.

*After controlling symptoms such as pain, nausea or vomiting, other symptoms emerge such as anguish, fear of death or anxiety, but there is no drug treatment to control these symptoms. Therefore, we often pray with families and patients or, sometimes alone, we intercede for these people (P1).*

*When I have a very difficult case, a very sick person, I leave that house thinking positive thoughts for the person, that something has to happen, and then the next day it actually happens. I've had this experience several times. A feeling of concern comes over me and I say "God, this patient needs help; something needs to happen and it does". I believe in this, I have faith in this; that we have to give it our all and ask for help, and then things happen. I've seen this many times (P4).*

The philosophy and practice of palliative care are related to the humanization of the death process of patients. This was observed in the accounts of the study participants, where the person in an end-of-life process also serves as a mirror and, upon realizing this, the professional becomes more empathetic, i.e., the manifestation that the patient's life, or death as a part of life, has meaning for the professional, and not the disease.

*I feel that spirituality humanizes us, draws us closer to each other and really gives us more love for what we do (P1).*

*Being in line enables the patient to adhere more to the treatment. Sometimes, as far as terminal cases, synergy is important to be able to reduce the symptoms (P2).*

*The person who is ill must feel you are doing something for him; you have to be giving of yourself, otherwise it's pointless (P4).*

*We can perceive, talk and support, just the act of touching, being close, hugging those accompanying the patient, the caregiver and the patient himself. If I wasn't a more spiritually-oriented person, perhaps I wouldn't get so involved in this end-of-life process. Sometimes, those accompanying the patient are very distressed and nervous, because they don't know what's going to happen (P5).*

## SPIRITUALITY AND THE TRAINING OF PROFESSIONALS

In the experiences of the professionals, they also cited lack of training on how to approach spirituality, which ends up being denied, since it was not determined who can attend to this need, creating a gap in health care. From the moment professionals become part of palliative care teams, it was no longer possible to avoid contact with this need of patients.

*We are not prepared during our training and throughout life. Before I worked in a type of care that attributes importance to spirituality, it was denied. When patients wanted to talk about spiritual matters, transcendence and the death process itself, we refused to talk about it. We said we weren't prepared for this, that it was up to someone else, but we didn't identify who that person was, because within the hospitals here there are no spiritual assistants (P1).*

*During our undergraduate studies, we weren't exposed to the issue of spirituality. There were religion courses at the Catholic University, which is customary, but nothing about spirituality and reflecting on it in any moment, course or content (P3).*

## DISCUSSION

Caring for patients in an end-of-life process needs to be given as much importance as the care given to help a patient recover from a heart attack, since death is a part of life. The provision of dignified care, meeting all the health needs of the patient and family, is a way in which palliative care professionals can develop a work process focused on dying well, i.e., with a minimum amount of suffering and without pain to the patient and family<sup>(15)</sup>.

In this palliative care setting, professionals operate in an environment permeated with pain, anguish, and questions.

This team, comprised of professionals from a wide variety of specialties, requires skills over and above technical ones, since mutual help is necessary, each one leveraging the other, and all working for the benefit of patients and their families<sup>(16)</sup>.

Caring for people in terminal stages forces professionals to reflect on their attitudes and understanding of things and, consequently reassign meaning to their practices. As a result, they come to see that death is a natural event in life and that a multiprofessional approach can provide greater quality of life and comfort for patients and family members. To achieve this, it is necessary to build bonds between professionals and palliative care patients, so that they can share stressful situations, which causes suffering among workers, yet also results in satisfaction and professional realization, when they promote humanized care, which is the heart of palliative care<sup>(2)</sup>.

The normal healthcare model is reoriented in palliative care, since it is recognized that the needs, desires, and outlooks of patients in the terminal stages of a disease change; for this reason, the care given to them must also be consistent with their needs. In all of this, spirituality is one of the dimensions that govern this specialized care. It is considered relevant in palliative care since it is able, among other things, to encourage greater reflection on and acceptance of death – which is often the greatest paradigm to be faced by people experiencing cancer and the end of life. This often imbues the work of palliative care teams with meaning<sup>(17)</sup>.

Palliative care workers are also confronted with their own mortality when dealing with a patient who is dying, such that spirituality can impart meaning to their palliative care work. As the participants mentioned, a relationship of empathy is able to synergistically empower professionals to meet the needs of the human being they are caring for. In Frankl's view, individuals, even in the face of death, can discover a positive meaning for the suffering resulting from an illness, through an explanation for the circumstances in which they find themselves, by focusing on life experiences and future life projections, instead of pointless suffering<sup>(9)</sup>. From this perspective, professionals will perhaps be able to understand the situation of suffering arising from a patient's disease, and will also seek to help the latter to understand this end-of-life process.

Therefore, it is important that awareness is raised among interdisciplinary teams to encourage the practice of spirituality in palliative care, recognizing that it has various meanings for people who are ill, and also answers questions regarding their own existence. It is necessary for health professionals to recognize and assign value to the dimension of spiritual care of patients as a tool that promotes quality of life for people receiving palliative care<sup>(18)</sup>. In this sense, it is recognized that spirituality is present in the daily lives of individuals, throughout the entire human existence<sup>(19)</sup>.

The spiritual dimension is often part of people's lives in their search for answers, relief from suffering and motivation<sup>(20)</sup>. However, the spirituality of health workers also permeates the palliative care environment, since caring for people is a human experience and, thus, requires care that extends beyond that which is visible.

Based on the understanding that the spiritual dimension is part of the comprehensive care of human beings, theoretical support was sought in the work of Frankl. He saw the need for a different conception of people and the world than that offered by the traditional psychotherapies in his time, in order to structure a theory and practice that would include human beings in their totality and human singularity<sup>(9)</sup>. Over the course of developing his approach, he strove for the recognition of the humanity potentially present in individuals. His pursuit was the humanization of health practices based on reassigning meaning to the concept of humanism, by adding an eminently existential quality. He understood that the totality of human beings would only be achieved through inclusion of the spiritual dimension, representing their true legacy, value, and importance within the approach of the meaning of life<sup>(21)</sup>.

As professionals assist people with life-threatening diseases, i.e., when working within the realm between life and death, they must have tools other than merely technical ones, such as culture, art, among others. They must assume a moral and ethical attitude toward the pain and suffering of others, providing humanized care, as set forth in the precepts of the Hippocratic tradition<sup>(22)</sup>.

One of the tools mentioned by the study participants was prayer. Praying can encourage optimism among patients as they cope with their diseases, through contact with their innermost self, leading to a belief in control over one's self, mind and body<sup>(23)</sup>. This may also reflect the search for meaning in life, which accompanies human existence. A common symptom nowadays is the frustration of this need. When logotherapy was developed, it also sought to draw theory and practice closer together in a harmonious way, in an effort to humanize medicine through the clinical relationship. This required being mindful of all the dimensions of the human personality, where the spiritual dimension would not be affected by the physical illness, but would serve as a support for the other dimensions of the person<sup>(10,24)</sup>.

To provide professional care from a humanized perspective, which considers human beings in their totality, it is essential to take a look at the academic education in health. In Brazil, training in medicine and other courses in the area of health is poor in curricular terms for addressing death. Students are not prepared to deal with these aspects, leading to dehumanization in the end-of-life care of patients. The exclusion of death from health education hinders and incapacitates professionals who will care for terminal patients<sup>(22)</sup>.

The sense of their own spirituality and understanding that spirituality is a facilitator in stressful situations is crucial for these professionals, making it important to integrate this aspect into care practices. However, even though professionals recognize the importance of care in the spiritual dimension, there are frequent difficulties in providing this care, mainly due to lack of knowledge and discomfort in broaching the subject. This leads to care being based more on the biological needs of patients<sup>(25)</sup>.

Therefore, education in the area of health leaves much to be desired due to the strong objective focus and, as a result, many professionals still have difficulties addressing religious

and spiritual issues. However, there is currently a growing trend to incorporate spiritual and philosophical dimensions into health care<sup>(26-27)</sup>.

At the international level, there are greater efforts to build a connection between spirituality and health education. Courses on spirituality have been included in most of the curricula of North American universities in recent years. In line with this trend, more than half of the health schools in Britain have courses related to spirituality. The University of Massachusetts also established a required course on medicine and spirituality for all residents. Through theoretical and practical classes, residents learn, based on spiritual history, to recognize spiritual problems. This requires understanding the basic principles of all religions and participating in the care provided by local pastoral leaders. Due to the success of the course, it has remained on the program until the present<sup>(28)</sup>.

In Brazil, there are still few undergraduate courses with a curricular approach to spirituality and health. Insufficiencies for developing competencies in spiritual care were identified in a study with nursing students<sup>(29)</sup>, in addition to the fact that the search on the subject was not evidence-based. In another study, nursing and medical students, through a course entitled Spirituality and Health at the Universidade Federal de São Paulo, noted the inclusion of care practices that value human beings from a humanistic standpoint, based on sensitivity and empathy toward patients, with possibilities of providing care in terminal situations beyond the biomedical model<sup>(30)</sup>.

In this sense, comprehensive care of people and caregivers surpasses the biomedical model, which still prevails in health services, by incorporating palliative principles and practices in health teams to enhance people's quality of life. For this reason, it is essential for health professionals to understand and practice spirituality in order to provide comprehensive care<sup>(17)</sup>. Patients demonstrate needs to be understood in their wholeness, and not merely as isolated examples of diseases. This wholeness includes the spiritual dimension which is understood to be the only dimension that will not be affected by death<sup>(9)</sup>.

Finally, it should be noted that health professionals often do not search for spirituality throughout their lives, with the understanding that this is considered a personal matter. When workers start caring for the spiritual dimension of a person receiving palliative care, this represents a deeper understanding of their beliefs and values, enabling professionals to better satisfy the health needs of patients, in their totality.

Therefore, in view of the difficulties cited by the team resulting from the failure to address spirituality and palliative care in academic health education, it is hoped that the present study will help foster the development of skills, knowledge, and attitudes of health professionals in relation to aspects that go beyond physical, social and psychological needs, and that consider spirituality in healthcare actions. Limitations for generalizing the findings of this study are related to the number of participants, the investigation of only one palliative home care service and the fact that spirituality can be considered a taboo in the field of health. More studies are certainly needed on this topic.

## CONCLUSION

The spirituality exercised by health professionals in their care of patients was beneficial in coping with cancer and dealing with the conflict between life and death, in addition to facilitating the creation of bonds with palliative care patients and their families. Through the findings of the study, it was possible to affirm that spirituality-related actions, such as prayer and the provision of comprehensive care, impart meaning to the work of palliative care professionals, since they involve the end-of-life process of individuals and seek to humanize death, i.e., provide a dignified death.

The professionals also pointed out that patients serve as a mirror for their own mortality and, if health workers are open to listening and sharing distress, they will be able to understand the process that patients are undergoing and facilitate the search for meaning in the suffering arising from illness. However, professionals who are unable to deal with their own issues regarding death will have greater difficulty dealing with the death of another person and will seek to somehow distance themselves from it. This will be manifested by fragmenting patients into organs or referring to them by their disease or physical symptoms.

## RESUMO

**Objetivo:** Compreender a experiência vivida da espiritualidade no cotidiano da equipe interdisciplinar que atua em cuidados paliativos. **Método:** Estudo qualitativo realizado com uma equipe de cuidados paliativos oncológicos do sul do Brasil. Os dados foram coletados por entrevista fenomenológica, em 2014, e interpretados com a abordagem fenomenológica hermenêutica. **Resultados:** Participaram seis profissionais. As ações relacionadas à espiritualidade, como o ato de orar e a prestação de cuidados integrais, foram recursos terapêuticos úteis para a oferta de conforto, sobrevida digna e humanização da morte, auxiliando a equipe e os pacientes na compreensão do processo de terminalidade e na busca de sentido no sofrimento advindo do adoecimento. **Conclusão:** A espiritualidade exercida pelos profissionais junto aos pacientes propiciou sentido ao seu trabalho em cuidados paliativos, mostrando-se um facilitador na formação de vínculos entre equipe, paciente e sua família.

## DESCRITORES

Espiritualidade; Cuidados Paliativos; Enfermagem Holística; Equipe de Assistência ao Paciente; Existencialismo; Relações Profissional-Família.

## RESUMEN

**Objetivo:** Comprender la experiencia vivida en el cotidiano de un equipo interdisciplinario que actúa en cuidados paliativos. **Método:** Estudio cualitativo realizado con un equipo de cuidados paliativos oncológicos del sur de Brasil. Los datos fueron recolectados por entrevista fenomenológica, en 2014, e interpretados con el abordaje fenomenológico hermenéutico. **Resultados:** Participaron seis profesionales. Las acciones relacionadas con la espiritualidad, como el acto de orar y la prestación de cuidados integrales, fueron recursos terapéuticos útiles para la oferta de confort, supervivencia digna y humanización de la muerte, auxiliando al equipo y a los pacientes en la comprensión del proceso de terminalidad y en la búsqueda de sentido del sufrimiento advenido del hecho de enfermarse. **Conclusión:** La espiritualidad ejercida por los profesionales junto a los pacientes proporcionó sentido a su labor en cuidados paliativos, mostrándose un facilitador en la formación de vínculos entre equipo, paciente y su familia.

## DESCRIPTORES

Espiritualidad; Cuidados Paliativos; Enfermería Holística; Grupo de Atención al Paciente; Existencialismo; Relaciones Profesional-Familia.

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