Revista Brasileira de Saúde Funcional
ISSN on-line: 2358-8691.
DOI: 10.25194/rebrasf.v12i2.2110
UNIAENE Revista Brasileira de Saúde Funcional

WELL-BEING OF ADULTS ELIGIBLE FOR PALLIATIVE CARE IN FAVELAS IN BRAZIL

O BEM-ESTAR ESPIRITUAL DE ADULTOS ELEGÍVEIS AOS CUIDADOS PALIATIVOS EM FAVELAS NO BRASIL

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Abstract: Objective: To understand the perception of adults eligible for palliative care about spiritual well-being in a context of vulnerability. **Methods:** qualitative study in which 12 adults eligible for palliative care were included. Data were collected through a semi-structured interview guide based on the spiritual well-being scale. For data analysis, the conventional Content Analysis technique was used. **Results:** 91.6% of participants stated that they had some religion and 8.4% stated that they did not have any religious belief. However, it was possible to observe that spiritual well-being was present in a positive way, even in contexts where the subjects do not have a religion. Given this, four categories emerged: the meaning of spiritual well-being; the role of spirituality/religion in decision-making; practices to maintain connection with the sacred and spiritual (Dis)assistance. **Conclusion:** spiritual well-being is a beneficial response in coping with conditions that threaten the continuity of life and allows important reflections on positive feelings regarding improved health status, and is not necessarily linked to the fact of having a religious belief. **Contributions to practice:** the results found highlight the need to validate the spiritual dimension when providing health care and add strategies to professional training.

Keywords: Palliative care; Spirituality; Areas of poverty; Social vulnerability.

INTRODUCTION

The term favela is classified as urban communities that have forms of irregular occupation, fixed in distant locations. In addition, they have an inadequate urban pattern, with a lack of infrastructure, essential public services, land and urban adequacy in which the population of the communities lives in precarious socioeconomic, sanitation and housing conditions [(1)].

Considering this, the discussion about the process of illness and death in the Brazilian favelas becomes valid, given that it is noticeable that the low socioeconomic conditions compromise access to health services by this population, which results in a process of getting sick and dying in an extremely vulnerable context and without dignity [(2)].

Thus, it starts from the concept that vulnerability is understood as something dynamic, and not specific to a particular group, but concerns certain conditions and conjunctures. In this context, being vulnerable is being exposed to economic, cultural, natural and social risks. In addition, there are authors who affirm the existence of situations in which an individual may necessarily be experiencing some deprivation, such as poverty, disease and suffering that causes damage, these being considered vulnerable individuals [(3)].

The contemporary concept of vulnerability dialogues directly with the updated view of total pain. Cicely Saunders recognized that pain goes beyond the physical scope, encompassing emotional, social and spiritual dimensions. This multidimensional perspective highlights that total pain is a complex and integral phenomenon, transcending mere physical manifestation. The critical analysis of this approach points out that an exclusive emphasis on physical pain, common in scientific publications, may neglect other essential aspects related to the multidimensionality of pain, as outlined by Cicely Saunders [(4)].

The attentive listening of Saunders, who identified the physical, emotional, social and spiritual dimensions, emphasizes the importance of a non-reductionist approach that considers the various facets of the human being. This authentic perspective highlights the need for palliative care that goes beyond the one-dimensional approach to physical pain, aligning with the broader understanding of the phenomenon of total pain [(4)].

Following this assumption, Palliative Care is an approach that aims to improve the quality of life not only of adult patients and children, but also of their families who face problems concerning life-threatening diseases[(2)]. Patients eligible for palliative care present more evidently some aspects of human suffering, in which for the identification and effective treatment of pain, it should be considered in its entirety[(5)]. In this perspective, studies on palliative care have shown that the

approximation with religion and the development of spiritual well-being can reduce the suffering of individuals in the face of the issue of the end of corporeal life[6]. For this performance, it is possible to measure through validated instruments, the spiritual well-being.

Spiritual well-being is considered an important dimension for the balance of the individual and that also covers the concept of health, being part of a comprehensive care that is offered by the multidisciplinary team to the patient[7]. Authors also state that spiritual well-being is acquired when an individual finds a purpose of life, in which it entails a feeling of peace and balance with himself, with others and with nature[8]. In this sense, the defining attributes of spiritual well-being include: having a subjective feeling of happiness, affirmation of self-esteem, managing personal relationships with an open attitude and acceptance, having an internal energy [9].

In parallel, authors demonstrate that for the patient, spiritual care was able to provide confidence, reflection, sense of life, self-knowledge and direction in the face of decision-making, and it is possible to infer that spiritual care is important for holistic care[10]. There is evidence that, in palliative care, a biopsychosocial and spiritual model is essential to approach the patient in its entirety, being a tool in the process of rehabilitation, healing and overcoming [11].

In recent years, it has been noticed the immersion of a specialized care to the suffering resulting from life-threatening and disabling diseases, as well as a rescue to the most natural experience of the process of dying[12]. In this way, the practice of palliative care is necessarily interprofessional, in order to access and intervene in the different domains of human suffering, also including the spiritual [13].

In the fullness of being and spiritual attention, it is essential to focus on the person who is sick, not just on the disease itself, seeking spiritual well-being as one of the fundamental indicators of quality of life[14]. In palliative care contexts, spirituality is equally recognized as a driver of quality of life, with faith being the most significant component that represents it[15]. In this perspective, it is noted the existence of knowledge gaps regarding studies that deal with the presence of spiritual well-being in people living in a favela, which highlights the need to carry out future research.

In this way, the following guiding question arises: in the face of human vulnerability in the context of favelas, what is the understanding of adults eligible for palliative care about spiritual well-being? Therefore, the objective of this study is to understand the perception of adults eligible for palliative care about spiritual well-being in a context of vulnerability.

METHODOLOGY

Research design

This is a qualitative research, conducted from the Consolidated Criteria For Reporting Qualitative Research (COREQ).

Selection criteria

The selection of the participants for the study was made by non-probabilistic sampling for convenience, in which part of the adult patients eligible for palliative care who are under the supervision of the professionals linked to the Compassionate Community Project carried out in two favelas in the city of Rio de Janeiro, RJ, Brazil were included. The selection of only a part of the adults eligible for palliative care was carried out due to the limited availability of the number of patients. Therefore, a representative sample was selected based on the feasibility of access to participants within the context of the favelas where the Compassionate Community is located. This allowed a significant analysis of the collected data, while ensuring the efficiency and effectiveness of the research within the operational limitations.

As an exclusion criterion from the research, those patients of the Compassionate Community who were mentally unable to respond to the study were defined, who were evaluated by the application of the Mini Mental State Examination, which consists of two distinct parts. The first evaluates orientation, memory and attention, with a maximum score of 21 points. The second part addresses specific skills, such as naming and understanding, with a maximum score of 9 points. The total score is 30 points, in which higher scores indicate better cognitive performance [16].

Local

The present study was developed in the favelas of Rocinha and Vidigal, located in the South Zone of the city of Rio de Janeiro, RJ, Brazil, served by the Compassionate Community project, between September and October 2022.

The practice of Compassionate Community emerges as a strategy to create a culture based on compassion and community training, to increase the quality of life of its members who are in situations of great vulnerability and suffering, and which is complemented with an integral approach of health professionals working in communities[14]. In this perspective, in search of integrality, Compassionate Communities are rooted in a health promotion approach, with the purpose of supporting the members of the community at the end of life [15].

The communities mentioned are assisted by the university extension project called "Compassionate Community: a proposal for social engagement for the strengthening of palliative care" of the Federal Universities of the municipalities of Rio de Janeiro and São João del Rei in Minas Gerais.

The project is composed of health professionals, local and external volunteers, and

currently serves 22 patients. In this sense, there is the offer of health care to patients in palliative care and their caregivers, in which the inclusion of patients in the project occurs according to their eligibility for palliative care.

The professionals linked to the Compassionate Communities maintain a record of information with data of each patient assisted by the initiative, being them, full name, age, address and the health condition by which the patient is accompanied and being then accessed for the recruitment of the participants, as well as to make the initial contact with the patient prior to the date of the interview.

Data collection procedure

The information was collected through previously scheduled meetings that were held at the home of adult patients eligible for palliative care, in which a semi-structured script was elaborated based on the Functional Assessment of Chronic Illness Therapy Spiritual (FACIT-Sp) Scale, which covers themes related to: believing in something sacred, practices to connect with a spiritual force, interference of spirituality in physical and mental health, among others [(17)].

In relation to sociodemographic aspects, information such as age, sex, religion, education, marital status and income were collected. The semi-structured script prepared gathered questions regarding the relationship of religious practice exemplified by: How do you think your religion is related to your diagnosis? Do you feel spiritually capable of dealing with the evolution of your disease? What is spiritual well-being for you? The interviews were conducted on a day and time according to the availability of the participants, and the pre-scheduling between the participants and the researcher.

The initial contact was made through a pre-visit, which made it possible to explain the objective and purpose of the research, to later schedule a date for data collection. The interviews took place in a place of privacy and individually, and the researcher ensured that there were no constraints or discomfort to the participant. For the subsequent analysis of the data, the interviews were recorded in a mobile recorder application and the transcribed information was identified by letters and numbers.

A pilot test was carried out with four patients at the aforementioned study site, in order to align possible adjustments in the data collection instruments, in which the results of that test were also part of the analysis.

Data analysis and processing

In this study, it was used for data analysis, the analysis of conventional content anchored in Hsieh and Shannon, used in studies whose main objective is to describe a phenomenon, especially when the literature on the subject is limited [(18)].

Content analysis is conducted through the evaluation of the categories, aiming to discover meanings that the encoder perceives, according to the themes that emerge in the text. To categorize the elements, it is necessary to recognize their similarities, allowing their grouping based on the purpose of the study and the theoretical framework, which requires sensitivity to understand their meaning [(18)].

Thus, conventional content analysis begins with repeated readings of the texts to understand the general meaning. Then, the words and expressions that make it possible to capture thoughts or concepts are highlighted, originating the codes [(19)].

Sequentially, after coding and analysis, the codes are grouped and classified into categories. The categories and their meanings arise from the dynamics of the analysis, thus allowing interpretations and conceptions on the theme [(18)].

The data were collected by four undergraduate nursing students and two nurses, master's students, from a graduate program between September and October 2022.

Thus, the interviews were recorded and transcribed in full, with an average audio-recording time of 10 minutes.

Ethical aspects

The study was approved through the Ethics and Research Committee of the Federal University of São João del Rei - Campus Centro Oeste under the opinion number 5.465.365/2022 and CAAE number 48033321.6.0000.5545. The participants were submitted to an explanation about the objective and methodological proposal of the research and later signed the Free and Informed Consent Form. The research was conducted within the required ethical standards.

RESULTS

The study was attended by 12 patients who were under palliative care, residents of a favela in Rio de Janeiro, of whom six (50%) were male, aged 40 and 78 years. With regard to schooling, eight (66.6%) of the participants had incomplete elementary education and about marital status, four (33.3%) were married, four (33.3%) were single and three (25%) were divorced. Regarding income, eight (66.6%) participants received up to a minimum wage, and when asked about religion, 91.6% of respondents said they had some religion, five (41.6%) Catholic, four (33.3%) evangelical, two (16.6%) Spiritist and 8.4% of respondents said they did not have a religion.

In this context, considering the conventional content analysis proposed by Hsieh and Shannon, four categories were established: The meaning of spiritual well-being; The role of

spirituality/religion in decision-making; Practices to maintain the connection with the sacred, being able to be a superior force, the presence of God, among others, and spiritual assistance.

The first category entitled - The meaning of spiritual well-being - reveals the understanding of what spiritual well-being is for the interviewees:

Wow, I think it's when we're fine with God, it's not, with the family and with everyone we can help too. (E9)

Spiritual well-being is when the person is well. For the person to be well with God, the person needs to be well with themselves. That's how everything flows. When you're not well with yourself, nothing flows. (E2)

It is the well-being of when I am being strengthened by the Lord. (E8)

I think it's having a lot of faith, a lot of faith is not, it's going to church. (E6)

It's peace. (E8)

The second category deals with the mentions of patients about how spirituality/religion can help in decision-making, which emerged through the question "How does spirituality help you in decision-making?" In this sense, religious practice is noticeable as an example, in addition to the search for good, the meaning given to things, feelings, achievements and life as a whole:

Helping a lot to lighten my mind to be able to do what is right. (E9)

Yes, it helps. I have peace. I'm not desperate for anything. I have faith and that's all. There's nothing else that catches my attention. (E12)

Yes. Help. Having a lot of courage is not. I try to pray. Faith in God, everything helps you make a decision. (E1)

I feel strong to move on, it's crying. We are meat, we feel it. The worst I went through and I'm here. It may be that this is the worst surgery, but the one I went through, I feel it was worse and I'm sure God will train me for it. (E3)

It helps me to be a more understanding person. It's because God is love, and when I think about doing something stupid, you already think that God is love, so I say no, and I don't do that, God is with me, I can't do something like that, you know? (E7)

As for category three, - Practices to maintain the connection with the sacred - that emerged through the question "How can you achieve spiritual well-being?", the interviewees reported the means used to achieve spiritual well-being:

I think being aware that God is in our life. Knowing that Jesus is our savior and presents our ways. (E8)

It is with a lot of faith that you can move forward. Because if we don't have God in our lives, who will help us is not. In addition to the brothers, there is God first. (E9)

Observing the good things in life. It's better to be happy than to regret. (E6)

Prayer, thought. Always praying. With Jesus in front, God and nothing else. (E5)

Don't think about the negative, only the positive. (E11)

I hear a praise, I put a prayer, I say my prayer when I go to sleep and when I wake up, I pray for the people inside the hospitals, for those who are sick, for those who are in need. (E2)

Help others, advise. When people have the disease, I tell them to have faith, that God solves everything and only God can. (E4)

Finally, the fourth category - (Dis)spiritual assistance - deals with the offer or not of spiritual assistance by the professionals who provide health care, through the question "Have you ever received any spiritual assistance from the health team?":

No. None. From no one. (E9)

No, only I myself, with my faith, with my strength, and the strength of Him first, and then mine. (E3)

No. They treat me in a different way, they talk more about illness. Not religion. But they ask what religion is mine. (E7)

By exploring the spiritual challenges faced by participants in the context of palliative care and in a favela, several aspects can emerge. Among them are issues related to the lack of access to spiritual and religious resources, such as churches or religious leaders, due to the geographical location and the scarcity of services available in these communities. In addition, the lack of adequate emotional and spiritual support by health professionals can be a significant barrier, since many patients in palliative care may feel isolated and helpless in relation to their spiritual issues.

Another potential challenge is the presence of religious or spiritual beliefs that may conflict with medical practices or palliative care protocols, requiring a sensitive and respectful approach on the part of health professionals. In addition, the very condition of living in a favela community, with its characteristics of socioeconomic vulnerability and instability, can significantly impact the spirituality of patients, making them more likely to face existential and meaningful issues during the end of life process. In addition, there is the challenge that there is often no sensitive understanding of the spiritual dimensions in the provision of palliative care, which can lead to neglect or underestimation of the spiritual needs of patients.

In addition, cultural factors play a significant role in the way people understand and seek spiritual well-being. In different cultures, religious beliefs, practices and spiritual values are shaped by traditions transmitted over generations. These cultural factors influence individual perceptions of the meaning of life, death, suffering and transcendence. The community plays a central role in the construction and maintenance of these spiritual practices, offering social and emotional support networks.

DISCUSSION

The findings found in this research through the categories presented, enable the understanding and knowledge about the demonstration of the presence of spiritual well-being in adult patients, in palliative care and who live in a Brazilian favela. Thus, when seeking meaning for the experience of suffering, patients in palliative care find in the spiritual dimension relief and comfort to better face such a situation.

In the analysis of the data, it was found that the vast majority of the participants in this research claimed to have a religion. This finding is consistent with previous studies, where a high rate of religious affiliation was also observed among the participants. For example, a previous survey of 13 patients showed that 92.3% of them claimed to have a religious belief [(20)].

In this perspective, as for the 8.4% of respondents who claimed not to have a religion, it was observed that spiritual well-being was also present in a positive way, which shows that it is possible to live spirituality without necessarily having a religion. It is important to highlight the discussion about the influence of spirituality and religiosity on health care preferences. In this perspective, Catholics were less likely to sign an order not to resurrect and Buddhists received more aggressive interventions at the end of life [(21)].

In this way, there are authors who claim that, with regard to coping tools for people in situations of vulnerability, spirituality and religiosity can provide preventive aspects for drug use, promotion of well-being, self-efficiency, self-respect and self-control for adolescents [(22)].

These results are similar to those found in this study, in which 66.6% of respondents also had incomplete elementary school, suggesting that, despite the social vulnerability, patients living in the favelas demonstrate spiritual well-being and have it as a tool of strength and meaning in coping with the disease, as well as more than 90% of the participants claimed to have a religion.

With regard to the narratives about the meaning of spiritual well-being, participants find in it the meaning for the connection with the sacred, with the inner self and with the others of a meaningful relationship. Authors corroborate by expanding their vision of the spiritual approach by the multidisciplinary team, in which they highlight that spiritual assistance is a source of support that contributes to well-being and coping with everyday difficulties [(23)].

With regard to the narratives about the role of spirituality, all respondents stated that it is in spirituality and/or religiosity that they seek sustenance for decision-making in the face of the health condition. Evidence available in the literature also shows that the spiritual and religious aspect was able to provide direction in the face of decision-making [(10)].

As for the practices for maintaining the connection with the sacred, the awareness of the

presence of God has been recognized as an important resource to maintain the connection with the sacred throughout the entire treatment period. For many of the participants in this study, performing prayers, hearing praise and being well with other people are ways to achieve spiritual well-being and inner peace. Still on this category, a survey conducted with patients with chronic diseases also showed that for many of them, through prayer it is possible to feel the presence of God due to the presence of a relationship and dialogue [24].

With regard to the category of spiritual (dis)assistance, all the interviewees stated that they had never received spiritual assistance from the health team, which highlights the need to implement professional care that can cover the spiritual context in which the patient is inserted, aiming at comprehensive care. Result analogous to that found in a survey conducted with thirteen patients, in which 76.92% of them were interested in talking to the health team about spiritual issues[20]. In view of these results, it is crucial to discuss the practical implications for the provision of palliative care in the favela. We observe the relevance of integrating spiritual approaches into care programs, ensuring a holistic and sensitive approach to the needs of patients, aiming at an action that considers not only physical issues, but also the emotional and spiritual parts. This requires close collaboration between health professionals, religious leaders and members of the community to promote the spiritual well-being of patients and their families.

The approach to spiritual assistance by the multidisciplinary team can strengthen the bond and connection with the patient, being a complementary tool in the treatment[25]. In this sense, the term "evidence-based spirituality" emphasizes that spiritual and religious activities improve the satisfaction and condition of the patient's quality of life, satisfaction with medical care, and prevent negative psychological consequences. The team can support the patient through compassion, solicitude and concern[26].

However, it is evident that, for the most part, professionals relate spirituality only to religion, making prejudice and lack of knowledge become barriers for this approach in patient care. Thus, it is proposed that the health team improve several competencies for the implementation of high-quality spiritual care, among which: personal, spiritual and professional development; ethics of spiritual care; evaluation of spiritual needs and spiritual care interventions; empathetic and compassionate communication; relations of support and collaboration between the interdisciplinary team and inclusion and diversity [27].

In this perspective, authors emphasize the need to implement an approach by the health team, considering the religious and spiritual scenario present in Brazil, as well as the results found, in which 98% of the participants claimed to believe in God, and 66% consider themselves religious and spiritual, 20% spiritual, but not religious and 12% religious [28].

In this way, a recent study emphasized that patients in palliative care showed spiritual

needs, in which ways were found to meet such needs, such as moments of personal meaning and purpose of life. Considering this result, patients achieve tranquility and quality of life, based on the relevance of their needs met [28].

Finally, it is crucial that health professionals are aware of the need to actively encourage the practice of spiritual assistance in palliative care, given that this approach has a variety of meanings for the individual and, in fact, helps in coping with questions about their own existence and disease[27]. Subsidies are needed to cover the patient fully with regard to the balance between body, mind and soul. Therefore, this initiative should be stimulated in Universities, as well as new research, in order to collaborate to the familiarization and improvement of knowledge, given the positive impact of spirituality for patients with life-threatening diseases.

Limitations of the Study

Based on the above, it is important to recognize some limitations of this study. The selection of participants was carried out by means of convenience sampling, using the available records of patients attended by the Compassionate Communities, which may result in a non-representative sample of the general population of patients eligible for palliative care, limiting the generalization of the results. In addition, the inclusion of participants was based on the availability of records in the Compassionate Communities, which can introduce a selection bias, favoring the inclusion of patients who are already in contact with health services and excluding those who are not registered or accessible. The exclusion of patients who did not have mental conditions to respond to the study was carried out based on the application of the Mini Mental State Examination, however, this criterion may exclude patients who, despite being eligible for palliative care, could offer valuable insights on the topic in question. These limitations should be considered when interpreting the results of this study and when generalizing its conclusions to other populations or contexts.

CONCLUSION

It was observed that, although the presence of spiritual well-being was not significantly intensified or reduced among patients eligible for palliative care, the study revealed important aspects about the role of spiritual well-being in this context. The in-depth analysis showed that spiritual well-being emerged as a beneficial response to the challenges posed by the disease and the threatening condition of continuity of life.

This finding shows that spiritual well-being offers crucial support, helping patients to sustain their faith and cultivate a positive perspective on the improvement of health status, even without

significant changes in its intensity.

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