

## Palliative care and spirituality: an integrative literature review

*Cuidados paliativos e espiritualidade: revisão integrativa da literatura*

*Cuidados paliativos y espiritualidad: revisión integrativa de literatura*

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### ABSTRACT

**Objective:** to analyze scientific articles published in international online journals about palliative care and spirituality. **Methods:** an integrative literature review with data collected in September 2014 from the LILACS, SCIELO, MEDLINE/PubMed, and IBICS databases. **Results:** thirty-nine publications were identified and their textual analysis facilitated through four thematic approaches: the meaning of spirituality in the context of palliative care; palliative care and spiritual support; spirituality and relief of pain and other symptoms in patients under palliative care; and instruments to evaluate the spiritual dimension of the scope of palliative care. **Conclusion:** this study examined the relevance of the spiritual dimension in the care of patients with palliative care and the need for developing new studies to disseminate knowledge about this topic.

**Descriptors:** Palliative Care; Palliative Care at End of Life; Spirituality; Religion; Health.

### RESUMO

**Objetivo:** analisar artigos científicos disseminados em periódicos *on-line* no cenário internacional acerca da temática cuidados paliativos e espiritualidade. **Métodos:** revisão integrativa da literatura, com coleta de dados no mês de setembro de 2014, nas bases de dados LILACS, SCIELO, MEDLINE/PubMed, IBICS. **Resultados:** foram identificadas 39 publicações, cujas análises textuais permitiram a construção de quatro abordagens temáticas: significado da espiritualidade no contexto dos cuidados paliativos; cuidados paliativos e assistência espiritual; espiritualidade e alívio da dor e de outros sintomas que acometem pacientes sob cuidados paliativos; e instrumentos de avaliação da dimensão espiritual no âmbito dos cuidados paliativos. **Conclusão:** estudo verificou a relevância da dimensão espiritual durante a assistência de pacientes assistidos por meio de cuidados paliativos e a necessidade do desenvolvimento de novos estudos para disseminar conhecimento sobre o tema.

**Descritores:** Cuidados Paliativos; Cuidados Paliativos na Terminalidade da Vida; Espiritualidade; Religião; Saúde.

### RESUMEN

**Objetivo:** analizar artículos científicos diseminados en revistas *on-line* en el escenario internacional, acerca de la temática 'cuidados paliativos y espiritualidad'. **Método:** revisión integrativa de literatura, con recopilación de datos durante el mes de septiembre de 2014, con las bases de datos LILACS, SCIELO, MEDLINE/ PubMed, IBICS. **Resultados:** fueron identificadas 39 publicaciones, cuyos análisis textuales permitieron la construcción de cuatro enfoques temáticos: significado de la espiritualidad en el contexto de los cuidados paliativos; cuidados paliativos y asistencia espiritual; espiritualidad y alivio del dolor y de otros síntomas que acometen a pacientes bajo cuidados paliativos; e instrumentos de evaluación de la dimensión espiritual en el ámbito de los cuidados paliativos. **Conclusión:** este estudio verificó la relevancia de la dimensión espiritual durante la asistencia de pacientes asistidos por medio de cuidados paliativos y la necesidad del desarrollo de nuevos estudios para diseminar conocimiento sobre el tema.

**Descriptor:** Cuidados Paliativos; Cuidados Paliativos al Final de la Vida; Espiritualidad; Religión; Salud.

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## INTRODUCTION

In face of the need to consider individuals as holistic beings, health has moved away from the concept that restricted it to absence of disease, with healing as the main objective, toward looking at individuals as a whole. This way, the concept of health incorporated other dimensions in addition to the biological one, such as psychological, social, and spiritual dimensions, as recommended by palliative care guidelines<sup>(1)</sup>.

Palliative care is defined as active and integral care oriented to patients with diseases that no longer respond to healing therapies, and it aims to improve the lives of those individuals and their family members by relieving pain and biopsychosocial and spiritual issues<sup>(1)</sup>. It is a specialized approach that assists individuals in living and facing death in the best way<sup>(2)</sup>.

Palliative care must cope with a wide range of needs; however, spirituality is considered to be the most urgent one for patients with potentially lethal diseases, because of their situation of hopelessness in the face of death and the fear of the unknown<sup>(3)</sup>.

In this context, spirituality and religiosity must be distinguished, since these terms are typically used as synonyms and may be confused by those experiencing the disease process, their family members, and professionals. Spirituality refers to personal attempts to understand final questions about life and their relation to the sacred and transcendent, which can lead (or not) to the development of religious practices. Religion, in turn, corresponds to an organized system of beliefs, practices, rituals, and symbols aimed at facilitating closeness between individuals and the sacred or transcendent. Religiosity, in turn, is the most basic level of religion and concerns the extent to which individuals believe, follow, and practice a given religion<sup>(4)</sup>.

Patients can seek out spirituality as a way to cope with diseases, to minimize their suffering, or to expand their hope of cure with a therapy<sup>(5)</sup>. Many studies<sup>(3,6-7)</sup> emphasize the important role of spirituality in coping with diseases at advanced stages and in improving the well-being of patients with serious or terminal diseases. A survey of inpatients of a palliative care unit showed that proper spiritual support has positive impacts on patients and their family members regarding the end-of-life process, helping them to face the finitude process<sup>(3)</sup>. This kind of study warns health professionals to be ready to meet the needs of patients under palliative care in an integral and humanized way, through actions that ensure death with dignity and proper control of physical, psychological, social, and spiritual symptoms<sup>(6)</sup>.

The importance of recognizing spirituality as a strategy to deal with and identify patients' needs is that it assists health professionals, notably nursing professionals, to plan quality support and deliver integral care to patients<sup>(5)</sup>.

However, it is worth mentioning that although spiritual support is a therapeutic resource of utmost relevance in the care of these patients, it is still disregarded by health professionals<sup>(9)</sup> because of their lack of preparedness and the difficulty of meeting the patients' spiritual needs, evidenced by their lack of knowledge and information about the topic<sup>(10)</sup>. New investigations on this topic are needed to contribute to building knowledge about palliative care and spirituality and

generate input for health professionals so they can be more confident when providing support to terminal patients.

In face of the aforementioned, the objective of this survey was to analyze scientific articles published in international online journals about palliative care and spirituality.

The study of this topic is of utmost relevance to the field of health because it can lead professionals to consider the need to support patients' spiritual dimension and find alternative therapies that enable them to recover health, and to demand assistance to relieve their spiritual suffering. Likewise, it could support new investigations about the topic, since this dimension still lacks deeper exploration in an academic light.

## METHOD

An integrative literature review is a research method of great relevance in the health field because it enables a search, critical evaluation, and summary of evidence about a given topic. These aspects facilitate the identification of relevant results and gaps that direct the development of further research, and also assist professionals in selecting conducts and making decisions, by providing critical knowledge<sup>(11)</sup>.

This review followed a six-stage methodological path: elaboration of the guiding question; definition of criteria for inclusion and exclusion and for the literature search; definition of information to be extracted from the selected studies; evaluation of the included studies; result interpretation; and review disclosure<sup>(11)</sup>. The following guiding question was defined for this study: What is the existing international scientific production on the topic of palliative care and spirituality?

The bibliographic survey was conducted through an electronic search in the following databases available at the Virtual Health Library: the Latin-American and Caribbean Center on Health Sciences Information (LILACS), the U.S. National Library of Medicine (MEDLINE/PubMed), and *Índice Bibliográfico Español de Ciencias de la Salud* (IBECS), as well as in the Scientific Electronic Library Online (SciELO).

Regarding the inclusion criteria, full articles electronically available in Portuguese, English, and Spanish from January 2005 to July 2014 approaching the topic in the title, abstract, or descriptors were selected. The following were the exclusion criteria: letters to the editor; case reports; editorials; duplicated articles; articles published in languages other than Portuguese, English, or Spanish prior to 2005; and those not approaching the topic directly.

Articles were surveyed in September 2014, using the following health sciences descriptors (DeCs) as investigation criteria: palliative care AND spirituality OR cuidados paliativos AND espiritualidade OR cuidados paliativos AND espiritualidad.

After selecting articles, the information to be extracted from the studies was defined. The software used was Microsoft Office Excel 2010, and the following variables were extracted: article title, year of publication, country, database, journal name, study outline, abstract, intervention, outcome, and conclusion. Data obtained were pooled in charts and thematic approaches, being read based on literature.

**RESULTS**

The study comprised 540 publications related to the topic being investigated, of which 39 were part of the sample because these met the inclusion criteria. Most of the publications (28.21%) dated back to 2011. The countries producing the most articles on this topic were the United States (23.08%) and Brazil (17.95%). Most of the studies (35.90%) were reviews and came from the MEDLINE/PubMed database (74.36%).

*The Journal of Palliative Medicine* presented the most articles about the topic (12.82%). The journal deals with issues related to end-of-life care, thus explaining the number of publications found there. The full distribution of articles selected for this review is presented in Box 1.

**DISCUSSION**

After reading the studies selected for this review and pooling the information, four thematic approaches were established: I: the meaning of spirituality in the field of palliative care; II: palliative care and spiritual support; III: spirituality and relief of pain and other symptoms that affect patients under palliative care; and IV: instruments to evaluate spiritual dimensions in the field of palliative care.

**Thematic approach I - The meaning of spirituality in the field of palliative care**

Spirituality is a multidimensional concept that comprises the search for meaning in life and transcendence<sup>(12-14)</sup>. It can be related to faith in God or in another superior power<sup>(13,15)</sup>. It

**Box 1** – Distribution of studies included in the integrative review according to title, year, country, outline, intervention, and outcome

Title	Year/country	Outline	Intervention	Outcome
Spirituality and religiosity in palliative care: learning to govern	2014 Brazil	Review n = 6 books and 1 handbook	Speeches about R/S	Literature approaches R/S as part of the PC
<i>Cuestionarios de evaluación e intervención espiritual en cuidados paliativos: una revisión crítica</i>	2014 Spain	Review n = 57 instruments	Evaluation of instruments approaching spirituality employed in the PC	There are limitations to instruments.
“To Cherish Each Day as it Comes”: a qualitative study of spirituality among persons receiving palliative care	2013 Iceland	Qualitative, phenomenological n = 10 patients	Meaning of spirituality according to patients under PC	Spirituality is considered to be important and can involve religion or not.
Spirituality in palliative home care: a framework for the clinician	2013 Belgium	Qualitative n = 35 experts	Identification of spiritual support elements in the context of palliative home care	It identified 14 elements of spiritual support.
Spiritual coping and anxiety in palliative care patients: a pilot study	2013 USA	Pilot study n = 31 patients	Link between spiritual coping and anxiety	Anxiety was inversely related to coping (P < 0.01).
Atención espiritual em cuidados paliativos. Valoración y vivencia de los usuarios	2013 Spain	Quantitative, descriptive, comparative of a cross-sectional cohort n = 1 patient, 55 caregivers	Perception of patients under PC and caregivers about spiritual support	Spiritual support helps to give hope (88%), comfort (83%) and meaning (79.1%).
GPs’ views concerning spirituality and the use of the FICA tool in palliative care in Flanders: a qualitative Study	2012 Belgium	Qualitative n = 23 general practitioners	Verification of points of view about the FICA for spiritual evaluation	The FICA could be a feasible instrument to evaluate spirituality.
Can Spirituality Be Taught to Health Care Professionals?	2012 Australia	Quantitative, longitudinal n = 113 professionals	Evaluation of workshops to improve the PC team’s knowledge about spirituality	Increase was observed for spirituality, spiritual support, and trust after the workshops (p < 0.001).

To be continued

Box 1

Title	Year/country	Outline	Intervention	Outcome
Spirituality and spiritual caring: nurses' perspectives and practice in palliative and acute care environments	2012 Australia	Quantitative, cross-sectional n = 42 PC nurses and 50 intensive care nurses	Link between caring and the spiritual perspective	There was a link between caring and the spiritual perspective ( $p = 0.02$ ).
What can we learn about the spiritual needs of palliative care patients from the research literature?	2012 United Kingdom	Review n = 35 studies / 1,374 patients	Evidence about the spirituality of patients under PC	There was a prevalence of studies with reductive representations of spirituality.
The "Spirit 8" successfully captured spiritual well-being in African palliative care: factor and Rasch analysis	2012 England	Quantitative, cross-sectional n = 285 patients	Evaluation of spiritual well-being of patients under PC	Being a patient from Uganda ( $p = 0.002$ ) or having HIV ( $p = 0.002$ ) was associated with a lower well-being.
The role of spirituality and religious coping in the quality of life of patients with advanced cancer palliative radiation therapy	2012 USA	Quantitative, cross-sectional n = 69 patients	Characterization of R/S and religious coping	Most of the participants (84%) use R/S to deal with the disease.
The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit	2011 USA	Quantitative n = 113 patients	Analysis of factors associated with spiritual distress	Distress was associated with age (OR = 0.96, $P = 0.012$ ) and depression (OR = 1.27, $P = 0.020$ ).
Spirituality, distress, depression, anxiety, and quality of life in patients with advanced cancer	2011 India	Quantitative, descriptive, cross-sectional n = 50 patients	Influence of spiritual well-being on distress and depression	It showed a negative association between distress, sadness, depression, anxiety, and spiritual well-being ( $p < 0.005$ ).
A psychometric evaluation of measures of spirituality validated in culturally diverse palliative care populations	2011 England	Review n = 191 articles, 85 instruments	Evaluation of instruments approaching spirituality in PC	No instrument met all the psychometric criteria.
The central importance of spirituality in palliative care	2011 England	Review n = not informed	Evaluation of the importance of spirituality in PC	Spirituality is crucial in cases of terminal disease.
Perspectives on spiritual support at Hospice Africa Uganda	2011 Africa	Qualitative, phenomenological n = 15 professionals	Understanding spiritual support in the African context.	Financial resources and beliefs were regarded as harmful for spiritual support.
The measurement of spirituality in palliative care and the content of tools validated cross culturally: a systematic review	2011 England	Review n = 191 articles, 85 instruments	Evaluation of instruments that approach spirituality in PC	Nine instruments were validated in a cross-cultural way among PC populations.
Spirituality of parents of children in palliative care	2011 USA	Quantitative n = 121 parents of children with terminal diseases	Identification of factors associated with the spirituality of parents	Being married and having children with higher sight and hearing capacities were associated with higher spirituality ( $p < 0.05$ ).
Spirituality and end-of-life care in disadvantaged men dying of prostate cancer	2011 USA	Quantitative n = 35 men with prostate cancer	Association between spirituality and care received	Care of patients at the end of life was similar between men with higher or lower spirituality.
How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times	2011 USA	Qualitative, prospective cohort n = 64 parents of children under PC.	Role played by spirituality, religion, or philosophy with regard to parents	Religion, spirituality, and philosophy were relevant to help parents deal with the situation.

To be continued

Box 1

Title	Year/country	Outline	Intervention	Outcome
Meanings and practices of spirituality in the context of palliative care for adult cancer patients	2011 Brazil	Review n = 11 articles	Meanings and practices of spirituality in the PC context	Spirituality assists individuals in better coping with end-of-life situations.
Spirituality in the interdisciplinary team that works with palliative Care to cancer patients	2011 Brazil	Qualitative, descriptive, exploratory n = 8 professionals	Meaning of spirituality to the interdisciplinary team working in PC	Spirituality involved provision of integral and holistic care, and was related to faith.
La mejora de la calidad de los cuidados espirituales como una dimensión de los cuidados paliativos: el informe de la Conferencia de Consenso	2011 USA	Qualitative n = 40 leaders	Recommendations about the use of spirituality in PC.	Recommendations involve practices to implement spiritual support and integrate spirituality in therapy.
The understanding of spirituality and the potential role of spiritual support in end-of-life and palliative care: a meta-study of qualitative research	2010 United Kingdom	Review n = 19 articles, 178 patients, and 116 professionals	Summary about spirituality and spiritual support at the end of life	Several obstacles to spiritual support were found.
The spirit of palliative practice: a qualitative inquiry into the spiritual journey of palliative care physician	2010 Canada	Qualitative, descriptive n = 6 physicians working in palliative care	The influence of PC practice on spirituality and spiritual growth	Spirituality had an impact on care and growth that resulted from interaction with the patient.
Content and spiritual items of quality-of-life instruments appropriate for use in palliative care: a review	2010 Holland	Review n = 29 instruments	Evaluation of QOL instruments used in PC	It showed that 15 instruments approached the spiritual domain.
Impact of spirituality on palliative care physicians: personally and professionally	2009 Canada	Qualitative, phenomenological n = 10 physicians	PC physicians' understanding about spirituality	Understanding involved the concept of spirituality and its difference from religion.
Bienestar espiritual de enfermos terminales y de personas aparentemente sanas	2009 Colombia	Quantitative, descriptive, comparative n = 44 patients and 44 healthy individuals	Comparison between the spiritual well-being of individuals at the end of life and healthy individuals	Healthy individuals presented more spiritual well-being ( $p = 0.034$ ) and a higher existential component ( $p = 0.000$ ).
Measures of spiritual issues for palliative care patients: a literature review	2008 United Kingdom	Review n = 29 instruments	Evaluation of instruments that approach spirituality in PC	There were few spirituality instruments specifically for PC.
Spirituality and the care of patients at the end of-life: an essential component of care	2008 USA	Review n = not informed	Approach of PC and spirituality-related issues	Spirituality is crucial for treating terminal patients.
Analysis of the nature of spiritual pain in terminal patients and the resignification process through the relaxation, mental images and spirituality (RIME) intervention	2008 Brazil	Quanti-qualitative, phenomenological n = 11 terminal patients	Investigation about the new meanings of spiritual pain during the RIME application	The RIME has promoted peacefulness, dignity, and quality of life in the process of dying.
Incorporating spirituality and religiosity in pain management and palliative care	2007 Brazil	Review n = not informed	Strategies used in patients suffering from chronic pain related to R/S	There is a wide range of R/S strategies aimed at patients with chronic pain; however, they lack scientific evidence.
Training program about the therapeutical intervention "relaxation, mental images and spirituality" (RIME) for re-signify the spiritual pain of terminal patients	2007 Brazil	Quanti-quali, phenomenological n = 11 patients and 6 professionals	Evaluation of the training program for the RIME intervention	The training program proved to be efficacious to prepare health professionals to use the RIME intervention.

To be continued

Box 1 (concluded)

Title	Year/country	Outline	Intervention	Outcome
Collective soul: The spirituality of an interdisciplinary palliative care team	2006 Canada	Qualitative, self-ethnographic n = 20 professionals	A PC team's understanding about spirituality	Participants showed difficulty in defining spirituality.
A Thematic Review of the Spirituality Literature within Palliative Care	2006 Canada	Review n = 58 articles	Analysis of spirituality within the PC scope	Most of the discussions approach conceptual issues about spirituality.
Spirituality, psychotherapy and music in palliative cancer care: research projects in psycho-oncology at an oncology center in Switzerland	2005 Switzerland	Qualitative n = 135 patients with terminal cancer	Feasibility of music, psychotherapy, and spiritual support for patients with cancer	Music therapy, psychotherapy, and spiritual support provide essential methods to PC.
Spirituality and Distress in Palliative Care Consultation	2005 USA	Pilot study n = 31 patients	Link between spirituality, religious coping, and distress symptoms	Negative religious coping was associated with distress, confusion, and depression (P < 0.05).
New perspectives in palliative care: ethics, geriatrics, gerontology, communication and spirituality	2005 Brazil	Review n = not informed	Understanding the dimensions of life	The study emphasized the important role of spirituality in face of mortality.

Notes: PC = palliative care; R/S = religion/spirituality; QL = quality of life; Quanti-quali = quantitative-qualitative

is an inherent trait of human beings and refers to the search for transcendent meaning in life, which can take place through religion, art, music, nature, or solidarity. It is a component that assists individuals in discovering their true potential, being more self-confident, and having courage to love and forgive, enabling them to transcend suffering<sup>(16)</sup>.

Spirituality refers to a dynamic power that moves inside individuals and helps give sense to their personal life, history, and reality. It can be related to a transcendental power, a reality, and God. It is a resource to understand the self as a human being, or to deal with one's own suffering. In addition it can stand for a way of giving those suffering the hope to keep on living and deal with the awareness about finitude<sup>(17)</sup>.

In this light, spirituality is an important instrument for coping with hard situations. For patients under palliative care, it is a way of dealing with a terminal state with no distress because it reduces suffering and pain caused by incurable diseases. In this sense it can serve as a cover, a *palium* for patients with terminal diseases so they feel loved, covered by a welcoming mantle, and seek, in faith or in something transcendental, a way to improve their lives<sup>(17)</sup>.

This review aimed to get to know the meaning and practices of spirituality in the context of palliative care in the view of nurses, patients, and family members. The results showed different perceptions about the term "spirituality," especially the source of comfort among nurses and patients, and the source of healing and maintenance of health for family members<sup>(18)</sup>.

Two surveys carried out in Canada investigated the physicians' understanding about spirituality<sup>(13,19)</sup>. According to one study's findings,<sup>(13)</sup> the term is related to meaning in life, a belief in a superior being, a sense of belonging, and universality. Another study<sup>(19)</sup> conceived it as the power that on one hand assists patients with no perspective of any therapy that allows healing

of their illness and of keeping on living, and, on the other hand, assists health professionals in providing care to patients under palliative care. Both surveys showed the link between personal spirituality and the practice of palliative care.

In order to identify consensual points between spirituality and its application to health care and palliative care, a conference was held in the city of Pasadena, California (USA), in 2009. During the event, experts reached consensus about the definition of the term<sup>(20)</sup>.

Spirituality was defined as an aspect of the human condition related to seeking meaning in life and expressing a state of connection between the individual and the self (intrapersonal), others (interpersonal), nature, and the sacred (transpersonal)<sup>(20)</sup>. However, it is widely known that this term is different from religion, because religion is part of an organization with rules to be followed, involving celebrations and rituals, and it is one of the approaches used by individuals to express their spirituality<sup>(13)</sup>.

The literature is limited regarding the similarities between the descriptions of personal and professional experiences with spirituality. These descriptions can hardly be empirically investigated. Any definition of spiritual dimension is acceptable, because spirituality can comprise several aspects<sup>(21)</sup>.

In fact, spirituality is a complex, polysemic term that denotes different understandings, mainly when considering religious and nonreligious focuses<sup>(17)</sup>. This brings about the need for a clearer definition<sup>(21)</sup> to better understand this dimension.

Clarifying the concept of spirituality is necessary and can help health professionals in the identification of aspects of this dimension that should be approached during medical visits to patients under palliative care, facilitating more comprehensive and effective spirituality-focused care, in the sense of meeting the patient's spiritual needs.

However, quality spiritual support also demands considering the personal values and beliefs of health professionals, because these influence the care delivered, but the wills and desires of patients must be met regardless of the professionals' personal beliefs<sup>(22)</sup>.

It is worth mentioning that care delivered to critically ill patients is based on the influence of health professionals' spiritual and religious beliefs, as well as on the appraisal of patients' spirituality and religiosity. When professionals use their religious beliefs, it helps them to cope with difficulties found in the care of critically ill patients, strongly influencing their perceptions and attitudes towards patients. As such, knowing the different readings of disease and death shared by different religions is necessary to build the required sensitivity when delivering spiritual support to patients<sup>(22)</sup>.

### **Thematic approach II - Palliative care and spiritual support**

Care focusing on spiritual aspects is gaining more attention by academics and professionals in the health field, but its main contribution consists in changing the care provided to individuals lacking a possibility of treatment and needing palliative care, improving their clinical condition.

Spiritual needs are of utmost significance in the care of patients under palliative care, because its identification allows health professionals to cope with the grieving process<sup>(3,23-24)</sup>. These needs include finding meaning in life, hope, forgiveness, love, transcendence, and connection with others, with God, and with the sacred<sup>(24)</sup>.

Although people with conditions that restrict life have expressed willingness to have their spiritual concerns approached during care in health services, some evidence shows that these problems are typically avoided by professionals working in the field of palliative care. Although spirituality can contribute to improving these patients' lives, this dimension is not fully utilized in most palliative care services<sup>(7,25)</sup>.

Among the potential barriers that hinder the promotion of effective spiritual support, as shown in the publications reviewed herein, the following stand out: difficulty in defining the term "spirituality"<sup>(24)</sup>; lack of time<sup>(23-24,26-27)</sup>; lack of privacy<sup>(26)</sup>; financial costs<sup>(24)</sup>; personal, cultural, and institutional factors; and the need for professional development and training in this area<sup>(23-24)</sup>. A survey showed a lack of privacy and workload as barriers to the spiritual dimension<sup>(28)</sup>.

A study of professionals working in a hospice in Africa found that spiritual support to patients with traditional African religious beliefs, like witchcraft and curses, for example, made some professionals uneasy<sup>(27)</sup>.

A survey showed that uneasiness in approaching the topic, the fear of imposing religious views, and the idea that it is not part of their work or relevant to therapy can also impair spiritual support by professionals. However, according to a study, these barriers are overcome as health professionals broaden their knowledge about the topic and get rid of their ignorance and prejudices<sup>(29)</sup>.

In face of the aforementioned, the palliative care environment is favorable to spiritual support<sup>(26)</sup> and demands that palliative care services incorporate spiritual support into their

practice, assisting individuals that show spiritual well-being and feel spiritual distress when facing a serious disease<sup>(30)</sup>.

As palliative care is being developed as a field, health professionals are being urged to find ways of defending and including the spiritual dimension of care.<sup>(24)</sup> In this context, they should improve their knowledge about the spiritual dimension and incorporate spirituality into care of patients under palliative care.

During palliative care, reason should make way for sensitivity, so that these professionals, including nursing professionals, perceive the spiritual needs of patients and meet them, respecting the patients' and their family members' wills<sup>(18)</sup>.

The interest of nursing in spiritual support, mainly in the field of palliative care, is worth notice. Professional nursing entities have proposed spirituality and spiritual support as integral components of holistic nursing<sup>(26)</sup>. A deeper look into nursing shows that many of these professionals promote spiritual support<sup>(28)</sup>.

### **Thematic approach III - Spirituality and relief of pain and other symptoms that affect patients under palliative care**

Spiritual symptoms are strictly related to psychosomatic symptoms involving terminal diseases, and they affect patients under palliative care. Among them, terminal disease is a threat to well-being, and spiritual coping can help mitigate this feeling<sup>(29)</sup>.

Studies of this thematic approach show evidence of the link between spirituality and relief of symptoms that affect patients under palliative care, like spiritual distress<sup>(31-32)</sup>, anxiety<sup>(28-29)</sup>, depression<sup>(33)</sup> and chronic pain<sup>(34)</sup>.

Chronic pain is the main reason for seeking health services and is a physical sign typically reported by patients in the end-of-life stage. In these cases, physical suffering should be relieved prior to any other symptom, since when it is not done, there is a threat to the feeling of fullness longed for by those facing terminal conditions<sup>(34)</sup>.

Spirituality and religiosity have proved to be important tools to cope with pain, mainly chronic pain<sup>(34-35)</sup>. The benefit of spirituality and religiosity to reduce perceptions of pain can be related to the higher efficiency and interactivity of the hypothalamic-pituitary-adrenal system in response to painful stimuli and the release of important mediators (GABA, serotonin, dopamine) into the central nervous system<sup>(35)</sup>.

However, physical pain is not the only symptom that can be relieved through spiritual support. Papers published in Brazil and abroad show the efficacy of relaxation, mental images, and spirituality (RIME by its acronym in Portuguese) in the resignification of spiritual pain of patients under palliative care<sup>(31-32)</sup>. Studies show that RIME therapy assisted the spiritual pain resignification process by promoting improved quality of life, serenity, and dignity in the process of dying, and favored the process of accepting imminent death. This proves the therapy's effect for the relief of spiritual distress.

A study carried out at New York University (USA) with 31 patients under palliative care showed that religious beliefs and practices had a positive relation to their anxiety, showing that spiritual coping can effectively help patients with terminal disease to handle their anxiety.<sup>(29)</sup>

It should be pointed out that religious and spiritual beliefs and performing spiritual practices, like meditation and praying, for example, can reduce anxiety and distress caused by terminal diseases because these facilitate easing patients' mind<sup>(29)</sup>. This may happen because of the reduced counts of immune cells involved in stress.

Professionals working with palliative care should be attentive to the symptoms of spiritual distress that affect patients whose healing therapy lost the power of reasonably controlling the disease, and be open to using chaplains and providers of spiritual support to help them with these patients<sup>(36)</sup>. Thus, it is relevant to recognize these and other symptoms when delivering care, mainly to patients under palliative care and needing full care, comprising all relevant dimensions, including the spiritual one, to promote death with dignity and peacefulness.

#### **Thematic approach IV - Instruments to evaluate spiritual dimensions in the field of palliative care**

For this thematic approach we found studies referring to the evaluation of tools used in palliative care and comprising spiritual issues. After the analysis of the studies, 73 instruments dealing with the spiritual dimension of patients receiving this kind of care were identified.

It is worth mentioning that most of the instruments presented focus on patients with cancer, for example, the Functional Assessment of Chronic Illness Therapy – Spiritual Well Being (FACIT-Sp-Ex), the Meaning in Life Scale (MiLS), the Spiritual Needs Related to Illness Tool (SPiRIT), and the Spiritual Health Inventory (SHI). However, a few instruments were designed specifically for patients under palliative care, notably the Spiritual Needs Inventory (SNI)<sup>(37)</sup>.

While the quantity of instruments adopted by studies on the spiritual dimension is relevant, researchers consider only a small the number of those as validated in a cross-cultural way only nine, as follows: the Missoula-VITAS Quality of Life Index (MVQoLI), the McGill Quality of Life Questionnaire (MQOL), the Palliative Care Outcome Scale (POS), the Beck Hopelessness Scale (BHS), the Existential Loneliness Questionnaire (ELQ), the Existential Meaning Scale (EMS), the FACIT-Sp, the Ironson-Woods Spirituality/Religiousness Index Short Form (I-W SR Index), the World Health Organization's Quality of Life Measure Spiritual Religious and Personal Beliefs (WHO-QOL SRPB), and World Health Organization's Quality of Life Instrument-HIV (WHOQOL-HIV)<sup>(38-40)</sup>.

The FACIT-Sp has been successfully used to evaluate the spiritual well-being of individuals with cancer and other chronic diseases. The instrument was translated to and validated in several languages: English, Arabic, Chinese, Danish, Dutch, French, German, Italian, Japanese, Korean, Norwegian, Spanish, Swedish, and Portuguese<sup>(41)</sup>. The Palliative Outcome Scale (POS), in turn, is an instrument that, adjusted to the Brazilian context, evaluates the quality of life of patients under palliative care and approaches the main difficulties experienced by them in a multidimensional perspective<sup>(42)</sup>.

A survey has analyzed the presence of spirituality dimensions (intrapersonal, interpersonal, and transpersonal) promoted by the Group of the Spanish Society of Palliative Care

(SECPAL) in the aforementioned instruments, and concluded that only four of them (MVQoLI, ELQ, I-W SR Index, WHO-QOL SRPB) presented the three items of the dimension<sup>(38)</sup>.

The McGill Quality of Life Questionnaire (MQOL) and the Palliative Care Outcome Scale (POS) are the main instruments with spiritual items used among different palliative care populations; however, none of these measures accurately meets all psychometric criteria and multireligious adequacy, demanding further tests<sup>(40)</sup>.

When selecting a proper instrument to measure spiritual dimensions, researchers should consider the clinical and cultural traits of the population wherein the instrument was validated and the psychometric properties of the instrument, but this is not a frequent practice<sup>(40)</sup>. In this sense, further research should investigate the most feasible instrument for spiritual evaluation in situations of specific care, like patients under palliative care<sup>(43)</sup>.

It is worth pointing out that this study faces some limitations. LILACS, MEDLINE/PubMed, IBECs, and the SciELO electronic library were used to obtain studies referring to the topic of palliative care and spirituality. However, other international databases could have been investigated; this may have led to the noninclusion of some studies on this topic. Another highlight is the difficult access to international publications, because most of these are not available for free, thus hindering this approach. The methodological variety of studies regarding objectives, research, and population outlining was another restraining factor that hindered the comparative analysis of publications. Another limitation concerns the instruments to evaluate spirituality in patients under palliative care, since not all instruments that did this were identified.

It is worth mentioning that this study can contribute to strengthening critical readings on the topic, because it proposes advancing understanding about care for patients under palliative care beyond the biological aspects, and raises the need of considering the spiritual dimension of this population. In addition, it can encourage health professionals to take into account this dimension when delivering care to patients in clinical conditions where healing therapies can no longer control the disease and therefore provide humanized care and quality spiritual support to help them in the search for meaning in life, relief of pain, and handling the distress and fear that permeate this process.

#### **CONCLUSION**

The articles reviewed in this study about palliative care and spirituality have shown the spiritual dimension as a core component of care to patients with no possibility of recovering health through healing therapy, because it promotes better well-being, relieving pain and other symptoms.

Spirituality is a term that has several meanings. As such it can be hard for professionals to meet the spiritual needs of patients and hamper the production of proper instruments for the spiritual evaluation of patients under palliative care, due to the wide range of instruments that fail to comprise all items of the spiritual dimension (intra-, inter-, and transpersonal). In this sense there is a need for a clear definition of the concept

of spirituality to allow health professionals to offer their patients proper and high-quality spiritual support capable of meeting all of their spiritual needs.

New surveys should be developed, mainly at the national level, to sustain the spiritual support delivered by professionals

assisting patients under palliative care. There is also an urgent need for studies that investigate the instruments that evaluate spirituality, focusing on patients under palliative care and their transcultural adjustment, since, in this study, some instruments may have been left aside.

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