

Expressing spirituality in palliative care: a narrative review

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Abstract

End of life requires a comprehensive approach to relief physical, emotional, family and social pain, addressing spiritual issues as a way to ensure patients all sources of comfort. Given this scenario, this narrative literature review discusses the effects of spirituality/religiosity in palliative care. Based on a manual search for papers in the PubMed and Virtual Health Library databases, 11 articles were selected for the review. The discussions were divided into three axes: spirituality of terminally ill patients, spirituality of health professionals and spirituality of family members. In conclusion, spiritual practices during the end of life and in coping with anguish are crucial both for patients and their families and for professionals.

Keywords: Integrative palliative care. Spirituality. Religion. Palliative medicine.

Resumo

Expressão da espiritualidade nos cuidados paliativos: revisão narrativa

A terminalidade da vida requer uma abordagem ampla, com o alívio das dores física, emocional, familiar e social. Ademais, questões espirituais devem ser abordadas como forma de garantir ao paciente todas as fontes de conforto. Em vista disso, esta revisão narrativa da literatura tem o intuito de discutir os efeitos da espiritualidade/religiosidade nos cuidados paliativos. A partir de uma busca manual de trabalhos nas bases PubMed e Biblioteca Virtual em Saúde, foram selecionados 11 trabalhos para a revisão. As discussões foram divididas em três eixos: espiritualidade dos pacientes terminais, espiritualidade dos profissionais da saúde e espiritualidade dos familiares. Conclui-se que as práticas espirituais durante o fim da vida e no enfrentamento das angústias são cruciais tanto para pacientes e familiares quanto para os profissionais.

Palavras-chave: Cuidados paliativos integrativos. Espiritualidade. Religião. Medicina paliativa.

Resumen

Expresión de la espiritualidad en los cuidados paliativos: una revisión narrativa

El final de la vida requiere un enfoque amplio, con alivio del dolor físico, emocional, familiar y social. Además, las cuestiones espirituales deben abordarse como forma de ofrecer confort al paciente. En este contexto, esta revisión narrativa de la literatura tiene como objetivo discutir los efectos de la espiritualidad/religiosidad en los cuidados paliativos. A partir de una búsqueda de artículos en PubMed y en la Biblioteca Virtual de Salud, se seleccionaron 11 artículos para la revisión. Los debates se dividieron en tres ejes: espiritualidad de los pacientes terminales, espiritualidad de los profesionales sanitarios y espiritualidad de los familiares. Se concluye que las prácticas espirituales durante el final de la vida y en el afrontamiento de la angustia son cruciales tanto para los pacientes y sus familias como para los profesionales de la salud.

Palabras clave: Cuidados paliativos integrativos. Espiritualidad. Religiión. Medicina paliativa.

The authors declare no conflict of interest.

Much has already been discussed about the interference of spirituality and religiosity in the health-disease process. Spirituality is understood as a comprehensive belief in a superior being that influences human life in its various aspects; religiosity consists of the guidance and direction of that belief. The benefits attributed to spirituality/religiosity during illness may be associated with the assistance provided by support networks, especially for people who are members of religious groups. In addition, religious people are encouraged to express positive feelings such as love, forgiveness and peace, and curb negative feelings like fear, worry and sadness¹.

Palliative care, an approach that has been growing, is based on principles that aim to improve the quality of life of those suffering from a life-threatening condition. This approach seeks to assess and treat physical (mainly pain), emotional, family, social and spiritual issues. It should be noted that, in an unprecedented way in the area, spirituality came to be seen as a human dimension that is worthy of care and attention².

According to the World Health Organization (WHO), multidisciplinary teams should be guided by the following principles: providing relief from pain and uncomfortable symptoms, considering the concept of total pain; viewing death as a natural process of life; privileging orthothanasia, without speeding up or postponing death; including psychological and spiritual aspects in care management; providing autonomy and preservation of activity until the moment of death, when possible. Moreover, the team should help family members cope with the illness and subsequent grieving process; adopt a multidisciplinary approach in order to offer comprehensive care; and provide improved quality of life. Palliative care should be started early, along with other treatments³.

These principles show the importance of also considering spiritual aspects in end of life. In order to avoid spiritual suffering, based on the principle of total pain relief, spirituality should be included as yet another vital sign⁴. Some feelings are associated with spiritual distress, such as hopelessness, lack of meaning, disappointment and remorse, and are commonly manifested at the end of life, which attests to the relevance of

paying attention to this aspect, along with other kinds of care⁵.

The goal of this review is to analyze, based on the literature, the effects of spirituality and religiosity on palliative care and coping with death. It considers the patient's view and the perspective of families who have a loved one at the end of life, and evaluates the means of incorporating this approach into the work of multidisciplinary teams.

Method

In accordance with the goal of this work, a narrative review of the literature was undertaken in order to discuss the proposed subject in an expanded and descriptive manner. Non-systematic searches were carried out in the PubMed and Virtual Health Library (VHL) databases from December 2022 to February 2023. The following descriptors were used, in English and Portuguese, plus the Boolean operators "and" and "or": *cuidados paliativos integrativos/integrative palliative care*, *espiritualidade/spirituality*, *religião/religion*. The intention with this search was to answer the question: what are the effects of the expression of spirituality in palliative care?

Studies in Portuguese and English in the field of medical knowledge were considered and other literature reviews were excluded. Despite being an arbitrary selection of articles, subject to bias, it was decided to develop a narrative review, precisely for providing freedom for the debate on such an essential topic. Eleven articles were ultimately selected, which will be presented, discussed and compared with the current literature on the subject of spirituality in palliative care.

Therefore, for didactic purposes, the results and discussions of the topics were divided into the following sections: "Spirituality of terminally ill patients"; "Spirituality of healthcare providers"; and "Spirituality of family members."

Results and discussion

Spirituality of terminally ill patients

The distinction between the concepts of spirituality and religiosity is significant and most people consider themselves spiritual rather than

religious⁶. However, an episode of suffering increases the inclination to turn to religious or spiritual sources for support, hope and comfort. Often religion itself provides tools for facing the challenges of a health problem: religious writings provide guidance and religious leaders help patients find a new perspective to deal with such situations. In addition, non-religious people may suffer from more acute psychological stress than those who have a strong spiritual identity⁷.

For palliative care providers, these practices play an important role in interdisciplinary support in end of life⁸. However, unlike other types of interventions such as pharmacological treatment, it is difficult to dose or balance spiritual support, as well as its benefits—which contradicts some of the dictums of Western medicine⁷. In this case, integrative medicine should know how to act in relation to the healing process and relief of suffering, based on the spiritual help sought by the patient.

In religious terms, the concepts of spirit and soul have similar interfaces and many religions prevalent in the West refer to these concepts as a metaphysical, eternal and incorruptible part of the “self.” In contrast, Buddhist practices recognize the cycle of birth, suffering, death and rebirth, with the “spirit” represented by a force that transcends death and moves on to other lives. Hinduism, in turn, also relates the eternal metaphysical to the so-called *Ātman*, an inner essence⁷.

These should be points of interest for healthcare providers and their areas of activity: spiritual care for patients is probably convergent with their belief and may benefit them on a spiritual level, even when biological cure is not possible⁹.

Paiva and collaborators¹⁰ did an observational study to analyze the influence of religious practice on the quality of life of women undergoing breast cancer treatment in a hospital in the interior of the state of São Paulo. They found a positive association between religiosity, especially in the presence of prayer, and acceptance of body self-image, a common challenge among breast cancer patients.

Moreover, prayer was related to an improvement in emotional and cognitive functioning and the maintenance of quality of life, without worsening symptoms that usually affect non-religious patients.

It is concluded that religious practice may influence resilience to chemotherapy treatment, reducing patients' vulnerability.

King and collaborators¹¹ also carried out a study with patients with terminal cancer to assess whether spirituality is related to lower rates of distress and depression and reduced prescription of painkillers and antidepressants. They used the beliefs and values scale, which makes it possible to determine the nature and strength of the belief, and found no significant relationships between the variables, which was explained by the psychological stress caused by death, which may not be overcome by spiritual beliefs. A limitation of this study was the lack of analysis of the influence of religious practices.

Finally, the study by Balboni and collaborators¹² also resulted in a few reservations about the support of religious communities to patients undergoing end-of-life care. They suggest that these groups tend to emphasize belief in miracles, as well as sanctification through suffering, which may influence the acceptance of more aggressive medical therapies. However, this study noted an initial improvement in patients' quality of life and existential well-being resulting from spiritual support. As a way of resolving this impasse, the authors stress the importance of spiritual support coming from the medical team, since they are better prepared to deal with end-of-life situations and thus may avoid an increase in more aggressive treatment.

Spirituality of healthcare providers

As we have seen, it is important that the healthcare staff should know how to address spirituality and religiosity. Also from this perspective, Longuiniere, Yarid and Silva¹³ analyzed, in an intensive care unit in Bahia, the influence of the spirituality of health professionals in understanding the health-disease process, investigating whether belief modifies how care is provided to critically ill patients. They observed that, as this dimension is associated with well-being and appreciation of others, providers with greater spirituality are able to establish a greater connection with patients and other colleagues.

These relationships, in turn, improve decision-making and reduce stress in the work environment.

Despite the importance of these issues, one notes that many professionals neglect them or feel unprepared to address them¹³.

Also, O'Brien and collaborators¹⁴ developed a study that offered training on spirituality for nurses and healthcare providers dealing with patients in palliative care. The course included topics on recognizing spirituality, its meaning and the importance of differentiating it from religiosity. Moreover, to support patients' spiritual needs, it offered classes on recognizing spiritual stress and developing communication skills. The participants showed greater confidence in dealing with such topics and more ability to offer holistic care, without neglecting spiritual issues that were previously avoided.

The study by Van Meurs and collaborators¹⁵ provided training in communication for doctors and nurses of a palliative care team to explore the spiritual dimension in care. With the use of patient actors, this approach obtained good results for being closer to clinical practice. One of the strengths of the work was also encouraging the description of these non-somatic aspects in the medical records of the "patients," which contributes to applying the lessons in the multidisciplinary team's everyday routine.

Lastly, the study by Pessagno, Foote and Aponte¹⁶ explores the experiences of medical students in coping with the loss of their patients. The grieving mechanisms were diverse: talking about their feelings, building self-confidence to continue the course, crying, engaging in rituals and doing religious activities. As a result, almost the entire sample expressed some degree of stress when faced with the death of patients, especially in cases of children and professional errors in medical decisions.

Furthermore, the part of the sample that relied on religion as a grieving mechanism admitted that this exercise involved the thought of possibly seeing loved ones again. They acknowledged that religion helped them feel less incapable in their medical activity, besides enhancing their desire to help patients with chances of improvement.

Spirituality of family members

Miqueletto and collaborators¹⁷ interviewed several families with a member in an end-of-life condition in order to analyze the influence

of spirituality and religiosity in coping with this process. They reported that having the opportunity to talk about these issues gave them strength to get through this situation. For the family members, faith gives them hope that the patient will get better at some point, which highlights the importance of addressing this dimension also with the patient's family, given the reports that medical staff are generally unavailable to do so.

With the aim of examining the relationship between spirituality and illness in the reports of families with a sick family member, Bousso and collaborators¹⁸ concluded that certain religious beliefs and practices helped in coping with illness and death, while others made it more difficult to accept the situation. Adaptation and adjustment to suffering were facilitated in faiths that believed in the continuity of life after death. On the other hand, families who viewed the disease as punishment for or consequence of the patient's actions were more resistant to the guidance of medical care.

The study also identified that religious institutions responded to the search of family members for emotional support and answers. However, often the explanation given by a religion did not answer all the family's questions, leading them to look for more convincing explanations in other religious sources.

Puggina and Silva¹⁹, in analyzing messages from family members to patients with consciousness disorders in a previous clinical trial, found ways of coping through spirituality. They were divided into five thematic categories: faith in a divine influence as an outcome; prayer as a comforting strategy; faith as necessary for healing; divine intercession in the recovery of the loved one; and request for blessing and deliverance to the patient.

In these cases, one observes the strategy of outsourcing responsibility for the suffering family member due to human incapacity to cope with end of life. The resulting spirituality helps the family face these situations with more sobriety and offer patients social support even if they are not able to exercise their own spiritual activity.

Final considerations

In short, it is observed that spiritual or religious practices are essential when coping with end of life. Therefore, it is understood that terminally ill patients

require support in the spiritual sphere and, therefore, palliative care providers should be involved with these issues. In addition, based on evidence from the literature, one notes that healthcare providers with training to engage in communication about spirituality were able to connect more deeply with their patients, offering comprehensive care.

Moreover, a distinguishing feature of this review is the approach to the effects of spirituality

in the family's process of coping with disease and grieving. Such support proved to be effective for both people who are close to terminally ill patients and the patients themselves, who feel more reassured. This shows that new studies related to this dimension of medical care are required for providers to be prepared and willing to meet the particular needs of terminally ill patients also in the spiritual sphere.

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Both authors contributed to all the steps in the production of the article.

Received: 3.9.2023

Revised: 7.13.2023

Approved: 9.20.2023