

Spirituality in patient care under palliative care: A study with nurses

Espiritualidade no cuidar de pacientes em cuidados paliativos: Um estudo com enfermeiros

Espiritualidad en la atención al paciente en cuidados paliativos: Un estudio con enfermeros

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ABSTRACT

Objective: To understand spirituality from the point of view of nurses who care for patients under palliative care. **Methods:** This is a qualitative field study, conducted with ten nurses working at a hospital in João Pessoa (PB). The empirical material was collected through semi-structured interviews and analyzed using the content analysis technique. **Results:** The results showed that nurses consider spirituality as a source of strength, comfort and faith, and that when cultivated by patients under palliative care, it helps to improve their condition and accept the dying process. Family support, forgiveness, love, belief, faith and hope were identified as the spiritual needs of these patients, which can be met using various strategies. **Conclusion:** It is evident that nurses recognize the importance of the spiritual dimension in the palliative care of patients, however, there is still unpreparedness to deal with spiritual matters.

Keywords: Palliative Care; Spirituality; Health; Nursing.

RESUMO

Objetivo: Compreender a espiritualidade sob o ponto de vista de enfermeiros que cuidam de pacientes em regime de cuidados paliativos. **Métodos:** Trata-se de uma pesquisa de campo, de natureza qualitativa, realizada com dez enfermeiros vinculados a um hospital de João Pessoa (PB). O material empírico foi coletado mediante entrevista semiestruturada e analisado por meio da técnica de análise de conteúdo. **Resultados:** Os enfermeiros consideram a espiritualidade como fonte de força, conforto e fé e que, quando cultivada pelos pacientes em cuidados paliativos, contribui para melhorar a sua condição e aceitar o processo de finitude. Identificaram o apoio familiar, perdão, amor, crença, fé e esperança como necessidades espirituais desses pacientes, as quais podem ser atendidas por eles utilizando variadas estratégias. **Conclusão:** Evidencia-se que os enfermeiros reconhecem a importância da dimensão espiritual no atendimento de pacientes sob cuidados paliativos, no entanto, ainda existe despreparo para lidar com as questões espirituais.

Palavras-chave: Cuidados paliativos; Espiritualidade; Saúde; Enfermagem.

RESUMEN

Objetivo: Comprender, bajo la perspectiva del enfermero, la espiritualidad implicada en la atención a pacientes en régimen de cuidados paliativos. **Métodos:** Investigación de campo de naturaleza cualitativa, realizada con diez enfermeros de un hospital de João Pessoa (PB). El material empírico fue colectado por medio de entrevistas semiestructuradas y analizado a partir de la técnica de análisis de contenido. **Resultados:** Los enfermeros consideran la espiritualidad una fuente de fuerza, confort y fe, que cultivada por los pacientes en cuidados paliativos, contribuye para la mejora de su condición y aceptación del proceso de finitud. Se ha identificado que el apoyo familiar, el perdón, amor, fe y esperanza son necesidades espirituales de estos pacientes, alcanzadas por ellos a través de diversas estrategias. **Conclusión:** Los profesionales reconocen la importancia de la dimensión espiritual en la atención de pacientes en cuidados paliativos, sin embargo, todavía no hay una preparación para abordar los asuntos espirituales.

Palabras clave: Cuidados Paliativos; Espiritualidad; Salud; Enfermería.

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INTRODUCTION

Palliative care is a care approach that aims to improve the quality of life of patients and families facing a medical condition that threatens their continuity of existence, through prevention, assessment and treatment of pain, as well as psychosocial and spiritual support¹.

The spiritual dimension has been recognized as an important resource, which helps individuals to face adversity, traumatic and stressful events, particularly related to the health-disease process, as in the case of patients without healing possibilities². Thus, the principles of spiritual care can be applied in all stages and contexts to patients under palliative care, regardless of culture, religious tradition and spiritual reference³.

Spirituality is a term that can cover several meanings, with religious or non-religious focus, so it can be confused with religion. Religion is a specific set of beliefs and practices related to faith⁴, which recognize, approach and facilitate access to the Sacred, the Divine, God and Absolute Truth. It is usually based on a set of scriptures and teachings and generally offers a moral code of conduct⁵. Spirituality, in turn, is a broader term which refers to the aspect of the human condition that relates to the way in which individuals seek and express the meaning and purpose of life, as well as how they express a connection status with the moment, with themselves, with the world, with nature and with the sacred³.

Spirituality is a topic of growing interest in health and palliative care^{2,6} and several studies highlight the importance of this dimension of care by nursing professionals^{6,7}. Research emphasizes that nurses need to meet the spiritual needs of patients so that they can reflect and clarify the concerns that disturb the spiritual balance of each individual⁶.

Nursing, as a profession that is in direct contact with the patient, is responsible for a holistic look that in the care process contemplates the biological, psychological, social and spiritual dimensions of the human being. From this perspective, understanding the phenomenon of spirituality is critical to the provision of a quality nursing care^{6,7}. To the extent that the human being is a unit composed of body, mind and spirit, it is necessary that nurses assess the need for intervention in the spiritual field⁷.

It should be noted that discussions about spirituality are vital and can contribute to rescuing the essence of comprehensive care for the patient⁶, and despite evidence of the importance of spiritual care in the context of palliative care, the professionals rarely dispense this kind of care to patients with life-threatening diseases⁸. For health care professionals, including nurses, addressing the spiritual issues in the practice of palliative care is not an easy task for the following reasons: because they have insufficient education on the subject, they lack time, privacy and confidence⁶.

It is evident that the successful application of concepts about spirituality in clinical nursing practice is directly linked to the construction of knowledge underlying the assistance, and can be accomplished through the development of new research

and skills for healthcare approaches in the various scenarios of professional practice⁷.

From this perspective, new investigations on the theme are necessary, in order to contribute to the construction of knowledge within the scope of palliative care and spirituality, and to serve as bases for health professionals, especially nurses, to feel more confident in assisting patients without healing possibilities.

Thus, the findings of this study will be of great importance, as it will allow a wider debate on the theme "palliative care and spirituality" in the field of nursing, which will help its professionals to plan and develop skilled nursing care, and consequently an effective spiritual assistance directed to patients under palliative care.

In this sense, the proposed study contributes to fill the knowledge gap of nursing for patients under palliative care, focusing on the spiritual dimension. In order to do so, the study has the following objective: to understand spirituality from the point of view of nurses who care for patients under palliative care.

METHODS

This is a field study with a qualitative approach. This study aims to achieve information about a particular problem, which demands a response⁹ and has as its data source the very field where the phenomena occur¹⁰.

The study was conducted in a philanthropic hospital, which assists cancer patients under palliative care system in the city of João Pessoa (PB). It should be noted that the hospital has a ward that treats patients under palliative care.

The study's population involved forty clinical nurses who provided care to oncology patients in the hospital selected for the study. For sample selection, the following criteria were used: working during the data collection period; having at least one year's employment in the institution selected for the study, having an interest in participating and a willingness to do so. It is worth pointing out that the sample was taken by availability and consisted of ten nurses, to whom the researcher had access to during the collection of empirical data.

Data collection occurred in the period from August to October 2014, through the semi-structured interview technique, using as the instrument a script with questions, composed of two parts. The first involved the participants characterisation data and the second covered open questions aimed at achieving the proposed objective.

The study's participants' statements were recorded using an MP3 player as the technological resource. To guarantee anonymity, the interview statements were identified by the letter "N", from the word 'nurse', from N1 to N10.

After transcription, the empirical material obtained was analysed using the content analysis technique, which comprises three phases: pre-analysis, coding, inference and data interpretation¹¹.

The research project was submitted to the Research Ethics Committee of the Health Sciences Centre (CCS) at the Federal

University of Paraíba, through CAEE nº 32194614.2.0000.5188. The ethical aspects established in Resolution 466/2012 of the National Health Council on research involving human beings were considered, especially regarding the participants' informed consent form (ICF)¹².

RESULTS AND DISCUSSION

The study participants were ten nurses, of which seven were female and three male, with an age range from 21 to 55 years. Most participants declared they were married and had an income above three minimum salaries. With regard to religion, the participants were included in the two religions prevalent in our society - Catholic (8) and Evangelic (2).

Category I - Meaning of spirituality in the context of palliative care

Category I enabled the construction of two sub-categories. The first relates to the understanding of nurses about spirituality and the second refers to spirituality as a resource that helps patients under palliative care to accept and cope with their situation.

Subcategory I - Spirituality as a source of strength, comfort and faith

In Subcategory I, the nurses participating in this study mention their understanding about spirituality. For them, spirituality promotes strength, comfort and faith.

It is faith ... faith in God. (N1)

It's the faith that exists in each one of us, spirituality is inside us. (N2)

The strength they find in themselves to live. (N8)

Spirituality [sic] are those who believe, isn't it? To believe not in what you see [...] to believe that in some way someone is helping you, someone is giving you strength, someone is comforting you. (N3)

The referenced lines reveal that these professionals consider spirituality as something intrinsic to the human being and which is related to faith in God, or simply to something to believe in and that it can help individuals, promoting comfort and strength.

Spirituality is inherent to the human being and refers to the human quest for the meaning of life, through a relationship with themselves, with others and with the divine. It can be what brings comfort and empowers individuals to continue to live, and may involve a divine figure or a higher power¹³.

A study conducted in Ribeirão Preto aimed to describe the understanding of nurses about spirituality and religiosity, and concluded that participants understand spirituality as a force that transcends the biological and sometimes may be related to a higher being⁷.

Spirituality can exist independently of having a religion, as quoted by Nurse 4:

You have to have a faith [...] because we have to believe in something regardless of religion. (N4)

For the respondent, spirituality is something that people believe, and can exist independently of a religion. Spirituality involves the universal human needs and may or may not include religion¹³. For its part, religion is a set of beliefs that involve the supernatural, sacred or divine and moral codes, values and rituals associated with such beliefs¹⁴.

For people who have a system of religious beliefs, spirituality can offer care and answers to existential questions, and for those who do not have one, it can promote comfort through solidarity and compassion, which reduces the anxieties and the fears associated with pain and suffering¹⁴.

Subcategory II - Spirituality as a resource that helps patients under palliative care to accept and cope with their situation

Spirituality is a very important tool for the practice of palliative care, promoting the improvement of the condition of patients without healing possibilities and helping them to accept the situation and continue to live, even in the face of imminent death. This can be demonstrated in the following reports:

The person who believes in one God, in anything that they can see, they have the strength to survive. They'll never think they're going to die. (N3)

Spirituality [...] is one of the tools that the patient has for healing, right? (N4)

[...] Patients who have spirituality [...] are stronger patients. We see that patients here who are undergoing treatment for ten years and do not succumb, they have metastasis, lung and liver problems, and are well apparently, all say they have faith and believe when we ask [...]. (N5)

I believe that a patient who is spiritualised, they suffer less. They can better accept the situation they're going through. (N7)

These passages reveal that the spiritual dimension is an essential component of care for patients who are under palliative care, as it provides comfort in the face of health issues. It is through spirituality that the patient acquires the strength to deal with and accept the disease.

As observed in these testimonials, several studies have shown the benefit of spirituality in coping with life-threatening diseases^{2,3,14}. Spirituality is the key component in the practice of palliative care because promotes comfort and suffering relief for patients with life-threatening diseases without therapeutic possibilities of cure, which contributes to improve their health situation and their lives³.

Spiritual beliefs reassure patients who believe in the afterlife. For the nurses in this study, this other life is a synonym for passage, as reported by Nurses 6 and 7:

The importance is that the patient know that there can be a life beyond this one. For some patients yes, they evaluate this as signs of diminishing their suffering, they will rest and for those who have a religion this rest is a flowered home, a good passage of tranquillity. (N6)

[...] The spiritualised patients, they are not angry, they understand it as a passage in their lives. (N7).

These testimonies express that these nurses understand that spirituality promotes a peaceful passage to another dimension. This idea of passing is related to various religious beliefs, coming from Christianity, Buddhism, Spiritualism, Judaism and Islam¹⁵.

Spirituality helps terminally ill patients to resist stress and physical and psychological discomforts, in such a way as to promote their well-being until the last moment of their lives. Thus, it can help them, their relatives, nurses and other professionals working with palliative care to cope with situations of imminent death, or death itself, with more tranquillity¹⁶.

Category II - Spiritual needs of patients under palliative care

For a better understanding of this category, the statements of the respondents were divided into two subcategories. The first, entitled "Spiritual needs of family support, forgiveness, love, belief, faith and hope" and the second "Communication, listening, music, bond formation and collaboration of other professionals as strategies to meet the spiritual needs of patients under palliative care".

Subcategory I - Spiritual needs of family support, forgiveness, love, belief, faith and hope

The spiritual needs of patients under palliative care, reported by some respondent nurses, are presented in these sections:

It is familiar, is a family support. Many are abandoned, so I think they need that family support, belief in God is also very important. (N5)

Most patients when they are in the final stage, they have that strength to forgive, you know? That strength of also wanting to be forgiven. It's like they [...] forgive or if someone forgives them they go in peace, they are in peace. There will be no more suffering. (N3)

Forgiveness and also love. They are very needy, sometimes of love, of hugging, you know? (N10)

[...] the search for hope, hoping that it's going to be all right, positive thinking. (N4)

So we have some patients who are very fond of the church, so if they are Catholic, for them the difficulty is not going to Mass, then others look to television to watch a religious program, believers who have other religions also like it a lot when people from the church come here to preach for them, you can feel a total change in their behaviour. (N6)

The patient most of the time when they are conscious, they cry a lot to get better, it is a time when they seek to overcome that moment in every way, then you identify their faith in that moment. (N2)

In light of these reports, it is clear that the spiritual needs of patients under palliative care, which are present in the nurses testimonies, refer to the needs of family support, forgiveness, love, belief, faith and hope. These needs were present in a study¹⁷ that sought to synthesize the fundamental spiritual needs considered in the literature. According to the author, the need for belief is the most expressed in studies and may or not be related to a religious practice.

Nurse 6 reveals that patients under palliative care need religious beliefs because, in face of the illness and hospitalisation process, they can no longer go to church, so they look for other ways to meet this need, whether watching television, or being visited by religious people.

A study showed that patients in the final stage, for the most part, manifest needs to talk to a priest, a pastor or other spiritual leader, and that this need for spiritual support can manifest at any time, however, it is more frequent when their final moment is approaching. The desire to speak to a religious person and to watch Mass on TV was considered by the author as necessary to be identified by the nurse, however, one must previously know the patient's religious orientation. In addition, the study points out that these nurses consider religious support as very beneficial for the life of patients because, to the extent that their need for religious belief is met, they feel more comforted, forgiven and at peace with themselves¹⁸.

Forgiveness is a necessity as important as religious and spiritual beliefs, as individuals who have life-threatening diseases can die without guilt and do not suffer more. It's as if the disease they are experiencing was a divine punishment, and forgiveness could free them of this punishment and reduce the suffering they are going through. This understanding is shown in the following excerpt:

They think that they're going through it as a punishment. So they think that from the moment they're forgiven, their suffering will decrease. (N3)

In ancient times, it was believed that the causes of oncological and terminal diseases were due to a divine punishment and for sins to be purified. These punitive notions relating to diseases persist in the social imagination¹⁹.

Nurse 1's report shows that the family abandonment provides physical and psychological distress to patients without healing possibilities, which harms their health.

When the family does not act and abandons them it is totally different. The patient feels more pain [...] feels abandoned, they cry more, the pain increases, the care you provide, you do not see the comfort that is expected. (N1)

This passage reveals that family abandonment is one of the spiritual complaints from patients and nurses. Research has shown that 18% of communications missed by nurses referred to the situations of fear of death by the patient and family abandonment, which could cause the need for family support to not be met. This need seems to strengthen their condition and minimize the symptoms related to the disease³.

In this sense, the relationship between the nurse and the patient without healing possibilities should be centered on love. The need for love was also identified by respondents. For Nurse 10, this need was considered important because patients under palliative care craved affection.

Some nurses also highlighted the need for faith and hope as spiritual needs of patients under palliative care. It should be noted that they can increase the patient's confidence in the improvement of their health, even in the face of a terminal process.

Subcategory II - Communication, listening, music, bond formation and collaboration of other professionals as strategies to meet the spiritual needs of patients under palliative care

This subcategory reveals the strategies used by nurses to meet the spiritual needs of patients under palliative care. Among them, verbal communication, listening, music, bond formation and collaboration with other professionals stand out, as the following reports:

OK I'm visiting then I realize that patient is crying, right? Hopeless, thinking this is it. And so when they give me a chance I say where is your faith, right? I start talking about good things that everything will be all right. (N1)

This is when we will focus on spirituality to bring that comfort, talking about God, then it is very important. (N2)

We have to meet the patient's expectation. So then, sometimes we just listen. (N4)

Often listening, because the patient has no one to vent to, so I've spent six years working in the ward only listening. (N5)

These testimonials show the importance of verbal communication and listening for the care of the spiritual dimension of patients who are without healing possibilities. This is justified because often the patient is desperate and anguished about how

the illness develops, and in this case they need a positive word, a word of faith, or just someone that listens to them.

Communication represents an effective element in the care of patients without healing possibilities; thus, it is one of the skills that must be used by nurses for patients who are under palliative care²⁰, even to address spiritual issues.

Communication, as a strategy used by the interviewed nurses in order to meet the spiritual needs of patients, also involved Bible readings and praying, according to the following statements:

I read, pray, show them that psalm verse. (N09)

I come, and then I see they're very, very sad, then I start reading the Bible for them. (N10)

Prayer and readings from sacred texts, like the Bible, the Koran and the Torah, for example, can be used to meet the spiritual needs of patients under palliative care and promote their relaxation²¹. Music was also reported by one of the interviewed nurses.

[...] when we have time to provide the assistance we like to play music during the patient's bath, a religious song, right? Sometimes they like that we sing a hymn, so it will greatly depend on the patient and their need. (N6)

This testimony demonstrates that music is a resource that promotes the spiritual well-being of the patient and makes their daily life lighter in the face of imminent death.

A review study showed that the use of music in the palliative care environment can promote comfort, improve the quality of life for patients without healing possibilities and help the family relationship with saying goodbye to their loved one²².

It should be noted that some respondents cite the collaboration of other professionals to help in meeting the spiritual dimension, as in the case of psychologists and chaplains from various religions:

If I see that I can't go beyond my limit, I call someone seeking help. I call the psychologist, call someone, if they are a Spiritist, I call someone from Spiritism, if they're Catholic, I call someone from Catholicism, do you understand? I respect each one's religion. (N3)

We have volunteers here from Catholic and Evangelical Churches, who go through the wards, many anoint the sick, they read the Word, play music, praise God, bring a little comfort and somehow try to cheer them up, because unfortunately we work in a hospital where there isn't a lot of joy, we lose patients every day, so the environment itself is very heavy. (E5)

These passages emphasize that, to meet the patient's needs, the assistance of other professionals, including religious, may be needed, but the patient's will and their religion must be respected.

For this reason, professionals working with palliative care should be attentive to the demands of patients and their families while respecting different beliefs and allowing their free expression, if this is the wish of the patient²³.

Corroborating the findings of this study¹⁸, research carried out in Portugal with nurses who attended terminally ill patients has shown that, in order to provide some spiritual comfort for the patient, nurses turn to a chaplain or religious worker.

O depoimento de E2 relata uma vivência profissional com paciente terminal, durante a qual ele afirma não conversar tanto com o paciente sobre religião:

N2's statement reports a professional experience with a terminally ill patient, during which he says he does not talk much with the patient about religion:

[...] The religious part, I have said very little, because I feel like he's afraid when something about religion is mentioned. [...] I have spoken very little about God because he doesn't let me, he accepts it, but doesn't give me much space. (N2)

This excerpt shows the lack of preparation of this nurse to deal with spiritual issues of patients who are without healing possibilities, for when the professional encounters a denial of the patient on religious issues, it shows a limitation and he no longer addresses the issue.

Other studies also show the lack of staff training to address the spiritual concerns of patients without healing possibilities. Therefore, healthcare providers, including nurses, need to be trained to meet the spiritual issues of patients. This training could be offered by those professionals working in chaplaincy services from hospitals²⁴.

In situations of disease, people can express their spiritual needs in the most subtle ways. Thus, the sick person and the family can benefit from the spiritual care if nurses value this dimension of care and conduct a systematic, competent and rigorous approach. The satisfaction of these needs becomes a dynamic event, accompanied by a sequence of changes that involve the patient, significant others and health care providers²⁵.

CONCLUSIONS

The results allow us to understand that the nurses participating in the study considered spirituality as an important dimension in palliative care. For them, spirituality translates as a source of strength, comfort and faith, thus enabling an improvement in the clinical situation of patients under palliative care, as it facilitates acceptance and their coping in relation to the disease process.

The study highlights that nurses perceive family support, forgiveness, love, belief, faith and hope as the main spiritual needs of patients, and to meet these needs they employ strategies, for example, communication, which, for them,

appears as a necessary element of health promotion, as it allows obtaining information essential to palliative care, and helps to minimize the feelings and emotions related to the dying process.

In addition to communication, other practices such as listening to music, forming bonds and the collaboration of other professionals were also cited. The use of various strategies for palliative care shows that almost all participants nurses in this study feel able to offer spiritual care, except for one nurse who showed certain unpreparedness to meet the spiritual needs of the patient, regarding his difficulty to address religious issues.

Based on the aforementioned, it is considered that this study is of great relevance to the nursing field because it can encourage professionals to reflect on the need to attend to the spiritual dimension of the patient under palliative care, and who needs assistance that enables the relief of spiritual suffering. Additionally, this study can strengthen critical readings on the theme and support further research, since this theme should be further explored in the academic environment.

Therefore, it is suggested that further research could be undertaken to find out how the patients themselves under palliative care perceive the spiritual dimension, in order to identify their spiritual needs and best help them by offering a humanised care. It is also suggested that studies be undertaken that highlight the spiritual development of nurses themselves, since it was considered to be an important tool to be used in palliative care, in the everyday actions of the profession.

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