



RESEARCH

Spirituality in palliative care: a public health issue?

Mary Esperandio¹, Carlo Leget²

1. Programa de Pós-Graduação em Bioética, Escola de Ciências da Vida, Pontifícia Universidade Católica do Paraná, Curitiba/PR, Brasil.
2. Departamento de Ética em Cuidados, Universidade de Estudos Humanísticos, Utrecht, Holanda.

Abstract

Recognized by the World Health Organization as essential for good practices in palliative treatments, “spiritual care” is a recent term in the context of Brazilian healthcare, and should be more well-defined. To fill this gap, this study presents an overview of the updating of spiritual care in Brazil, the United States and Europe, provides brief guidance on how to identify spiritual needs, and outlines four useful tools for this type of care. After the contextualization follows an interdisciplinary and introductory reflection based on bioethics and public theology, questioning whether this care would be a public health issue. The text concludes by presenting some recommendations that may support public policies aimed at implementing spiritual support in palliative care in Brazil.

Keywords: Palliative care. Spirituality. Bioethics. Public health. Theology.

Resumo

Espiritualidade nos cuidados paliativos: questão de saúde pública?

Reconhecido pela Organização Mundial da Saúde como essencial às boas práticas em assistência paliativa, “cuidado espiritual” é termo recente na saúde brasileira e carece de reflexão específica. A fim de diminuir tal lacuna, este estudo apresenta o estado da arte sobre a temática, traz breves orientações sobre como identificar necessidades espirituais e descreve quatro ferramentas úteis para esse cuidado. Após contextualização, reflete-se, de forma introdutória e com base nos campos da bioética e da teologia pública, se esse tipo de cuidado seria questão de saúde pública. O texto conclui com recomendações para subsidiar políticas públicas voltadas à implementação do cuidado espiritual na assistência paliativa no Brasil.

Palavras-chave: Cuidados paliativos. Espiritualidade. Bioética. Saúde pública. Teologia.

Resumen

Espiritualidad en los cuidados paliativos: ¿un problema de salud pública?

Aunque reconocido por la Organización Mundial de la Salud como esencial para las buenas prácticas en cuidados paliativos, “cuidado espiritual” es un término reciente en el contexto de la salud brasileña, acerca del cual todavía falta reflexión específica. Para contribuir a llenar este vacío, este estudio presenta una breve guía sobre como identificar las necesidades espirituales, describiendo cuatro herramientas útiles para este cuidado. Después de la contextualización se refleja, de forma introductoria y con base en los campos de la bioética y de la teología pública, si este tipo de cuidado es un tema de salud pública. El texto concluye con recomendaciones que pueden apoyar las políticas públicas orientadas a implementar el cuidado espiritual en la asistencia paliativa en Brasil.

Palabras clave: Cuidados paliativos. Espiritualidad. Bioética. Salud pública. Teología.

The authors declare no conflict of interest.

The dissemination of the philosophy of palliative care (PC) and the expansion of its offer (which should reach primary health care in the coming years)¹ allow us to debate whether spiritual care (SC) would be a public health issue, given its importance for good practices in PC. The issue is pertinent, considering that the World Health Organization (WHO) recognizes the spiritual dimension as an intrinsic component of palliative care².

Although still recent in Brazil, research on spirituality in PC is spreading. What have these studies shown? Are Brazilian empirical studies distinct from North American and European research, which have been investigating the subject for longer? Do its results give support to public policies to implement spiritual care in PC? Can SC be considered a public health issue? And how can bioethics and other knowledge fields come together in an interdisciplinary dialogue to improve understanding of the topic and develop knowledge? These questions are at the basis of this study.

Current state of the art

The Brazilian context

We searched for Brazilian empirical scientific productions on spirituality in the context of PC in the Portal de Periódicos Capes, Biblioteca Virtual em Saúde, Scientific Electronic Library Online (SciELO) and PubMed databases, using the terms “spiritual care and palliative care,” “spirituality and palliative care,” and “bioethics”. We found 18 empirical studies published between 2003 and 2018: four dissertations, two theses and 12 articles. Three of the articles were published in 2003³, 2006⁴ and 2014⁵, and the other nine⁶⁻¹⁴ were published as of 2015.

Research on spirituality in PC is recent, growing alongside the provision of this type of care in Brazil, with most studies focusing on proving the relationship between spirituality and health. Although the term “spiritual care” is often mentioned in the articles published as of 2015, only two theses^{15,16} and one dissertation¹⁷ defined it. Before that, the concept appears in a 2007 text, not included in the survey, published in a journal that has been discontinued since 2014¹⁸.

The literature analyzed shows that, in the context of PC, spirituality provides meaning for the disease¹⁹, produces feelings of well-being²⁰ and quality of life^{6,12}, acts as a coping resource²¹, a

support for the patient and relatives²², and a means of development and reframing of life⁸. Even so, health professionals struggle to identify and meet spiritual needs^{12,23}, with a study¹⁴ showing that less than 15% of hospitalized patients had these needs met or received psychological support.

The medical staff usually does not assess spiritual suffering, as this dimension is mistaken for religiosity and seen as a private matter²³. Few professionals provide SC, by practices such as prayer, offering comfort and help in the meaning search process, for both patients and the multidisciplinary team itself¹². Some studies even highlight the lack of professional training to integrate this type of assistance in palliative care^{10,24,25}.

Among the works focusing on the practice of SC in PC, three authors stand out: Ana Catarina de Araújo Elias³, Michell Ângelo Marques Araújo¹⁵ and Luciana Winterkorn Dezorzi¹⁶. Elias³ created and tested an intervention technique called “relaxation, mental Images and spirituality” (Rime), whose purpose is to give new meaning to the spiritual pain of patients (children, adolescents and adults) and family members in a PC situation. Six health professionals received training and applied the technique to 11 patients. The reported results proved positive for both patients and health care providers, such as promoting well-being, improving quality of life during the death process and reframing spiritual pain⁴.

In the intervention study developed for his doctoral thesis, Araújo¹⁵ delivered SC to three adult patients and from that built a care model based on 17 theoretical assumptions, related to five basic concepts: human being, health-disease process, nursing, environment and spiritual care.

In her doctoral thesis, the nurse Luciana Dezorzi¹⁶ developed a proposal for training in the practice of SC in this context. The author validated a competency scale and applied it to 52 health professionals, before and after participating in a four-hour education module in SC, specially developed for health professionals involved in palliative treatments (but not restricted to it) and published it as an electronic booklet²⁶. The training addressed notions of spirituality, religiosity, crisis and spiritual care, ways of assessing resources and needs of patients and families. She reports positive results from the educational intervention, indicating its contribution to minimize training gaps¹⁶, but its effectiveness requires further research.

In addition to these empirical studies, we found three theoretical publications²⁷⁻²⁹ related to the topic. Hefti and Esperandio²⁸ present an interdisciplinary model in the broad context of health (including PC), stating that interdisciplinary SC consists of assessing the patient's spirituality, which can be done by any member of the multidisciplinary team, to integrate this dimension in healthcare. The spiritual support specialist (chaplain) integrates the team and use his/her knowledge and experience to support the spiritual needs of patients and families, as well as professionals.

In the field of bioethics, Salles²⁷ indirectly addresses SC by defending, based on the principles of autonomy and beneficence, the importance of considering the religious beliefs of end-of-life patients. The author mentions beliefs about death present in Buddhism, Spiritism, Afro-Brazilian religions (*Candomblé*, *Umbanda* and *Quimbanda*) and Catholicism. On the other hand, Garanito and Cury²⁹ discuss the topic specifically in pediatrics, emphasizing that children also have spiritual needs. The authors highlight the importance of the hospital chaplain and the need to include spirituality and palliative care in the training of health professionals.

In Brazil, unlike the North American and European context, specialized spiritual care (chaplaincy) is scarce²⁸⁻³⁰, offered as "religious support," often by volunteer agents or religious leaders called to deliver it. In the survey of scientific production on SC (or chaplaincy) in the specific context of PC, no study was found with the descriptors used.

The North American context

American researchers point out that patients crave SC at the end of their lives^{31,32}, evidencing that meeting the spiritual needs of dying patients is associated with better use of hospice, lower mortality rates in intensive care units, decrease in aggressive treatments (especially among those using coping strategies), higher quality of life and lower hospital costs and risk of depression³³⁻³⁵.

A two-part literature review conducted by ten American researchers^{36,37} addressed, in part I³⁶, definitions of spirituality, research methods and assessment instruments and evidence of SC health outcomes. In part II³⁷, the researchers analyzed how the topic has been treated, how interventions are carried out, and how professionals have been trained for this type of approach.

Regarding SC in PC, the authors stress that parameters for team formation exist since 2009, established in the first American consensus conference on spirituality in palliative care. Professionals should: have training in spiritual care compatible with their scope of practice, know how to conduct anamnesis, discern spiritual resources available to patients regarding SC, be properly trained to provide spiritually and culturally sensitive care, have basic training in how spiritual values and/or beliefs can influence patient and family medical decisions, be aware of the various spiritual care roles of different providers and, when to refer to each, develop compassionate presence and active listening, and have training in spiritual self-reflection and self-care^{36,37}.

Regarding interventions related to spiritual needs, models focusing on quality of life have been emphasized, including psychotherapy, life review and multidisciplinary, physical and mental interventions³⁷. As for the SC provided by specialized assistants (chaplains), the researchers remark that quantitative research is needed to indicate results more clearly, since the work performed by such professionals generally focuses on the process rather than on the outcomes^{36,37}.

The European context

In a recent literature review on SC (not on spirituality), Gijssberts and collaborators³⁸ found 53 studies, many conducted in the United Kingdom and Netherlands, forming a total sample of more than 30,000 participants. Most studies had as main object the perspective of health professionals and patients under SC and the interaction between providers and recipients of this type of care.

The authors note that attention to spirituality in palliative care also involves the question of hope – spiritual caregivers seek to be a full presence, providing hope, comfort and peace. Their care practice includes creative, narrative and ritual work. For researchers, health professionals should look at this subject not only from a "realistic" perspective, but also recognize the "functional" (linked to well-being) and "narrative" (life story) perspective³⁸.

Although the results of the studies analyzed suggest that SC has a positive effect on the patient, relieving, for example, discomfort, evidence is still low. For the implementation to be successful, we must develop spiritual competence by education and self-reflection, giving more

visibility to the spiritual dimension in healthcare in general. In this context, chaplaincy service plays an important role³⁸ and, as in North American studies³⁷, further research on specialized spiritual care is required.

While SC interventions in the US are related to quality of life, and there is a lack of works based on *a priori* hypotheses, Europe feels the need to, first, conduct research with more adequate outcomes³⁸. For the authors, the issue of quality of life failed to fully capture the effect of creative, narrative and ritual works identified as paths to provide spiritual care³⁸. Finally, European and North American researchers stress the urgent need to research the impact of SC education for the health of the patient, family and multidisciplinary team^{37,38}.

Spirituality and spiritual care

Defining spiritual care and spirituality is a complex task, as these concepts are subject to continuous debate^{36,37,39}. Leget³⁹ remarks that the consensus difficulty is related both to cultural and academic differences and to the method used to delimit terms. But providing definitions is the necessary starting point, even if they are provisional.

Defining the terms

Of the 18 Brazilian studies published between 2003 and 2018, 14 (77.8%) defined “spirituality” as a measure to give existential meaning and purpose, something broader than “religiosity”. Most studies published in Brazil follow the global consensual definition, established in two international conferences held in 2012 and 2013: *spirituality is a dynamic and intrinsic aspect of humanity through which people seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices*⁴⁰.

The theses and dissertations that defined “spiritual care” considered the term as synonymous to “transpersonal caring”¹⁷. Essentially relational, SC would have *as its central focus the search and discovery of the meaning of life*⁴¹ for the full realization and for the end of despair, recognizing and responding to *the needs of the human spirit, especially when faced with traumas, health problems or sadness.*(...)

[It] begins by encouraging human contact and a compassionate relationship (...), able to move in the direction that the need requires⁴².

Spiritual care is not a synonym of “religious care,” which we can define as a form of assistance based on identifying and tending to spirituality-related needs. In other words, SC includes helping people in the search for meaning, purpose, hope and connection in situations that seem profoundly meaningless or hopeless, such as a serious, progressive life-threatening illness. Spiritual care implies an accurate look, attentive and compassionate listening, which welcomes the person who suffers, seeking to minimize their suffering, be it physical, emotional, psychosocial or spiritual.

The criticism that “spirituality” is a vague concept seems to compromise the practice of SC. However, Swinton and Pattison⁴³ argue that it is precisely in the imprecision of the term that its strength lies, as it speaks of what is usually absent or little recognized in healthcare. Agreeing with these authors, we emphasize here that spirituality expresses something of the existential process that is conditioned to historical time, geographic space, culture and language, in addition to social and economic conditions. There is something that always escapes conceptualization, locating and dating definitions and, consequently, spiritual care practices, expressing in their form the conditions of their emergence.

Besides these constraints, identifying spiritual needs depends on the healthcare provider’s attitude and theoretical and technical competence. These needs can be identified in many ways, on many levels, and are inseparable from the physical, psychosocial and existential dimensions, as noted by Leget³⁹. However, this does not mean that the person always has them.

How to identify spiritual needs

Leget³⁹ observes that spiritual needs can be explicit, implicit or even hidden, and may even be linked to other types of needs. Based on a literature review, Kellehear⁴⁴ showed that spirituality appears in multidimensional needs, described in three categories: situational (purpose, hope, meaning and affirmation, mutuality, connectivity, social presence), moral and biographical (peace and reconciliation, reunion with others, prayer, moral and social analysis, forgiveness, closure), and religious (religious reconciliation, divine

forgiveness and support, religious rights/sacraments, clergy visits, discussions about God, eternal life, and hope)⁴⁴.

Leget³⁹ adds that spiritual needs are expressed in different ways, according to the character and culture of each person. For some, spirituality is lived intellectually, studying and reading books, discussing and trying to understand what is happening to them, and relating it to a larger framework of meaning. For others, the spiritual quest is more a inner world journey, using meditation or other practices that focus more on experiencing and feeling what is happening to them. Others focus more on action, putting things in order, helping other people or contributing to a better world. Identifying spiritual needs is crucial to providing SC, requiring knowledge of tools and developing skills that help to recognize and meet such needs.

Tools to assess spirituality in palliative care

What are the best tools available to assess spirituality/religiosity to facilitate SC in PC? In a systematic review, Lucchetti, Bassi and Lucchetti⁴⁵ identified 25 instruments for clinical or research use, choosing five as the most appropriate: FICA, SPIRITual History, FAITH, HOPE, and Royal College of Psychiatrists.

Blaber, Jone and Willis⁴⁶ analyzed FICA, SPIRITual, FAITH and HOPE, considering their strengths and weaknesses based on five criteria: 1) focus on the patient; 2) conciseness; 3) flexibility; 4) easy memorization; and 5) reliability (approach other than “item check”). The authors indicated HOPE as the most suitable instrument for use in SC, as it helps the care provider to draw up individualized plans for continuous SC of each patient. However, FICA was the only instrument validated.

Here we present the four instruments of practical approach considered most suitable for the context studied. Developed in the context of family medicine⁴⁷, HOPE assess the dimension of spirituality based on four components indicated in its name. The first component (letter *h*, as in “hope”) seeks to determine the patients’ sources of hope, strength, comfort and peace, what they hold on to in difficult times, what sustain and allow them to continue fighting, despite difficulties. The second element (letter *o*) seeks to identify whether the patient participates in an

organized religion, and the extent to which it is important and useful to them.

The third element (letter *p*) questions *personal* practices – whether respondents have beliefs regardless of organized religion, if they believe in God and what aspects of their spiritual practice (meditation, prayer, reading religious texts, songs, attending religious services etc.) they find most useful. Finally, the last element (letter *e*) deals with the effect of end-of-life issues on medical care – for example, if the patient worry about any conflict between their spiritual/religious beliefs and healthcare decisions⁴⁷.

Proposed by Christina Puchalski⁴⁸, the acronym FICA aims to identify values and beliefs, coping mechanisms and support systems that correspond to the provision of compassionate care. Each letter asks several questions to raise questions about faith and its importance for the patient as to provide religious support and meet spiritual needs:

- *F* (faith): do you have spiritual beliefs that help you cope with stress/difficult times? If the patient answers “no,” the health professional might ask: what gives your life meaning?
- *I* (importance): how important is your spirituality in coping with the disease and what role does your beliefs play in your healthcare decision-making?
- *C* (religious community): Do you participate in a church or spiritual community? Do they give you support? How? Is there a group of people you really love or who are important to you?
- *A* (address in care): how would you like us to address your spiritual needs? Is there anything you would like to be done to meet them?

The third instrument, made available by the Mount Vernon Cancer Network in 2007, has been widely used by health professionals in Europe³⁹. It consists of three questions whose purpose is to verify basic aspects related to meaning, resources and spiritual support: 1) how do you understand what is happening and what does the experience mean to you?; 2) what resources do you use when life is difficult, and what helps you in difficult times?; 3) do you think it would be useful to talk to someone about spiritual and faith issues?

Finally, the last instrument consists of a single question: what do I need to know about you as a person to care for you in the best way possible?⁴⁹ The question expresses a concern centered on individuals, leaving them the decision

to provide the caregiver with the information they deem appropriate.

Bioethics, spiritual care and public health

Empirical evidence on the impact of spirituality/religiosity should be sufficient to change healthcare in at least two instances: 1) the discourse of health professionals about the lack of training or time to integrate SC in their practice^{50,51}; 2) public policies.

Regarding the lack of professional training, it is a fact that few courses in Brazil offer content on spirituality⁵². However, the significant volume of studies on the subject needs to be better used by health professionals. Lack of time^{50,51,53} refers to structural issues in the public health system and its organization, revealing the “price of life”. In capitalist society, “commodity” time is an important dimension of policies, structures and economic systems⁴³. Thus, the justification is politically charged, since spiritual care is conditioned by the time required; it refers to a “calculation” of life and priorities – time is dedicated to what is most valued. This departure from the human dimension of care practices reveals something incongruous in health policies.

The dimension of spirituality cannot be ignored, as it allows us to build meaning for the suffering of facing a serious, life-threatening illness. SC promotes the dignity of the person, improves the quality of life, increases the feeling of well-being and provides greater clarity regarding important decisions in this scenario.

Due to its essentially interdisciplinary character and its ethical references, bioethics is the agglutinating field of the discussion about spiritual care as a public health issue. There are common concerns and approaches between the field of bioethics (global⁵⁴, narrative^{9,55} and protection⁵⁶) and public theology^{57,58}.

Leo Pessini⁵⁴ underlines solidarity, vulnerability and precaution when discussing the contribution of global bioethics. Protective bioethics highlights both *the conditions for the possibility of sanitary bioethics*⁵⁹ and the interdisciplinary dialogue on the quality of life of human populations. “Protection” here refers not to the paternalistic relationship between those who provide care and those who receive it passively, but to the care of vulnerable populations, considering vulnerability as a condition of existence⁵⁶.

“Vulnerability” results from the lack of full conditions for exercising autonomy. In PC, autonomy is impaired by factors that can exacerbate suffering and affect decision-making.

Public theology also enriches the debate, as it shows solidarity^{57,58}, compassion and the ethics of care⁵⁸, underlining the fundamental role of those who provide SC – generally, people trained in theology^{49,58}. Sometimes, patients and family members feel more comfortable discussing ethical decisions with those who provide this type of assistance than with health professionals, proving the importance of this specialty in the multidisciplinary team – an aspect usually disregarded in Brazil.

Chaplains could contribute singularly and significantly to the patient, their family and the team itself. This support is illustrated in a narrative recorded in a study that investigated principles and values involved in the practice of palliative sedation (although not the main focus, the spirituality emerged in the results)⁶⁰. The research evaluates the case of a patient with extreme pain who decides not to undergo palliative sedation, probably due to religious convictions. The narrator claims to be frustrated with the decision, but accepts it in the name of the bioethical principles such as respect for autonomy and religious values: *if the patient (...) wants to die with suffering, we work with the team and his decision is respected*⁶¹. Another interviewee writes: *and then it turns out that the one who suffers is the one who has all the principles of PC and believes that something could be done to alleviate the suffering*⁶¹.

Several questions could be raised, but it is important to highlight, from the referents of the bioethics of protection, the following: 1) wouldn't the vulnerable patient, given his extreme suffering, be recognized by the health provider himself?; 2) in this situation, is it possible to fully exercise autonomy?; 3) would dying with suffering really be an option or express hidden spiritual conflict, and therefore a need to be met?; 4) should the suffering expressed by the health professional also be the subject of medication?; 5) does the team really have “all the principles of PC” to alleviate suffering?; and 6) was SC, for both the patient and the team, included in palliative care? The example shows the relevance of spirituality in PC, reinforcing the need to discuss the topic as a public health issue⁵⁶.

In turn, narrative bioethics^{9,60} is based on the “life story” told by the patient, to search for

elements that justify and give meaning to decision-making. Ethical issues in the context of PC are closely linked to beliefs and values that guide choices and define behaviors⁵⁵. Due to its characteristic of active listening and valuing of the relational aspect, narrative bioethics promotes human dignity, valuing the past and the present, considering the way in which personal history expresses meaning and purpose and enabling a deeper reflection in the deliberations about treatment.

In the context of PC, patients face not only the physical pain arising from the symptoms of serious illness; they experience multifactorial suffering that surpasses the limits of the physical body and manifests itself in relational problems, crises and spiritual conflicts untreatable by drugs and that can aggravate the perception of pain. Cicely Saunders⁶² characterized this experience as “total pain,” as it encompasses, besides the physical component, psychological, social, emotional and spiritual struggle.

Search for the meaning of suffering lies in the context of the person’s life history. Likewise, ethical decisions are not isolated from the relational and social context of the treatment unit (patient and family), as pointed out by Muldoon and King⁵⁵. In the patients’ narratives, their values and beliefs are present, which helps them find meaning and underpins their decisions.

Narrative bioethics, public theology and spiritual care share a sense of responsibility and compassion for the suffering person, the promotion of dignity via relationships and techniques that value life history and help to build meaning and connect with oneself, with others and with what the person considers sacred.

From barriers to potential

The organization of PC services in Brazil must consider the Country’s socio-cultural reality, where religiosity, as an expression of spirituality, is important for the population’s subjectivity. Data from the last census of the Brazilian Institute of Geography and Statistics⁶³ show that, although the Brazilian religious map has changed, the population remains highly religious. In Brazil, 64.6% of the population is Catholic; 22.2% are Pentecostal; 2% spiritists; 0.3% profess Afro-Brazilian religions; and 2.7% have other beliefs. For the first time, a group appears that claims to be “without religion” (8%), and another group (5%) that claims to be “double” or “multiple belonging”⁶³. The growing number

of people without religion indicates the need to consider spirituality beyond it.

Beliefs and values (of patients, families and health professionals) influence health outcomes. Brazilian studies^{50,51,53} indicate that patients express the desire for spirituality to be integrated into healthcare, and professionals recognize its impact on treatment. However, the Country’s public health policies seem to ignore this data. To reverse this situation, based on the literature analyzed, it is possible to make some recommendations for integrating SC focusing on four axes: 1) theory and research; 2) care practices; 3) education; and 4) organizational policy.

In the theory and scientific research axis, we must build and disseminate SC models with theoretical-practical and culturally sensitive bases, so that assistance has a clear and adequate purpose to respond to the real needs of patients and families. Research on topics such as decision making, bereavement, communication of difficult news, SC in primary health care and home care, care models, specialized spiritual assistance and its role in the multidisciplinary team, dignity, hope, advance directives, training of professionals, etc. should be expanded. Finally, it is necessary to encourage international cooperation between researchers.

In the care practices axis, the focus is to encourage the use of tools to know the patient’s life history and identify their spiritual needs. Space can be provided in the medical record to report the assessment of spirituality/religiosity, the proposed care plan and the evolution of spiritual assistance. Another objective is to encourage the gradual implementation of SC in PC teams.

In the education axis, we must provide specific training for professionals who already work in palliative care, including aspects such as the identification of implicit and explicit spiritual/religious needs, SC models, and when and how to refer patients and families to specialized spiritual assistance. Other objectives are: to integrate SC in PC in curricula of the health area programs, training the eyes, ears and hearts of future health professionals; offer specific courses on the topic for people trained in theology; and raise awareness of the importance and role of specialized spiritual care.

In the organizational policy axis, we must draw attention to the potential of theology in training specialists in spiritual assistance in PC. To this end, a specific discipline addressing SC in palliative care must integrate the curriculum of the undergraduate

programs. It is also necessary to build a collaborative relationship and interdisciplinary exercise between spiritual caregivers and health professionals, as well as integrating a competent professional as a “spiritual care specialist” in multidisciplinary PC teams. Finally, national meetings can be organized to share experiences, build bridges between research and practice and plan joint strategies to implement SC as part of public policies.

Final considerations

The debate on SC as a public health issue is just beginning. Since the WHO regards

spirituality as one of the intrinsic components of good practices in palliative care, and considering the government resolution that deals with implementing PC in primary healthcare, this reflection is essential. Based on it, the spiritual dimension can be effectively integrated into this type of assistance, improving the quality of care for both those who are closing their biography and those who accompany them. Different areas are invited to develop studies on the topic, producing evidence that may lead to the transformation of public policies and the theoretical-practical production of a bioethics of care, so that comprehensive and person-centered care is the starting and ending point.

References

1. Brasil. Ministério da Saúde. Resolução nº 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, p. 276, 31 out 2018 [acesso 25 jun 2019]. Disponível: <https://bit.ly/2ChxQhc>
2. Worldwide Palliative Care Alliance. Global atlas of palliative care at the end of life [Internet]. Geneva: World Health Organization; 2014 [acesso 25 jun 2019]. Disponível: <https://bit.ly/30ft6Mi>
3. Elias ACA. Re-significação da dor simbólica da morte: relaxamento mental, imagens mentais e espiritualidade. *Psicol Cienc Prof* [Internet]. 2003 [acesso 22 nov 2019];23(1):92-7. DOI: 10.1590/S1414-98932003000100013
4. Elias ACA, Giglio JS, Pimenta CAM, El-Dash LG. Therapeutical intervention, relaxation, mental images, and spirituality (RIME) for spiritual pain in terminal patients: a training program. *Scientific World Journal* [Internet]. 2006 [acesso 27 nov 2019];6:2158-69. DOI: 10.1100/tsw.2006.345
5. Paiva CE, Paiva BSR, Yennurajalingam S, Hui D. The impact of religiosity and individual prayer activities on advanced cancer patients' health: is there any difference in function of whether or not receiving palliative anti-neoplastic therapy? *J Relig Health* [Internet]. 2014 [acesso 27 nov 2019];53(6):1717-27. DOI: 10.1007/s10943-013-9770-6
6. Camargos MG, Paiva CE, Barroso EM, Carnesecca EC, Paiva BSR. Understanding the differences between oncology patients and oncology health professionals concerning spirituality/religiosity: a cross-sectional study. *Medicine* [Internet]. 2015 [acesso 2 jun 2019];94(47):e2145. DOI: 10.1097/MD.0000000000002145
7. Ferreira AGC, Duarte TMM, Silva AF, Bezerra MR. Concepções de espiritualidade e religiosidade e a prática multiprofissional em cuidados paliativos. *Rev Kairós* [Internet]. 2015 [acesso 27 nov 2019];18(3):227-44. DOI: 10.23925/2176-901X.2015v18i3p227-244
8. Paiva BSR, Carvalho AL, Lucchetti G, Barroso EM, Paiva CE. “Oh, yeah, I’m getting closer to god”: spirituality and religiousness of family caregivers of cancer patients undergoing palliative care. *Support Care Cancer* [Internet]. 2015 [acesso 27 nov 2019];23(8):2383-9. DOI: 10.1007/s00520-015-2604-1
9. Manchola C, Brazão E, Pulschen A, Santos M. Cuidados paliativos, espiritualidade e bioética narrativa em unidade de saúde especializada. *Rev. bioét. (Impr.)* [Internet]. 2016 [acesso 27 nov 2019];24(1):165-75. DOI: 10.1590/1983-80422016241118
10. Evangelista CB, Lopes MEL, Costa SFG, Abrão FMS, Batista PSS, Oliveira RC. Spirituality in patient care under palliative care: a study with nurses. *Esc Anna Nery* [Internet]. 2016 [acesso 27 nov 2019];20(1):176-82. DOI: 10.5935/1414-8145.20160023
11. Benites AC, Neme CMB, Santos MA. Significados da espiritualidade para pacientes com câncer em cuidados paliativos. *Estud Psicol* [Internet]. 2017 [acesso 27 nov 2019];34(2):269-79. DOI: 10.1590/1982-02752017000200008
12. Matos TDS, Meneguim S, Ferreira MLS, Miot HA. Qualidade de vida e coping religioso-espiritual em pacientes sob cuidados paliativos oncológicos. *Rev Latinoam Enferm* [Internet]. 2017 [acesso 2 jun 2019];25:e2910. DOI: 10.1590/1518-8345.1857.2910
13. Miqueletto M, Silva L, Figueira CB, Santos MR, Szyllit R, Ichikawa CRF. Espiritualidade de famílias com um ente querido em situação de final de vida. *Rev Cuidarte*. [Internet]. 2017 [acesso 27 nov 2019];8(2):1616-27. DOI: 10.15649/cuidarte.v8i2.391

14. Arrieira ICO, Thofehrn MB, Porto AR, Moura PMM, Martins CL, Jacondino MB. Espiritualidade nos cuidados paliativos: experiência vivida de uma equipe interdisciplinar. *Rev Esc Enferm USP* [Internet]. 2018 [acesso 25 jun 2019];52:e03312. DOI: 10.1590/s1980-220x2017007403312
15. Araújo MÂM. O cuidado espiritual: um modelo à luz da análise existencial e da relação de ajuda [tese] [Internet]. Fortaleza: Universidade Federal do Ceará; 2011 [acesso 27 nov 2019]. Disponível: <https://bit.ly/3fBGRQq>
16. Dezorzi LW. Espiritualidade na atenção a pacientes em cuidados paliativos e os processos de educação dos profissionais de saúde [tese] [Internet]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2016 [acesso 22 nov 2019]. Disponível: <https://bit.ly/2WsOv8e>
17. Resende TM. Acupuntura para pacientes oncológicos ambulatoriais: um cuidado espiritual de enfermagem [dissertação] [Internet]. Juiz de Fora: Universidade Federal de Juiz de Fora; 2014 [acesso 27 nov 2019]. Disponível: <https://bit.ly/32on4QJ>
18. Selli L, Alves J. O cuidado espiritual ao paciente terminal no exercício da enfermagem e a participação da bioética. *Bioethikos* [Internet]. 2007 [acesso 27 nov 2019];1(1):43-52. Disponível: <https://bit.ly/391tl0l>
19. Tomaszewski AS, Oliveira SG, Arrieira ICO, Cardoso DH, Sartor SF. Manifestações e necessidades referentes ao processo de morte e morrer: perspectiva da pessoa com câncer. *Rev Pesqui Cuid Fundam* [Internet]. 2017 [acesso 27 nov 2019];9(3):705-16. DOI: 10.9789/2175-5361.2017.v9i3.705-716
20. Rezende VL, Derchain S, Botega NJ, Sarian LO, Vial DL, Morais SS *et al.* Avaliação psicológica dos cuidadores de mulheres com câncer pelo General Comfort Questionnaire. *Paidéia* [Internet]. 2010 [acesso 27 nov 2019];20(46):229-37. DOI: 10.1590/S0103-863X2010000200010
21. Lima CP, Machado MA. Cuidadores principais ante a experiência da morte: seus sentidos e significados. *Psicol Ciênc Prof* [Internet]. 2018 [acesso 27 nov 2019];38(1):88-101. DOI: 10.1590/1982-3703002642015
22. Medeiros WCM. A clínica psicológica e a experiência da espiritualidade de pacientes em cuidados paliativos [dissertação] [Internet]. Recife: Universidade Católica de Pernambuco; 2012 [acesso 2 jun 2019]. Disponível: <https://bit.ly/2DGLoD8>
23. Marinho SO. Cuidados paliativos e práticas de saúde: um estudo sobre a gestão da morte na sociedade contemporânea [tese] [Internet]. Rio de Janeiro: Universidade do Estado do Rio de Janeiro; 2010 [acesso 27 nov 2019]. Disponível: <https://bit.ly/2DFEYof>
24. Rocha RCNP. Experiências e necessidades espirituais do familiar cuidador de paciente em atenção paliativa oncológica [dissertação] [Internet]. Niterói: Universidade Federal Fluminense; 2017 [acesso 27 nov 2019]. Disponível: <https://bit.ly/2B34r9M>
25. Zaccara AAL. Cuidados paliativos e espiritualidade: estudo com residentes da área da saúde [dissertação] [Internet]. João Pessoa: Universidade Federal da Paraíba; 2014 [acesso 27 nov 2019]. Disponível: <https://bit.ly/2Ou2Exw>
26. Dezorzi LW, Raymundo MM, Goldim JR. Espiritualidade na atenção a pacientes/famílias em cuidados paliativos: um guia de apoio para profissionais de saúde [Internet]. Porto Alegre: WWLivros; 2016 [acesso 25 jun 2019]. Disponível: <https://bit.ly/32nK825>
27. Salles AA. Bioética e processos de religiosidade entre os pacientes com doenças terminais no Brasil. *Rev. bioét. (Impr.)* [Internet]. 2014 [acesso 27 nov 2019];22(3):397-406. DOI: 10.1590/1983-80422014223021
28. Hefti R, Esperandio MRG. The interdisciplinary spiritual care model: a holistic approach to patient care. *Horizonte* [Internet]. 2016 [acesso 27 nov 2019];14(41):13-47. DOI: 10.5752/P.2175-5841.2016v14n41p13
29. Garanito MP, Cury MRG. A espiritualidade na prática pediátrica. *Rev. bioét. (Impr.)* [Internet]. 2016 [acesso 27 nov 2019];24(1):49-53. DOI: 10.1590/1983-80422016241105
30. Gentil RC, Guia BP, Sanna MC. Organização de serviços de capelanía hospitalar: um estudo bibliométrico. *Esc Anna Nery* [Internet]. 2011 [acesso 27 nov 2019];15(1):162-70. DOI: 10.1590/S1414-81452011000100023
31. Best M, Butow P, Olver I. Do patients want doctors to talk about spirituality? A systematic literature review. *Patient Educ Couns* [Internet]. 2015 [acesso 27 nov 2019];98(11):1320-8. DOI: 10.1016/j.pec.2015.04.017
32. MacLean CD, Susi B, Phifer N, Schultz L, Bynum D, Franco M *et al.* Patient preference for physician discussion and practice of spirituality: results from a multicenter patient survey. *J Gen Intern Med* [Internet]. 2003 [acesso 27 nov 2019];18(1):38-43. DOI: 10.1046/j.1525-1497.2003.20403.x
33. Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA *et al.* Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol* [Internet]. 2010 [acesso 27 nov 2019];28(3):445-52. DOI: 10.1200/JCO.2009.24.8005
34. Balboni T, Balboni M, Paulk ME, Phelps A, Wright A, Peteet J *et al.* Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer* [Internet]. 2011 [acesso 27 nov 2019];117(23):5383-91. DOI: 10.1002/cncr.26221
35. Pearce MJ, Coan AD, Herndon JE, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer* [Internet]. 2012 [acesso 27 nov 2019];20(10):2269-76. DOI: 10.1007/s00520-011-1335-1

36. Steinhauser KE, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI *et al.* State of the science of spirituality and palliative care research part I: definitions, measurement, and outcomes. *J Pain Symptom Manag* [Internet]. 2017 [acesso 27 nov 2019];54(3):428-40. DOI: 10.1016/j.jpainsymman.2017.07.028
37. Balboni TA, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI *et al.* State of the science of spirituality and palliative care research part II: screening, assessment, and interventions. *J Pain Symptom Manag* [Internet]. 2017 [acesso 27 nov 2019];54(3):441-53. DOI: 10.1016/j.jpainsymman.2017.07.029
38. Gijsberts MJHE, Liefbroer AI, Otten R, Olsman E. Spiritual care in palliative care: a systematic review of the recent European literature. *Med Sci* [Internet]. 2019 [acesso 27 nov 2019];7(2):25. DOI: 10.3390/medsci7020025
39. Leget C. Spirituality in palliative care. In: MacLeod RD, Van den Block L, editores. *Textbook of palliative care* [Internet]. Cham: Springer International Publishing; 2018 [acesso 17 jun 2019]. p. 1-11. Disponível: <https://bit.ly/2WqnQZQ>
40. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med* [Internet]. 2014 [acesso 27 nov 2019];17(6):642-56. p. 646. Tradução livre. DOI: 10.1089/jpm.2014.9427
41. Araújo MÂM. Op. cit. p. 125.
42. Dezorzi LW. Op. cit. p. 31.
43. Swinton J, Pattison S. Moving beyond clarity: towards a thin, vague, and useful understanding of spirituality in nursing care. *Nurs Philos* [Internet]. 2010 [acesso 27 nov 2019];11(4):226-37. DOI: 10.1111/j.1466-769X.2010.00450.x
44. Kellehear A. Spirituality and palliative care: a model of needs. *Palliat Med* [Internet]. 2000 [acesso 27 nov 2019];14(2):149-55. DOI: 10.1191/026921600674786394
45. Lucchetti G, Bassi RM, Lucchetti ALG. Taking spiritual history in clinical practice: a systematic review of instruments. *Explore* [Internet]. 2013 [acesso 27 nov 2019];9(3):159-70. DOI: 10.1016/j.explore.2013.02.004
46. Blaber M, Jone J, Willis D. Spiritual care: which is the best assessment tool for palliative settings? *Int J Palliat Nurs* [Internet]. 2015 [acesso 27 nov 2019];21(9):430-8. DOI: 10.12968/ijpn.2015.21.9.430
47. Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. *Am Fam Physician* [Internet]. 2001 [acesso 27 nov 2019];63(1):81-9. Disponível: <https://bit.ly/2OtdHav>
48. Puchalski C. Spirituality in health: the role of spirituality in critical care. *Crit Care Clin* [Internet]. 2004 [acesso 27 nov 2019];20(3):487-504. DOI: 10.1016/j.ccc.2004.03.007
49. Johnston B, Gaffney M, Pringle J, Buchanan D. The person behind the patient: a feasibility study using the patient dignity question for patients with palliative care needs in hospital. *Int J Palliat Nurs* [Internet]. 2015 [acesso 27 nov 2019];21(2):71-7. DOI: 10.12968/ijpn.2015.21.2.71
50. Esperandio MRG, Machado GAS. Brazilian physicians' beliefs and attitudes toward patients' spirituality: implications for clinical practice. *J Relig Health* [Internet]. 2019 [acesso 27 nov 2019];58(4):1172-87. DOI: 10.1007/s10943-018-0707-y
51. Lucchetti G, Ramakrishnan P, Karimah A, Oliveira GR, Dias A, Rane A *et al.* Spirituality, religiosity, and health: a comparison of physicians' attitudes in Brazil, India, and Indonesia. *Int J Behav Med* [Internet]. 2016 [acesso 27 nov 2019];23(1):63-70. DOI: 10.1007/s12529-015-9491-1
52. Lucchetti G, Oliveira LR, Koenig HG, Leite JR, Lucchetti ALG. Medical students, spirituality and religiosity: results from the multicenter study SBAME. *BMC Med Educ* [Internet]. 2013 [acesso 27 nov 2019];13(1):162. DOI: 10.1186/1472-6920-13-162
53. Esperandio MRG. Teologia e a pesquisa sobre espiritualidade e saúde: um estudo piloto entre profissionais da saúde e pastoralistas. *Horizonte* [Internet]. 2014 [acesso 27 nov 2019];12(35):805-32. DOI: 10.5752/P.2175-5841.2014v12n35p805
54. Pessini L. Elementos para uma bioética global: solidariedade, vulnerabilidade e precaução. *Thaumazein* [Internet]. 2017 [acesso 27 nov 2019];10(19):75-85. Disponível: <https://bit.ly/2ZwQ6fc>
55. Muldoon M, King N. Spirituality, health care, and bioethics. *J Relig Health* [Internet]. 1995 [acesso 27 nov 2019];34(4):329-50. DOI: 10.1007/bf02248742
56. Schramm FR. A bioética de proteção: uma ferramenta para a avaliação das práticas sanitárias? *Ciênc Saúde Coletiva* [Internet]. 2017 [acesso 27 nov 2019];22(5):1531-8. DOI: 10.1590/1413-81232017225.04532017
57. Sinner R. Public theology in Brazil: a first overview. *Tor J Theol* [Internet]. 2014 [acesso 27 nov 2019];30(1):33-46. DOI: 10.3138/tjt.2534
58. Lange F. Public theology and health care. In: Kim S, Day K, editores. *A companion to public theology* [Internet]. Leiden: Brill; 2017 [acesso 6 jul 2019]. p. 325-46. Disponível: <https://bit.ly/30iMXis>
59. Schramm FR. Op. cit. p. 1531.
60. Eich M, Verdi MIM, Finkler M, Martins PPS. Princípios e valores implicados na prática da sedação paliativa e a eutanásia. *Interface Comun Saúde Educ* [Internet]. 2018 [acesso 27 nov 2019];22(66):733-44. DOI: 10.1590/1807-57622016.0853
61. Eich M, Verdi MIM, Finkler M, Martins PPS. Op. cit. p. 738.
62. Saunders C. Introduction: history and challenge. In: Sykes N, Edmonds P, Wiles J, editores. *Management of advanced disease*. 4ª ed. Londres: Arnold; 2004. p. 3-8.

63. Instituto Brasileiro de Geografia e Estatística. Sinopse do Censo Demográfico 2010 [Internet]. Rio de Janeiro: IBGE; [s.d.] [acesso 25 jun 2019]. Disponível: <https://bit.ly/3h7n381>


Participation of the authors

Mary Esperandio wrote the first version of the article. Carlo Leget contributed to the writing of some specific sections and to the final review. Both authors interacted during the preparation of the study and writing of the article.


Correspondence

Mary Esperandio – Rua Brigadeiro Franco, 4.185, apt. 11, Rebouças CEP 80220-100. Curitiba/PR, Curitiba/PR, Brasil.

Mary Esperandio – PhD – mary.esperandio@pucpr.br

 0000-0001-8521-8794

Carlo Leget – PhD – c.leget@uvh.nl

 0000-0002-6647-8141



Received: 7.14.2019

Revised: 5. 4.2020

Approved: 5. 5.2020