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RESEARCH

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## Palliative Care Towards Patients in The End-Life Stage: A Study With Nursing Professionals

Assistência ao Paciente em Cuidados Paliativos na Fase Final de Vida: Estudo com Profissionais de Enfermagem

Atención al Paciente en la Atención Paliativa en la Etapa de Fin de Vida: Estudio de Profesionales de Enfermería

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### ABSTRACT

**Objective:** This study targets to investigate the understanding of nursing professionals about the purpose of patient care in palliative care; furthermore, to identify the resources adopted by the participants towards patients in the end-life stage. **Methods:** It is a field research with a qualitative approach, in which 09 nurses and 09 nurse technicians have participated over the period from May to July 2019. A semi-structured interview technique was used for data collection. Data were analyzed using the content analysis technique. **Results:** From the analysis of the empirical material, two categories came about: 1- Palliative Care has as main objective to improve the patients' life quality with incurable diseases and their families; and, 2- Resources used by nursing professionals to promote palliative care towards patients in their final phase of life. **Conclusion:** The nursing team recognizes the importance of investing in resources that meet the needs involving the physical, psychosocial and spiritual dimensions, aiming to promote quality of life for patients in palliative care.

**Descriptors:** Palliative care, Nursing care, Quality of life, Terminal state, Death.

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## RESUMO

**Objetivo:** Investigar a compreensão de profissionais de enfermagem sobre a finalidade da assistência ao paciente em cuidados paliativos; e identificar recursos adotados pelos participantes da pesquisa direcionados para o paciente na fase final de vida. **Método:** Pesquisa de campo com abordagem qualitativa, na qual participaram 09 enfermeiros e 09 técnicos de enfermagem, no período de maio a julho de 2019. Para a coleta dos dados utilizou-se a técnica de entrevista semiestruturada. Os dados foram analisados mediante a técnica de análise de conteúdo. **Resultados:** Da análise do material empírico, emergiram duas categorias: 1- cuidados paliativos têm como objetivo principal a melhoria da qualidade de vida de pacientes com doenças incuráveis e de seus familiares e 2- Recursos utilizados por profissionais de enfermagem para promoção de cuidados paliativos ao paciente na fase final de vida. **Conclusão:** A equipe de enfermagem reconhece a importância de se investir em recursos que atendam às necessidades que envolvem as dimensões física, psicossocial e espiritual, para a promoção da qualidade de vida do paciente em cuidados paliativos.

**Descritores:** Cuidados paliativos, Assistência de enfermagem, Qualidade de vida, Estado Terminal, Morte.

## RESUMEN

**Objetivo:** Investigar la comprensión de los profesionales de enfermería sobre el propósito de la atención al paciente en cuidados paliativos; e identificar los recursos adoptados por los participantes de la investigación dirigidos al paciente en la fase final de la vida. **Método:** Investigación de campo con enfoque cualitativo, en el que participaron 09 enfermeras y 09 técnicos de enfermería, de mayo a julio de 2019. Para la recopilación de datos, se utilizó la técnica de entrevista semiestruturada. Los datos se analizaron utilizando la técnica de análisis de contenido. **Resultados:** Del análisis del material empírico, surgieron dos categorías: 1- los cuidados paliativos tienen como objetivo mejorar la calidad de vida de los pacientes con enfermedades incurables y sus familias y 2- Los recursos utilizados por los profesionales de enfermería para promover los cuidados paliativos para paciente en la fase final de la vida. **Conclusión:** Un equipo de enfermería reconoce la importancia de la investigación de los recursos que se necesitan, así como las necesidades que implican las dimensiones físicas, psicociación y espiritualidad en la asistencia al paciente para una promoción de la calidad de vida en los cuidados paliativos.

**Descriptor:** Cuidados paliativos, Cuidado de enfermería, Calidad de vida, Enfermedad Crítica, Muerte.

## INTRODUCTION

The scientific evolution and the incorporation of new technologies in health in the last decades have enabled innovations in the diagnosis and treatment of diseases and the increase of life expectancy. In parallel, the worldwide statistical data point to the growing need for specific and humanized care for people with life-threatening chronic diseases, such as metastatic cancer, advanced dementia, functional class IV heart disease, acquired immunodeficiency syndrome, and other comorbidities, cause systemic and irreversible deterioration.<sup>1</sup>

Faced with this problem, Palliative Care emerges as a new treatment modality based on bioethical principles and the maintenance of the patient's life quality, as much as possible, in situations of life-threatening diseases.<sup>2</sup>

Such care aims to promote comprehensive care, in other words, biopsychosocial and spiritual, promoted to the patient through a multidisciplinary team, from the diagnosis of an incurable disease to the final phase of life, with the scope to improve its quality of life by relieving pain and symptoms from pathology. Furthermore, they seek to provide family support during the coping with illness, terminality and grief process.<sup>3</sup>

Experiencing daily situations of imminent death is pointed as one of the main stressors for the patient and their families, sometimes generating psychological distress. Thus, it is important to understand that both patient and family need attention from a multidisciplinary team to better cope with the disease, to minimize suffering and generate better adherence and treatment response.<sup>4</sup> For a large portion of health professionals take care of a dying patient is a challenging task.<sup>5</sup>

In the context of palliative care, the participation of nurses and nursing technicians as members of the multidisciplinary team is essential, since these professionals provide continuous assistance to the patient from the diagnosis of a life-threatening disease to the terminal phase. In addition to supporting family members throughout their loved one's illness to mourning.

So, for the terminally ill patient to be assisted in his or her uniqueness and comprehensiveness, it is essential that the nursing staff, when providing palliative care, prioritize effective communication, authentic presence, and sincere dialogue. Therefore, professionals need to be able to act empathetically that favors patients and their families to better adapt to this process of family finitude and change.<sup>6</sup>

Considering this framework, it is relevant to mention the importance of approaching the nursing professional with the sick person and their family to identify the problems to be solved, planning efficient care strategies to improve the quality of life while preserving the dignity and autonomy of the patient.<sup>7</sup>

Thus, a very effective strategy is the Nursing Care Systematization (NCS), which aims to organize practices through a systematized and individualized nursing prescription. The organization of care allows the patient to relieve pain and other discomforts associated with the course of the disease, providing maximum quality of life for the binomial considered.<sup>8</sup>

Hence, there is a need to expand the understanding of the role of nursing professionals focused on assisting terminal patients in Palliative Care, so that there is an improvement in practices and quality of life of patients and families. It is also emphasized the importance of discussing the subject since there are a small number of studies in the national literature directed to this modality of care directed to patients in the finitude from the understanding of these professionals.

Given the aforesaid, this study starts with the following guiding questions: What is the understanding of nursing

professionals regarding the purpose of terminal patient care in palliative care? What strategies or resources did the study participants adopt for the promotion of palliative care towards the end-of-life patient?

To answer this question, the study aims: to investigate the understanding of nursing professionals about the purpose of patient care in palliative care; and to identify the resources adopted by the research participants towards the end-of-life patient.

## METHODS

It is a field research with a qualitative approach. Qualitative research is anchored in intersubjectivity, creativity, and communicability. This type of research describes the characteristics of a phenomenon or an experience through beliefs, values, opinions, representations, forms of relationship, customs, behaviors.<sup>9</sup>

For sample selection, the following inclusion criteria were used: that the nursing professional was active during the data collection period; have at least one year of experience in the institution selected for the study. Exclusion criteria were as follows: the professional was not in hospital activities during the empirical phase of the study, due to vacation, sick leave or other reason for removal.

The sample was obtained by accessibility, consisting of 18 nursing professionals, being 09 (nine) nurses and 09 (nine) nurse technicians working in the Progressive Care Unit (PCU) of a philanthropic hospital in *João Pessoa* city, *Paraíba* State, Brazil.

The research project was submitted to the Ethics and Research Committee from the *Universidade Federal da Paraíba* (UFPB), receiving the certificate of approval under the No. 731231. All operationalization of the study is in accordance with the ethical observances contemplated in the Resolution No. 466/2012, from the National Health Council, which regulates research with human beings in the country, especially concerning the Informed Consent Form (ICF).<sup>10</sup>

Data collection took place from May to July 2019, after the project approval by the Research Ethics Committee. For this, it was used the semi-structured interview technique containing questions pertinent to the study purposes.

For data analysis we used the content analysis technique, this technique seeks to describe the content emitted in the process of communication through speech or text and is composed of three sequential phases for its conduction: a) Pre-analysis, b) Material elaboration or coding and inference regarding the results obtained, c) data interpretation.<sup>11</sup>

In the pre-analysis, after fluctuating reading of all collected material, excerpts from the speeches of the nursing professionals participating in the study were highlighted for the definition of the corpus of analysis, following the

representativeness, homogeneity, and relevance of the mentioned speeches. In the coding and inference phase, all selected material was separated and categorized as the units of registration based on the rules of counting, classification, and aggregation of information into thematic categories.<sup>11</sup> Therefore, the categorization made it possible to define two categories: Category I - Palliative Care has as main objective to improve the patients' life quality with incurable diseases and their families; and Category II - Resources used by nursing professionals to promote palliative care towards patients in their final phase of life.

The last step corresponded to the interpretation of the results. These were analyzed in the light of the literature relevant to the topic under study.<sup>11</sup>

In order to identify the interviewed professionals while preserving their anonymity, the letter "N" was used to identify the nurses and "Te" to identify the nurse technicians, following the numerical sequence of the interviews.

## RESULTS AND DISCUSSION

Eighteen nursing professionals who work to assist patients in palliative care participated in the study. The sample consisted of 9 (nine) nurses and 9 (nine) nurse technicians. Regarding the characterization, female participants predominated, within the age group from 28 to 58 years old; married as marital status and Catholic religion. It is noteworthy that nursing care for patients in palliative care was analyzed according to the emerging thematic categories of this study.

**Category I** - Palliative Care has as main objective to improve the patients' life quality with incurable diseases and their families

For a better understanding of Category I, some reports of nurses and nurse technicians participating in the study will be presented, as follows:

*Palliative care, I understand that it is to give a little more stability to that patient, stability that is relieving his pain if it exists or alleviating any other concomitant symptoms or pathologies, giving the patient a better comfort not to aggravate the clinical condition (N 01)*

*Palliative care aims to provide pain relief to improve the quality of life of a sick person and their family members since their diagnosis. (N 02)*

*They are care provided to patients who have pathologies without a cure, improving their quality of life and relieving pain. (N 06)*

*They are assistance care offered to every incurable patient, which aims to offer dignity and reduction of suffering, more common in terminally ill patients or in advanced stages of a certain disease (N 07).*

*It has emerged as a therapeutic modality whose philosophy is to improve the quality of life of patients and family members in facing life-threatening illnesses by preventing and alleviating physical, psychosocial and spiritual suffering. (N 08)*

*Active health care is provided to people with serious, progressive and life-threatening illnesses, [...] promoting pain relief and other symptoms, and neither accelerating nor delaying death. (Te 03)*

*Palliative care is provided by a multidisciplinary team that aims to improve the quality of life of patients and their families in the face of a life-threatening disease through the prevention and relief of suffering. (Te 02)*

*Assistance aimed solely at maximizing the remaining quality of life of out-of-cure patients and their families, using techniques that increase comfort but do not increase or decrease patient survival. (Te 06)*

*Palliative care are actions aimed at improving the quality of life of patients and families facing problems, longings with life-threatening diseases through prevention and relief of suffering. (Te 07)*

*These are actions aimed at improving the quality of life of patients and families facing problems associated with life-threatening diseases. (Te 08)*

The statements mentioned by these professionals emphatically emphasize that palliative care is centered on promoting the quality of life of patients and their families, through the relief of pain and physical, psychosocial and spiritual suffering.

Therefore, it is clear that the understanding of these participants is aligned with the concept of the World Health Organization (WHO),<sup>12</sup> consisting of the assistance provided by a multidisciplinary team, which aims to improve the quality of life of patients and their families, in view of a life-threatening disease through prevention and alleviation of suffering, early identification, impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms.

Patients with advanced diseases commonly present uncontrollable signs and symptoms such as pain, nausea, vomiting, anorexia, fatigue, depression, anxiety, constipation, among others. Such manifestations cause intense patient discomfort and a circumstantially negative impact on the quality of life. Given this, the care provided to the patient is no longer curative and becomes palliative, that is, aimed at improving the quality of life.<sup>13</sup>

A study with patients in palliative care identified that sociodemographic and clinical factors identified in the

study population significantly affected their quality of life. The results showed that among the aspects that most present deficits in quality of life were: functional capacity with decline proportional to the progress of the disease, decreased ability to perform basic activities of daily living generating dependence on family members or caregivers, reduced social relationships and the presence of a desire for isolation, and especially negative financial impact due to time off work or increased health care expenses.<sup>14</sup>

Another aspect worth mentioning in the professionals' reports was related to pain relief. According to WHO, pain management should be multifactorial based not only on drug therapy but also incorporate psychological and social aspects that promote resilience in the face of painful moments.<sup>15</sup>

The therapeutic rationale for pain is opioid-based drug adjustment combined with non-opioids. The main goal of analgesic therapy is to achieve the best possible pain reduction and thus safeguard the quality of life.<sup>16</sup>

Category I makes it clear that patient care in palliative care should prioritize pain relief and control of signs and symptoms associated with life-threatening disease in order to alleviate minimizing suffering and promote patient comfort and quality of life, and your family members.

**Category II** - Resources used by nursing professionals to promote palliative care towards patients in their final phase of life

*Research participants' reports cover Category II regarding spirituality, respect for the dignity and autonomy of the patient in palliative care in the process of finitude.*

*Offering physical, mental, psychological and emotional well-being. Guarantee dignity. (N 02)*

*Promoting pain relief, integrate psychological and spiritual aspects. This care happens in a multidisciplinary way for the family. (N 04)*

*Comforting in bed, analgesia when prescribed, psychological support and listening. Emotional support, clarification on the need for alternatives to relieve suffering, intensify the spiritual side according to the religion of the family member. (N 05)*

*Promoting comfort, dignity in the terminal phase and relief from suffering. [...]. We hold conversations with family members. (N 07)*

*I try to effectively resolve the complaints that patients report. I use the help of other professionals (multidisciplinary team). I always try to include religiosity in my words, listening carefully to what the family has to say. (N 09)*

*Treating the patient with respect, understanding, putting himself in the other's shoes [...]. And for the family, try to show the patient's reality by giving them attention, confidence [...] and listening. (Te 01)*

*Providing adequate control of pain and emotional, spiritual and social aspects of the patient. Spirituality as a strategy for coping with family bereavement [...]. (Te 06)*

The above citations make it clear that nursing professionals use religiosity and spirituality as therapeutic resources during their work in palliative care directed to terminal patients. It is important to emphasize that the nursing staff knows how to differentiate religiosity and spirituality. The first has as definition a belief system and practices of a particular community that uses specific rituals and values, while the other search transcends the meaning of life and may or may not be related to religion. A study<sup>17</sup> emphasizes that faith and religion are of paramount importance in the approach to palliative care, which minimizes patient and family suffering, and this does not depend on the course or stage of life-threatening disease, as it positively influences the coping with the disease, providing well-being and improved quality of life.

Religiosity and spirituality help in coping with the difficulties that arise throughout the course of life-threatening illness, comforting the patient in palliative care until the last moment of his life. The nursing staff uses them as a contributing factor to the improvement of quality of life. When faced with finitude, the patient goes through a delicate process and begins to reflect on their existence and the meaning of life.<sup>18</sup>

Another very important aspect reported by the research participants is the appreciation of the patient's autonomy in palliative care and specifically during the process of finitude, placing emphasis on the patient's autonomy, he will be treated with respect, and consequently, his dignity will be preserved.

Autonomy is related to self-sufficiency, independence, and freedom, the freedom that every patient in palliative care needs to have to freely manage their life, making their own choices during their illness process.<sup>19</sup>

The patient with a life-threatening disease and palliative care needs to be cared for by the nursing staff so that their dignity is respected. Every approach used during the course of the disease must be carried out respecting its limits and minimum desires, which approaches should not extend their days but provide quality of life to the lived days, in which the patient should have the right to reach their finitude. with dignity and respect.<sup>20</sup>

Another feature highlighted by some nursing professionals addresses that to promote quality and comprehensive palliative care, was verbal and nonverbal communication reported in the following excerpts:

*[...] Offering a humanized, coherent, dynamic nursing care. Be a humanized professional, true, caring, communicative with the patient's family. (N 01)*

*I use communication as a strategy, approach to mourning. I try to talk, to comfort the hearts of family members with words appropriate for the moment. (N 03)*

*I value communication, respect for the patient's personal choices and question their wishes and explain all procedures. There must be an intimate relationship with the family member to communicate the patient's clinical condition, as well as highlighting the positive and negative points during treatment [...]. (N 06)*

*I must act in all human dimensions to alleviate suffering, comfort, ensure holistic, human and individual attention to the patient and his family, in order to transform the process of death into a less arduous situation [...]. (N 08)*

*I take care of the patient, giving comfort in the bed. We communicate family to patient care. (Te 04)*

*Talking to the patient, advise on medications, the importance of treatment, make personal hygiene, [...]. Basic guidelines for the family, always keeping track of everything, I know that sometimes it seems impossible to overcome pain, but remember that God always has a plan for us. (Te 05)*

*Communication first after a patient and family care approach to preserving a better quality of life. (Te 07)*

*Always trying to prioritize your physical and mental well-being of the patient. I seek a dialogue with the family with passion and attention to the smallest details. (Te 08)*

*Providing better care and always passing patient safety. Just a gesture of affection to the family as a simple and sincere hug. (Te 09)*

The testimonies of these professionals show the importance of communication as an essential resource for the promotion of humanized nursing care to patients in palliative care in the final phase of life, whether verbal or nonverbal.

Verbal communication is defined as all spoken or written language, through words, it is the most used in everyday life. Nonverbal communication is characterized by not using words, for instance, a facial expression, these two types of communication are often used in the routine of nursing professionals.<sup>21</sup>

Communication in palliative care is one of the most effective instruments, as it has numerous benefits for the patient and family, strengthening the bond between the nurs-

ing professional and patient, generating empathy and trust, providing numerous benefits to palliative care, should be offered voluntarily and not by professional obligation.<sup>22</sup>

Nursing professionals recognize verbal and nonverbal communication as an excellent resource to be used in their daily lives. Examples include active auscultation and therapeutic touch. Through them, professionals provide patient comfort and can identify existing weaknesses, so that they can take the necessary steps to generate comfort for the patient and his family.<sup>23</sup>

Category II highlighted the commitment of nurses and nurse technicians to promote palliative care towards the patients during their final phase of life, by valuing spirituality, respect for the dignity and autonomy of the patient, as well as the importance of using verbal and nonverbal as a fundamental resource to provide humanized care to patients and their families.

## CONCLUSIONS

The empirical data from this research show that nursing professionals use pain-control measures and other symptoms related to the life-threatening disease as patient-oriented strategies. They emphasize the importance of respecting the dignity and autonomy of the patient, address spirituality and religiosity, put into practice verbal and nonverbal communication through active listening and therapeutic touch, thus strengthening the bond and empathy with the patient.

The nursing staff involved in the research recognizes that these strategies provide benefits such as improving the quality of life and comfort of patients and families and allow the patient to achieve their finitude with dignity.

This study presents as a limitation the resistance of some professionals to participate in the interview, which may be justified due to the excessive demand for developed activities and the need for specific professional training, considering the subjectivity and complexity of palliative care in terminality.

It is hoped that the results of this study can generate subsidies to strengthen the continuing education of nursing professionals so that they can broaden their level of knowledge about palliative care and consequently enrich the strategies directed towards patients during their final phase of life.

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