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Older adults in palliative care: experiencing spirituality in the face of terminality

Idosos em cuidados paliativos: a vivência da espiritualidade frente à terminalidade

Adultos mayores en cuidados paliativos: la experiencia de la espiritualidad ante la terminalidad

Letícia Celestino Ferreira dos Santos[I]; *Silmar Maria da Silva*[I]; *Alexandre Ernesto Silva*[II]; *Isabel Yovana Quispe Mendoza*[I]; *Fabiano Moraes Pereira*[I]; *Rosimeire Angela de Queiroz Soares*[III]

[I]*Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil;* [II]*Universidade Federal de São João Del Rei, São João Del Rei, MG, Brazil;* [III]*Faculdade de Ciências Médicas da Santa Casa de São Paulo, São Paulo, SP, Brazil*

ABSTRACT
Objective: to understand the experience of spirituality in older adults in palliative care at a public hospital in Belo Horizonte. **Method:** this qualitative study of 11 older adults in palliative care was conducted by interview based on three guiding questions. Data were processed by three-step content analysis. **Results:** two categories emerged, "Spirituality in older adults in palliative care" and "Older adults' perceptions of the health team's approach to spirituality". **Conclusion:** the older adults in palliative care experienced spirituality, relationships with transcendence, regardless of whether or not they had a religion. They endeavor to adapt to the new conditions of life and relieve their symptoms through relationships with things sacred.
Descriptors: Aged; Palliative care; Hospice Care; Spirituality.

RESUMO
Objetivo: compreender a vivência da espiritualidade de idosos em cuidados paliativos de um hospital público de Belo Horizonte**.** **Método:** trata-se de uma pesquisa qualitativa com 11 idosos em cuidados paliativos, por meio uma entrevista a partir de três questões norteadoras. Para análise dos dados, foram aplicadas as três etapas previstas no processo de análise de conteúdo. **Resultados:** emergiram duas categorias, "A espiritualidade no idoso em cuidados paliativos" e "A percepção do idoso sobre a abordagem da espiritualidade pela equipe de saúde". **Conclusão:** os idosos em cuidados paliativos vivenciam a espiritualidade, as relações com o transcendente, independentemente de possuir uma religião. E buscam adaptações às novas condições de vida, dando alívio dos sintomas por meio da relação com o sagrado.
Descritores: Idoso; Cuidados paliativos; Cuidados paliativos na Terminalidade da Vida; Espiritualidade.

RESUMEN
Objetivo: comprender la experiencia de la espiritualidad en adultos mayores en cuidados paliativos en un hospital público de Belo Horizonte. **Método:** este estudio cualitativo de 11 adultos mayores en cuidados paliativos se realizó mediante entrevista basada en tres preguntas orientadoras. Los datos se procesaron mediante análisis de contenido de tres pasos. **Resultados:** surgieron dos categorías, "Espiritualidad en adultos mayores en cuidados paliativos" y "Percepciones de los adultos mayores sobre el enfoque de espiritualidad del equipo de salud". **Conclusión:** los adultos mayores en cuidados paliativos experimentaron espiritualidad, relaciones con trascendencia, independientemente de si tenían religión o no. Se esfuerzan por adaptarse a las nuevas condiciones de vida y aliviar sus síntomas mediante relaciones con cosas sagradas.
Descriptores: Anciano; Cuidados paliativos; Cuidados paliativos ao Final de la Vida; Espiritualidad.

INTRODUCTION

When the available therapies no longer offer satisfactory results to increase the survival rate, it is recommended to adopt care practices based on Palliative Care (PC). PC is understood as an approach which aims to promote the quality of life of the patient and their family in facing diseases which threaten the continuity of life through prevention and relief of suffering, pain and other problems of physical, psychosocial and spiritual natures, since these can generate physical, social, psychological and/or spiritual suffering[1].

Since the spiritual dimension cannot be dissociated from being, spirituality/religion constitutes the fifth domain of care among the eight essential domains established by the guidelines of clinical practice for quality in PC[2].

Therefore, PC crosses the physical condition dimension, intermingling with immaterial aspects of spirituality[1], as it considers that this essential domain contributes to pain and suffering relief in facing illness and finitude[3] in order to improve the quality of life possible to be promoted[4] to older adult patients in PC.

Based on the assumption that spirituality in older adult patients in PC helps to overcome fears, and that it can also help the patient find meaning for life, overcome obstacles and limitations imposed by the disease which threatens the continuity of life, and that care must go through the integrality of being, the question is: How is the experience of spirituality in the hospital context of older adults in palliative care?

Corresponding author: Silmar Maria da Silva. E-mail: silmarmaria@uol.com.br
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Understanding this experience can highlight the nuances related to the care provided and foster reflections on spirituality in care for older adult patients in PC with a view to providing comprehensive care practice in the hospital environment.

Thus, the present study aimed to understand the spirituality experience of older adults in palliative care at a public hospital in Belo Horizonte, Brazil.

THEORETICAL REFERENCE

According to Jane Watson's Theory of Transpersonal Care, Care is a human science developed from philosophical foundations and value systems, and understands that the human being is a biological, social and spiritual whole, which cannot be fragmented[5]. Care involves spiritual transcendence, intersubjectivity and human dignity. Its focus is on protecting, supporting, preserving human dignity, the integrality of being, humanizing care towards a more altruistic, spiritual axis founded on the bases of scientific knowledge[6].

In this sense, transpersonal care aims to override technology valorization which only estimates the cure, and seeks to consider the patients themselves as priority in all their physical dimensions, including spirituality[1].

Spirituality can be understood as universal and is manifested from within the individual. It is related to values of harmony and completeness, connection with the other, interest in others and in oneself, in unity with life, with the universe, and with the end of earthly life. It is a personal search to understand the meaning of life, the relationship with the sacred or transcendent, which may or may not lead to the development of religious practices or the formation of religious communities[7].

Spiritual concerns in PC are a common element of the disease experience, and spirituality can influence the ability to deal with diseases which cannot be cured[8], since they find in their spiritual beliefs ways that help to understand suffering, agony and the uncertainty of their lives[9].

METHODS

This is a qualitative study[10] conducted at the Hospital das Clínicas of the Federal University of Minas Gerais in Belo Horizonte, Brazil, with 11 inpatients who met the eligibility criteria: age of 60 years or older, undergoing monitoring by the PC team regardless of the follow-up time, and who had an understanding of the health situation in which they found themselves. Those who had records in the medical file of changes in cognition, inability to communicate verbally, those who had no knowledge of their situation, at the request of the family or companions, and who were being monitored by the PC team were excluded.

Data collection took place between June and July 2018 at the hospital itself in a private room designated for patients who were able to walk, while interviews were carried out at bedside for patients who were unable to walk and/or get out of bed, and using screens to preserve privacy. Three guiding questions were used[10]: *Is faith important to you? Tell me more about it; How do you believe your faith helps you at this time in your life? How would you like the healthcare team to address "faith" in your care?*

We opted for the term faith instead of spirituality because it was noticed that the participant in the first interview had difficulty understanding the term spirituality. However, understanding was facilitated by substituting for faith, without prejudice to continuing the interview.

The interviews were recorded on a digital recorder and the speeches were transcribed, respecting the sequence of ideas, language, pauses and repetitions. Afterwards, the three steps provided for in the Bardin content analysis process were applied: pre-analysis, material exploration and treatment of results[11].

The speeches were read and re-read in the pre-analysis, while the material exploration was performed by grouping the excerpts of the interviews which presented common ideas, thereby enabling the coding and later categorization for the analytical description. Next, we moved to inferential interpretation by separating the content with similar meanings from clippings of the statements, thus forming two categories: "Spirituality in older adults in palliative care" and "The perception of older adults about the approach of spirituality by the healthcare team". Each participant was identified with the letter I for interviewee, followed by the order number of the interview in order to preserve anonymity.

The study was submitted to and approved by the Research Ethics Committee of the Federal University of Minas Gerais (no. 2,650,177) and the Informed Consent Form was applied to the participants in two copies in accordance with Resolution No. 466/2012 of the National Health Council.

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RESULTS AND DISCUSSION

A total of 11 older adults in PC participated in the study. The majority (72.7%) were male, between 60 and 70 years old (63.6%), married/in a stable relationship (54.4%), with elementary school level education (72.7%) and coming from the interior of the state of Minas Gerais (54.5%). Most were being attended by the PC team for less than a month, with 4 (45.4%) less than a week, and 3 (27.2%) between two to four weeks.

Spirituality in older adults in palliative care

The understanding of spirituality:

> *For me, faith represents hope ... and there is a phrase that says: more important than living is what makes life right ... (I3).*
>
> *Ahhh, faith gives me more security! Faith is my shield (I2).*

Faith unleashes contemplation and reflection on existential experiences, in addition to guiding the search for the meaning of life[7]. This dimension of the meaning of spirituality is an intimately human phenomenon, which does not fit into a complete definition. It is difficult to find a consensus in the elaboration of this concept[12].

Sometimes faith for older adults in PC is related to God:

> *If a person doesn't have faith in God, they don't have faith in anything, right ... (I7).*
>
> *If it weren't for God I wouldn't be here anymore ... every morning I pray, I ask God to help me... (I8).*

Faith can be understood as an act of believing in the existence of something superior, dispensing with material evidence. And God can represent this superior being, a greater force that governs the universe and the life of each person[13].

Spirituality and religiosity are present in the daily lives of older adult patients with life-threatening illnesses, and constitute strategies used to face the challenges, discomforts, sufferings and uncertainties of the illness process; they turn to God and their beliefs in times of distress and despair. The search for the sacred occurs daily in confronting the installed existential void[14]:

> *I understand my illness ... I don't bow to the illness either ... I seek strength in the unpredictable, the impossible, because I've seen it happen... (I4).*

Uncertainties can emerge in the face of terminality, especially when there are difficulties in finding answers to new demands. This situation can jeopardize the relationship of older adults with the transcendent and the search for hope.

> *I used to go to church [...] you know, but then, I even talked to a boy there today and I'm even lost in their indoctrination there, you know? I'm starting to look for something else that touches me more... (I3)*

Faced with the news of a bad prognosis, an older adult subtly suggests the idea of negotiating with God in the quest to establish an agreement and obtain or expand the search for hope.

Although patients react differently to death, everyone experiences anticipatory mourning, a process composed of five phases: 1) denial and isolation; 2) anger; 3) negotiation/bargaining; 4) depression; and 5) acceptance[15].

Spirituality helps to lead to acceptance:

> *You study, analyze, do this, do that, but the boss is up there ... it is He who will determine, it won't be the doctor ..... There is no way I can complain about anything, just live and accept it well, without suffering and crying (I1).*

In situations where illnesses cannot be cured, the spiritual dimension enables patients to develop hope, a meaning for the disease and a purpose and meaning for life, which favors personal maturation, integrity and coping with the experienced situation[16].

Spirituality and religiosity are resources which are capable of providing relief in difficult times and help to seek the well-being and redefinition of the meaning of life in facing what cannot be changed[14]:

> *"I pray before I leave to ask God to improve the pain I feel ... I thought I would never walk again ... And God helped me ... And as there is no cure, and it only gets worse, God is the best medicine, I ask God for everything and the pain goes away !!" (I9).*
>
> *"The faith I have is that I will walk! And God is in power! And the faith that I have, to end all these pains in my body, because I will move in the wheelchair myself! If you put it in your life you will overcome it!" (I10).*

Suffering is attributed meaning from spirituality, relieving it[17]. Therefore, the human being feels stimulated to seek meaning for life, and life has meaning as a whole, and inevitable suffering also has its meaning and is part of life[18].

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Practicing spirituality in facing situations which promote the finitude of the human being is essential for continuing life and instilling hope for older adults in PC, and this practice is considered essential to respond to the opportunities of these individuals regarding their own existence. Hope is a feeling which stimulates human beings in their existence, allowing for an optimistic future. It is believing that something is possible even when there is strong evidence to the contrary[13].

Nursing professionals who understand the moment lived by patients and family members favor building sense in the midst of pain and fear, relieving guilt, recovering hope, reminding the patient of their dreams and desires and offering the family protection in their suffering[19].

The perception of older adults about the approach of spirituality by the healthcare team

Kübler-Ross[20] shares that when she started to address issues such as transcendence, fullness and life after death with patients, she was the target of numerous negative criticisms by the health team itself, because for many, death and contact with higher forces were matters which should never be addressed, and spirituality was seen as something that only churches, priests and doctrines could portray[20].

Some older adult patients expressed this understanding about the healthcare team's approach to spirituality:

> *Someone comes here and asks how I am, and they say that they know that God loves me, right ... I don't want that, you know? ... (I1).*
>
> *The bible explains to us ... not hospital people ... Because salvation does not come from man, it only comes from God. So someone here at the hospital talking about it, it wouldn't change anything for me... (I5).*

Confusing the meaning of spirituality with religiosity can impair interventions aimed at spiritual care, since religion is only one dimension of spirituality, and addressing spiritual aspects improves the acceptance of older adult patients in PC in the finality process of life[21].

Some respondents said they preferred to talk about spirituality with people close to them:

> *I already have my sister-in-law, right ... she's coming here to read the bible ... so it's good like that ... I like it to be people closer to me, to talk about it ... then I would feel better ... (I6).*
>
> *Each person has a different faith, right ... I think it wouldn't make a difference in my life if a health professional came here to talk about faith ... but I prefer to talk about it with my wife... (I11).*

The discussion on spirituality requires advanced communication. This becomes essential for the proper relationship between health professionals, patients and families. It is a vital tool in the health field, as it strengthens relationships, expands patient autonomy and strengthens the bond of trust. However, communicating is not a simple act; it involves unique beliefs and values which can interfere with information transmission[22].

Watson[6] relates "being cared for" with "being a caregiver" going beyond technical achievements and task fulfillment, focusing on desires, emotions, meeting the essence of the other, respecting their culture, origin and other situations which may interfere in the care process[6].

Thus, to facilitate approaching spirituality with patients, one must avoid using rigid and inflexible rules which can increase the complexity of the spiritual dimension or only refer to the idea of religion. Including religious and non-religious terms, as well as tracing actions which are defined by the patient themselves can facilitate this process. It is important that the greatest number of patients have the opportunity to have their spiritual needs identified, regardless of how they understand it.

The construction of therapeutic communication depends on the patient's degree of commitment. The professional can start communication by passing information which comforts, clarifies and dignifies human finitude. The interpersonal relationship which subsequently takes place between the professional-patient-family depends on communication skills[23].

However, sometimes many professionals are unable to establish adequate communication because they are in excess of managerial demands and due to the high number of patients they accompany, and because they do not allow the patient to talk about their issues[24]. In many cases, the health professional might address existential and spiritual issues in the first meeting with the patient early, thereby generating feelings of exposure and invasion of privacy in the patient.

For health professionals who work in the field of palliative care, it is necessary to prioritize the interpersonal relationships of patients in facing finitude and their families, knowing expectations, desires, fears and desires. It is possible to conduct each case through listening and dialogue, promoting acceptance based on compassion[6].

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CONCLUSION

Older adults in PC experience spirituality, relationships with the transcendent, regardless of having a religion. They also seek adaptations to the new living conditions, giving relief from symptoms through a relationship with the sacred. Spirituality is sometimes the source of hope for coping with the phases of anticipatory mourning and the driving force to overcome the news of a poor prognosis.

Although they recognized the benefits of spirituality, they said they were not in favor of the health team's approach to spirituality. With a view to comprehensive practice in the hospital environment, this finding is a reflection for healthcare teams with a view to humanized, comprehensive, holistic care, also encompassing the spiritual dimension of patients.

In view of this and in view of the limitation of specific studies for older adults who experience spirituality in the face of terminality, it is possible to identify the need for further studies in order to subsidize actions that help health professionals to provide care to older adults in PC based on love, compassion and human dignity.

Regarding the limitation of the research presented, the results found in the sample cannot be generalized for a population since it is a qualitative study.

REFERENCES

1. Worl Health Organization. WHO definition of palliative care. [Internet], Genebra; 2002. [cited 2020 Mar 10] Available from: http://www.who.int/cancer/palliative/definition/en/
2. National Coalition for Hospice and Palliative Care. Clinical practice guidelines for quality palliative care. 4ª ed. [Internet], Richmond; 2018. [cited 2020 Mar 10] Available from: https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf
3. Meneguin S, Matos TDS, Ferreira MLSM. Perception of cancer patients in palliative care about quality of life. Rev. Bras. Enferm. [Internet]. 2018 [cited 2020 Aug 20]; 71(4):1998-2004. DOI: http://dx.doi.org/10.1590/0034-7167-2017-0360
4. Borsatto AZ, Santos ADS, Progianti JM, Vargens OMC. Medicalization of death and palliative care. Rev. enferm. UERJ [Internet]. 2019 [cited 2020 Aug 20]; 27:e41021 DOI: http://dx.doi.org/10.12957/reuerj.2019.41021
5. Savieto RM, Leão ER. Nursing assistance and Jean Watson: a reflection on empathy. Esc. Anna Nery [Internet]. 2016 [cited 2020 Aug 20]; 20(1): 198-202. DOI: https://www.scielo.br/scielo.php?pid=S1414-81452016000100198&script=sci_arttext&tlng=en
6. Silva AE. A produção de cuidados paliativos no contexto da atenção domiciliar. [tese de Doutorado]. Belo Horizonte: Universidade Federal de Minas Gerais; 2018.
7. Balducci L. Geriatric oncology, spirituality, and palliative care. J. Pain Symptom Manage [Internet], 2018 [cited 2020 Mar 09]; 57(1):171-5. DOI: https://doi.org/10.1016/j.jpainsymman.2018.05.009
8. Cuartas-Hoyos P, Charry-Hernández R, Ospina-Muñoz P, Carreño-Corredor S. Spiritual care: a look from the perspective of the model of symptom management and palliative care. Rev. Colomb. Enferm. [Internet], 2019 [cited 2020 Mar 08]; 18(1):1-17. DOI. https://doi.org/10.18270/rce.v18i1.2341
9. Academia Nacional de Cuidados Paliativos. Manual de Cuidados Paliativos. [Internet]. São Paulo; 2012. 2ª ed. [cited 2020 Mar 08] Available from: https://paliativo.org.br/download/manual-de-cuidados-paliativos-ancp/
10. Polit DF, Beck CT. Fundamentos de Pesquisa em Enfermagem. 9.ed. Porto Alegre: Artmed, 2018.
11. Bardin L. Análise de conteúdo. Tradução de Luis Antero Reto e Augusto Pinheiro. São Paulo: Edições 70/Livraria Martins Fontes; 2011.
12. Nunes MGS, Leal MCC, Marques APO, Mendonça SS. Long-lived elderly: assessment of quality of life in the field of spirituality, religiousness and personal beliefs. Saúde Debate [Internet], 2017 [cited 2020 Feb 25]; 41:1102-15. DOI: https://doi.org/10.1590/0103-1104201711509.
13. Borges MS, Santos MBC, Pinheiro TG. Social representations about religion and spirituality. Rev. bras. enferm. [Internet], 2015 [cited 2020 Feb 28]; 68(4):609-16. DOI: https://doi.org/10.1590/0034-7167.2015680406i
14. Freitas RA, Menezes TMO, Santos LB, Moura HCGB, Sales MG, Moreira FA. Spirituality and religiousity in the experience of suffering, guilt, and death of the elderly with câncer. Rev Bras Enferm. [Internet]. 2020 [cited 2020 Aug 19]; 2020; 73(Suppl 3):e2019003. DOI: https://doi.org/10.1590/0034-7167-2019-0034
15. Kubler-Ross E. Sobre a morte e o morrer. 10ª ed. São Paulo: Martins Fontes; 2017.
16. Benites AC, Neme CMB, Santos MA. Significance of spirituality for patients with cancer receiving palliative care. Estud. Psicol. [Internet], 2017 [cited 2020 Feb 28]; 34(2):269-79. DOI: https://doi.org/10.1590/1982-02752017000200008
17. Arrieira ICO, Thofehrn MB, Milbrath VM, Schwonke CRGB, Cardoso DH, Fripp JC. The meaning of spirituality in the transience of life. Esc. Anna Nery 2017 [cited 2020 Aug 19]; 21(1):e20170012. Available from: https://www.scielo.br/scielo.php?pid=S1414-81452017000100212&script=sci_arttext&tlng=en
18. Arrieira ICO, Thofehrn MB, Porto AR, Moura PMM, Martins CL, Jacondino MB. Spirituality in palliative care: experiences of an interdisciplinary team. Rev. Esc. Enferm. USP. [Internet]; 2018 [cited 2020 Feb 28]; 52:e03312. DOI: https://doi.org/10.1590/s1980-220x2017007403312.
19. Góes MGO, Crossetti MGO. Developing a spiritual care model for patients and their relatives in illness. Rev. Gaúcha Enferm. [Internet]. 2020 [cited 2020 Aug 19]; 41(esp)e20190150. DOI: https://doi.org/10.1590/1983-1447.2020.20190150

DOI: http://dx.doi.org/10.12957/reuerj.2020.49853

20. Kubler-Ross E. A roda da vida. [Internet]. Rio de Janeiro: Sextante; 1998. [cited 2020 Mar 10] Available from: http://www.espiritualidades.com.br/Artigos/K_autores/Kluber-Ross_Elisabeth_tit_Roda_da_vida-A.pdf.PDF
21. Matos JC, Guimarães SMF. The application of transpersonal and spiritual care for older adults receiving palliative care. Rev. bras. geriatr. gerontol. [Internet]. 2020 [cited 2020 Aug 19]; 22(5):e190186. DOI: http://dx.doi.org/10.1590/1981-22562019022.190186
22. Koch CL, Rosa AB, Bedin SC. Bad news: meanings attributed in neonatal/pediatric care practices. Rev. Bioét. [Internet]. 2017 [cited 2020 Mar 08]; 25(3): 577-84. DOI: https://doi.org/10.1590/1983-80422017253214
23. Barbosa RMM, Ferreira JLP, Melo MCB, Costa JM. A Spirituality as a coping strategy for families of adult patients in palliative care. Rev. SBPH [Internet]. 2017 [cited 2020 Mar 08]; 20(1):165-82. Available from: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582017000100010
24. Meneguin S, Banja PFT, Ferreira MLS. Care for hospitalized elderly patients: implications for nursing team. Rev. enferm. UERJ [Internet]. 2017 [cited 2020 Mar 08]; 25:e16107. DOI: https://doi.org/10.12957/reuerj.2017.16107