## NURSING TEAM PERCEPTION ON SPIRITUALITY IN END-OF-LIFE CARE

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**ABSTRACT:** The objective was to investigate the nursing team's perception on spirituality in end-of-life care. A qualitative and descriptive study was undertaken with 20 nursing professionals from a hospital in the Central-West of Minas Gerais. The data were collected between May and June 2014 at the oncology sector by means of a semistructured questionnaire. The data were analyzed using the content analysis technique. The results appoint that, although the nursing team accepts death well, spirituality is hardly discussed and there is still a lack of preparation to address this aspect in end-of-life care. Based on these findings, the theme needs to be included in the curricula of higher and technical nursing education and further research in the area is needed to sensitize and train the professionals.

**DESCRIPTORS:** Palliative care; Spirituality; Nursing team; Nursing; Death.

## PERCEPÇÃO DE EQUIPE DE ENFERMAGEM SOBRE ESPIRITUALIDADE NOS CUIDADOS DE FINAL DE VIDA

**RESUMO:** O objetivo do estudo foi investigar a percepção da equipe de enfermagem acerca da espiritualidade nos cuidados de final de vida. Trata-se de estudo qualitativo descritivo, realizado com 20 profissionais de enfermagem de um hospital da região Centro-Oeste de Minas Gerais. A coleta de dados ocorreu no período de maio a junho de 2014 no setor de oncologia, por meio de um questionário semiestruturado. Os dados foram analisados na técnica de análise de conteúdo. Os resultados apontam que, embora a equipe de enfermagem tenha boa aceitação da morte, a espiritualidade é pouco abordada e ainda existe despreparo para abordar este aspecto na assistência ao paciente em fase final de vida. Com base nesses achados, torna-se necessária a inclusão do tema nos currículos das instituições de nível superior e técnico em enfermagem e ainda mais estudos na área, como forma de sensibilização e capacitação dos profissionais.

**DESCRITORES:** Cuidados paliativos; Espiritualidade; Equipe de enfermagem; Enfermagem; Morte.

# PERCEPCIÓN DE EQUIPO DE ENFERMERÍA ACERCA DE LA ESPIRITUALIDAD EN LOS CUIDADOS DE FIN DE VIDA

**RESUMEN:** La finalidad del estudio fue investigar la percepción del equipo de enfermería acerca de la espiritualidad en los cuidados de fin de vida. Es un estudio cualitativo descriptivo, realizado con 20 profesionales de enfermería de un hospital de la región Centro-Oeste de Minas Gerais. Los datos fueron obtenidos en el periodo de mayo a junio de 2014 en el sector de oncología, por medio de un cuestionario semiestructurado y sometidos a la técnica de análisis de contenido. Los resultados apuntan que, a pesar de que el equipo de enfermería tiene una buena aceptación de la muerte, la espiritualidad es poco planteada y todavía hay falta de preparación para plantear ese aspecto en la asistencia al paciente en fase final de vida. Con base en esas cuestiones, se constata que es necesaria la inclusión del tema en los currículos de las instituciones de nivel superior y técnico en enfermería, además de más estudios en el área, como forma de sensibilizar y capacitar profesionales.

**DESCRIPTORES:** Cuidados paliativos; Espiritualidad; Equipo de enfermería; Enfermería; Muerte.

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#### INTRODUCTION

The disease process causes negative impacts in people's life. Illness provokes feelings of anxiety, despair, anguish, emotional exhaustion, pain, guilt, fear of death, problems with sleep, eating, social contact and in the family routine/structure. On the opposite, different skills emerge in the patient and relatives to cope with the disease<sup>(1)</sup>.

Spirituality is an important strategy adopted to cope with the disease and reduce the discomfort that situation provokes. In that context, nursing care needs to consider the spiritual care needs, with a view to attending to the singularities and desires of the patients and their relatives<sup>(2-3)</sup>.

It is important to highlight that spirituality differs from religiosity. Spirituality is the relation between the subject and something that goes beyond the concept of materiality, which is any and all links with something "divine". Religiosity, in turn, is the belief in a specific religion, characterized by dogmas, hierarchies, holy book, rituals, among other aspects. Thus, we consider that any religion is spiritual, but that not all spirituality is linked to a religion<sup>(3-4)</sup>.

Nursing knowledge and know-how remain strongly impregnated with the biomedical model, in which individual health care is fragmented and impersonal<sup>(1-2)</sup>. The cause of this problem is mainly related to the technological advance, which offers positive advances in terms of better health promotion, disease prevention and treatment and, at the same time, increasingly turns the care process into something impersonal and mechanized<sup>(5)</sup>.

Researchers agree on the importance of end-of-life care based on spirituality to offer distinguished care. This distinguished care model aims not only to relieve the signs and symptoms of the disease and to minimize the suffering, but to take care of the being as a whole, also taking this sphere into account<sup>(6-7)</sup>.

Patients suffering from severe conditions like cancer are examples of patients in need of spiritual care, as they feel weakened by the severity of the diagnosis and the uncertainties of the prognosis. Cancer is considered the second cause of death in Brazil and had led to the death of 76 women and 94 men for every 100,000 inhabitants in the past five years<sup>(8)</sup>.

Studies evidence that patients diagnosed with cancer are more susceptible to negative repercussions of the disease in comparison with patients suffering from other diseases<sup>(1,9)</sup>. Cancer is a disease that carries stigmas like suffering, anguish, indignation, fear and insecurity. All this affects the patients, mainly their mental and biological structure, entailing the need for holistic care<sup>(10)</sup>.

In this perspective, in this study, the nursing team's perception of spirituality in end-of-life care was investigated at an oncology inpatient service of a large hospital in the Central-West of Minas Gerais. We believe that this research is fundamental to promote comprehensive and humanized care, capable of creating affective bonding, promoting interpersonal relationships and triggering actions that support the patient and relatives to cope with the disease.

#### METHOD

A qualitative and descriptive study was undertaken. This method permitted the characterization and measuring of variables, providing information on the study phenomenon. The qualitative approach permitted understanding the meaning of the human relationships, permeated by the emotions and feelings experienced in daily reality, based on perception, intuition and subjectivity<sup>(11)</sup>.

The study was developed at the oncology sector of a large hospital in a city in the Brazilian Southeast, with a population of about 213,016 thousand inhabitants. The city serves as an economic, political and health hub for 56 other cities. The nursing team at the sector consists of one coordinator, four supervisors, two clinical nurses, 16 nursing technicians and six auxiliary nurses. The sector offers 29 bed, six operating under the private care system and 23 under the Unified Health System (SUS).

The invitation was extended to all nursing professionals, in accordance with Professional Practice

Law 7498 from June 25<sup>th</sup> 1986<sup>(12)</sup>, registered in the Minas Gerais Regional Nursing Council (COREN-MG), who worked at the oncology sector of the study hospital and complied with the following criteria: work as a nurse, nursing technician or auxiliary nurse; having at least six months of experience at the oncology sector (minimum for the professional to get familiar with the environment, routine and people involved in work at the sector) and not being on medical leave or holiday.

The data were collected in May and June 2014, when the nurses, nursing technicians and auxiliary nurses were invited. The invitation contained a short presentation on the theme, written in a simple and clear manner, specifying the place, date, time and identification of the main researcher. After the presentation, the participants had the opportunity to clarify doubts, which the researcher answered. At the end, five nurses and 15 nursing technicians agreed to participate in the research.

Next, the participants met with the researcher in a private room to individually receive the Informed Consent Form, which was read together with the participant, who should understand it, and any doubts were solved before the form was signed.

In the next phase, each professional received a semistructured questionnaire the authors had elaborated, consisting of ten questions, aiming to characterize the research participants and discovering their perceptions on spirituality in end-of-life care. The researcher in charge read the questionnaire to the participants and explained the items one by one, solving any doubts. After the professionals had understood the questionnaire, they were asked to answer it individually and, at the end, the researcher collected the questionnaires to guarantee the secrecy of the information.

To analyze the data, the content analysis technique was chosen. According to Bardin<sup>(13)</sup>, this method complements the study of motivations, attitudes, values, beliefs and trends, that is, the set of communication analysis techniques developed by means of systematic and objective procedures. It goes beyond a simple data analysis technique, as it tried to explain not only the interviewees' characteristics and opinions, but to understand the sense and meanings attributed to the problem under analysis.

The secrecy of the information was guarantees, as well as the participants' possibility to drop out of the study at any time without non-material harm or punishments. For the purpose of quotation in the study, the data collected from the professionals were replaced by the word "Questionnaire", represented by the letter "Q", followed by a number they received. Approval for the project was obtained from the Research Ethics Committee at Universidade Federal de São João Del Rei under number 025740/2014.

#### RESULTS

The sample consisted of 20 professionals, being 16 (80%) female and four (20%) male. As regards the professional class, 15 (75%) were nursing technicians and five (25%) nurses. The ages ranged between 21 and 48 years (mean 28 years); the length of experience at the oncology inpatient sector ranged between a minimum of six months and a maximum of 72 months of experience (mean 30 months). Concerning religion, 16 (80%) indicated the Catholic religion, two (10%) declared they are protestant, one (5%) revealed the love for God above all things and one (5%) claimed to be "Catholic/spiritist".

Based on the analysis of the testimonies, three main research categories were constructed: Lack of preparation of the team to address spirituality in the face of death, spirituality as end-of-life care and the Acceptance of death.

## Category 1 – Lack of preparation of the team to address spirituality in the face of death

With regard to the professional approach of the patient concerning spirituality in the face of death, there is a lack of preparation to cope with this aspect. The lack of preparation is perceived in what the participants say and leave unsaid. The spirituality is described subjectively, based on beliefs and, sometimes, demonstrating the inaptitude to discuss the theme.

- [...] Spirituality means accepting death as a natural process of life[...]. (Q15)
- [...] Care is relieving a painful process, dyspnea[...]. (Q7)
- [...]Spirituality for me means having a belief[...] the most difficult is to cope with the family[...].(Q8)

[...]I can't answer[...].(Q13)

Sometimes, when discussing the spirituality concept, many interviewees were unable to answer, left the question unanswered or mentioned difficulties to talk about the theme. The question demonstrates that the nursing team feels uncertain when addressing the patient's spiritual aspects, demanding an understanding of what spirituality is. In the professional context, when the participants describe their experiences during end-of-life care, their approach is delimited to the biological aspects while ignoring the social and spiritual side.

## Category 2 – Spirituality as end-of-life care

In this study, we also looked at spirituality in end-of-life care, which shows to be a tool that adds quality to end-of-life care. Through the testimonies, it was noticed that a small part of the interviewees demonstrated that they discuss spirituality in nursing practice, as the following answers show:

[...]I always try to take the patient and his relatives closer to the meeting with God, to mitigate the suffering, have the divine strength to overcome all difficulties [...]. (Q 16)

[...]I do face difficulties to cope with the departure, but sometimes I pray for the person to go, as she doesn't deserve to keep on suffering, neither the patient nor the relatives[...]. (Q 2)

[...]I try to comfort the patients at that moment, offer the resources we have at the sector, support and solidarity to the relatives, talking and clarifying any doubt. I say my prayers in my head, asking for mercy and comfort for patients and relatives[...]. (Q 12)

Although the number of interviewees who mention spirituality in nursing practice is small, we perceive that the professional tries to strengthen the patient's belief as a way to mitigate his suffering. In addition, the professional uses his own spirituality in the attempt to transmit "strength" to the patient, with a view to the relief of his suffering.

Reports like comforting, talking, being solidary with patient and families, offering resources and clarifying doubts prove the use of spirituality as a care tool in end-of-life care. That is so because addressing someone's spirituality means helping him to link up with something that goes beyond the material. That is truly promoting conditions for the person to feel well, accomplish his desires, be able to practice his philosophy of life. Thus, the participants describe ways to cope with the patient's spirituality.

## Category 3 - Acceptance of death

As regards the acceptance of death, it was observed that most professionals accept death as a natural process of life, considering it to be the only certainty the human being has. They indicated that they use this idea as a way to cope with losing patients, also mentioning that it contributes positively to interrupt their suffering.

[...]That is the only certainty we have, that one day we are all going to die. It's crazy when we lose someone. I for one have no problem to accept death [...]. (Q4)

[...]After I got into oncology I had several death experiences and today I see a normal process, comfort for the people who suffer. We live with many finite patients, where we learn to live with death[...]. (Q14)

- [...] I accept it well. The only certainty everyone has[...].(Q1)
- [...] Something natural, in the process of life we all have a line to follow and death is the end of that

#### DISCUSSION

These study results arouse questions on the nursing care delivered to ill persons. Therefore, it should be reminded that, since the great therapeutic traditions of humanity, the care act demands a global process, involving the being as a whole. Spirituality is proposed as a way to unite the human beings mutually and with the world. Hence, in view of the totality of the being and using this perspective to support care, a new human balance is created which, in turn, will grant the patient biopsychosocial and spiritual comfort within ethical and moral values<sup>(14)</sup>.

Thus, to deliver comprehensive care to the patients, the premise should be accepted that the human being possesses "spirituality" as an intrinsic part of his/her subjectivity. Therefore, one may say that, based on that premise, nursing practice that does not approach this spiritual aspect of the patient turns into an act of malpractice.

Researchers strengthen the important role of nursing in spiritual care and affirm that they should help the patients and their relatives to reconnect with something that grants them support and strength from the spiritual/religious viewpoint. The importance of nursing professionals' assessment of intervention needs in this field is not valued yet<sup>(15)</sup>. That is so because the nursing professionals deal with a professional paradigm, which is to save lives, and sometimes forget about the human being as a whole<sup>(16)</sup>.

When asked about spirituality, the interviewees demonstrated lack of information on the theme. This unpreparedness arouses questions on the professional education process, in which discussions on the theme spirituality are limited or never happen. The Taxonomy proposed by the North American Nursing Diagnosis Association (NANDA), an international classification of nursing diagnoses, appoints the diagnosis "Impaired spirituality". Hence, the nurse can diagnose and promote an intervention, strengthening the patient's beliefs independently from his/her own religion/spirituality<sup>(17)</sup>.

These findings are similar to the results of a qualitative study involving a nursing team, which revealed the professionals' fear to cope with the patients' spirituality, demonstrating the lack of clarity on the concepts of spirituality and religion and their approach<sup>(18)</sup>. That implies an embezzlement in care, departing from a broad health concept in which spirituality is an element that predisposes to the patient's rehabilitation and even to a qualitative and calm death<sup>(2)</sup>.

Researchers highlight the need for the nursing team to truly acknowledge the importance of spirituality in end-of-life care in order to use measures like active listening; acknowledgement of religious practices by the patient and relative; strengthening of these practices without ignoring bodily care, integrating all dimensions of the human being. The nursing team is responsible for identifying the need for spiritual intervention and for including such measures in their care plan, in order to respect the other person's individuality, conduct a dignified end of life with integral care and as little suffering as possible<sup>(19-20)</sup>.

It is important to highlight that, although the dying process in combination with nursing care is frequently discussed in scientific studies, the spiritual approach is hardly mentioned. Therefore, the way spirituality is addressed in scientific papers and the dialogue with the patient about the theme arouse questions<sup>(4)</sup>.

In the aspects related to death, the research participants, like others in a study developed with a nursing team, evidenced the acceptance of this phenomenon. They face the theme as something inherent in the finite existence of human beings. They also appointed that, in care delivery to terminal patients, death is considered a relief and the cessation of suffering and plays a fundamental role in the acceptance process. It also serves as consolation for the suffering the loss of their patients provokes<sup>(21)</sup>.

Some authors present death as one of the main difficulties the nurse faces as, in most cases, it emerges as an issue that is difficult to accept, mainly for cancer patients, who go through a horrendous experience, arousing conflicting reactions in the professionals<sup>(16)</sup>.

Studies contribute by adding that the process of a patient's death can cause important impact in the nursing professionals' experience. The way they relate the concept of death with their own perspectives reflects aspects that influence their professional activities (16,18-22). In this context, the professionals who consider themselves spiritualized find it easier to accept patients' death in comparison with those who do not. Therefore, professionals who accept death are able to cease the pain, anguish and agony the loss of the patient under their care leaves behind (1).

On the opposite, another author reports that the nurses suffer in the practice of end-of-life care due to the therapeutic bond they created with those patients. Thus, the difficult to cope with the human finiteness clearly entails emotional exhaustion<sup>(23)</sup>.

In the context analyzed, the professionals' spiritual practice is submitted to the end-of-life care, and this can cause discomfort or loss in the treatment of a patient against the professional's belief. Therefore, further availability, reflection and training is needed for the sake of a better approach from the spiritual viewpoint inherent in nursing care.

## FINAL CONSIDERATIONS

In view of the matters discussed in this study, it was clear that the nursing team is unprepared to address spirituality in end-of-life care. This fact is alarming, as understanding the human being as a whole and not including spirituality in this care reveals an incompleteness that will negatively affect the patient's rehabilitation or finiteness.

Hence, it is extremely important to include the spirituality theme in the curricula of higher and technical nursing education institution. This approach should take place in a safe and ethical manner, preserving the individual's moral values and promoting the biopsychosocial and spiritual aspects of health.

Finally, this study also evidenced the importance of further research in the area to sensitize and train the professionals with a view to humanized care delivery to terminal patient, aiming to help them in this process in which spirituality is sometimes the way to relieve suffering and pain.

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