

## NURSES' LIVINGNESS ABOUT PALLIATIVE CARE

Vivência de enfermeiros acerca dos cuidados paliativos

Vivencia de enfermeros acerca de los cuidados paliativos

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**Objective:** to analyze the perception of nurses about their experience in palliative care. **Method:** a descriptive and exploratory study with a qualitative approach conducted in a referral hospital in palliative care. The sample consisted of 12 care nurses. For data collection an interview was conducted with a semi-structured script covering sociodemographic data and four questions to meet the objectives of the study. Data were transcribed and evaluated by content analysis. **Results:** the nurses emphasized that palliative care should not only contemplate patients, but the family, revealing feelings and important measures such as affection, affection, comfort and pain management. **Conclusion:** there is a process of implementation about the principles that permeate this type of care and it is worth noting that it is a new service that is in the process of continuous formation and training, which has contributed to the results.

**RESUMO**

**Objetivo:** analisar a percepção de enfermeiros acerca da sua vivência em cuidados paliativos. **Método:** estudo descritivo e exploratório com abordagem qualitativa realizado em um hospital de referência em cuidados paliativos. A amostra foi constituída por 12 enfermeiros assistenciais. Para coleta de dados foi realizada uma entrevista com um roteiro semiestruturado abrangendo dados sociodemográficos

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e quatro questões para atender aos objetivos do estudo. Os dados foram transcritos e avaliados mediante análise de conteúdo. **Resultados:** os enfermeiros destacaram que os cuidados paliativos não devem contemplar apenas os pacientes, mas a família, revelando sentimentos e medidas importantes como afeto, carinho, conforto e manejo da dor. **Conclusão:** há um processo de efetivação acerca dos princípios que permeiam esse tipo de cuidado e cabe salientar que é um serviço novo que está em processo de formação e capacitação contínuo, o que tem contribuído para os resultados.

**Descritores:** Enfermagem; Cuidados paliativos; Doente terminal; Humanização da assistência

## RESUMÉN

**Objetivo:** analizar la percepción de las enfermeras sobre su experiencia en cuidados paliativos. **Método:** un estudio descriptivo y exploratorio con un enfoque cualitativo realizado en un hospital de referencia en cuidados paliativos. La muestra consistió en 12 enfermeras de atención. Para la recopilación de datos, se realizó una entrevista con un guión semiestructurado que cubre datos sociodemográficos y cuatro preguntas para cumplir con los objetivos del estudio. Los datos fueron transcritos y evaluados por análisis de contenido. **Resultados:** las enfermeras enfatizaron que los cuidados paliativos no solo deben contemplar a los pacientes, sino también a la familia, que revelan sentimientos y medidas importantes como el afecto, el afecto, la comodidad y el manejo del dolor. **Conclusión:** existe un proceso de implementación sobre los principios que impregnan este tipo de atención y vale la pena señalar que se trata de un nuevo servicio que está en proceso de formación y capacitación continua, lo que ha contribuido a los resultados.

## INTRODUCTION

The process of demographic transition is very important to understand as transformations experienced by society. Coupled with increasing urbanization and technological advances, life expectancy has increased, and thus the noticeable changes in mortality rates for both children and infectious diseases or those affecting Brazilians' lifestyles.<sup>1</sup>

On the other hand, there is an increase in the incidence of chronic and incurable diseases, or that brings reflections and reflections on the process of terminality, in which it is common to notice feelings of fear and anguish on the part of patients especially when they see for diseases of the circulatory system, diabetes, cancer and chronic respiratory disease.<sup>2</sup>

In this context, emerging from Palliative Care (PC), considered an innovative form of assistance, performed by a multidisciplinary and interdisciplinary team, whose approach is holistic, that is, to contemplate the human being in its entirety, to consider the biopsychosocial and spiritual aspects that exercise influence on one's livelihood. Nurses play a major role in PC care, as they stay with the patient full-time and act on controls and warnings of various symptoms, including pain, with these comfort resources, support and humanized care features, always in use of a singularity and one's desires.<sup>3</sup>

In the 1980s, outbreak in Brazil as a philosophy of CP. The first signaling services for the states of Rio Grande do Sul, São Paulo and Santa Catarina. In Rio de Janeiro, it began with the Cancer Hospital IV, which has been operating since 1989 and is part of the National Cancer Institute, which

presents a model of outpatient care, hospitalization and home care, using the national reference in teaching as well as in vocational training.<sup>4</sup>

The nurse is the professional who provides direct assistance to the patient, therefore, daily monitors the progress, or regressions of the patient's health status, or corroborates the establishment of a helping relationship for the patient and their families. However, understand that death is a natural process, inherent in life, but live the feelings surrounding this event.<sup>5</sup>

The experiences lived by nursing students present weaknesses compromised in the formation of future professionals, especially regarding the PC. In addition, he realized that a means of PC consolidation in the country would be to change the level of knowledge management level as from reconstructions in the curricular levels of health professionals.<sup>5</sup>

Given this scenario, it is necessary to improve the teaching curriculum, because despite the technological advances, especially in the health area, the technician model in the training of professionals still predominates, leaving behind the approach of disciplines that awaken the student's critical sense and reflective that will be essential in professional practice. Health courses, especially those in Nursing, in recent years have sought a more humanistic formation. However, despite efforts, curricula still remain fragmented, with disciplines that primarily address theories and practices that will provide input for purely technical action.<sup>6</sup>

Given the thematic relevance and current discussions on the subject, the objective was to analyze the perception of nurses about their experience in palliative care in a referral hospital.

## METHOD

This is a descriptive and exploratory field study with a qualitative approach, performed in a reference hospital for the care of patients who need CP in the city of João Pessoa-PB. It was qualified as a Specialized Unit in Extended Care, through Ordinance No. 1.143<sup>7</sup>, of September 19, 2016 making it a reference in palliative care.

The research universe consisted of 25 nurses who work in that institution and the sample was for convenience and consisted of 12 nurses who met the following inclusion criteria: work in the referred sector as a nurse, have more than six months in service in the institution, and be active during the collection period. Nurses who performed only administrative activities or who were on vacation were excluded.

For the quantitative, the sample saturation criterion was used, in which the number of participants is operationally defined from the perception of redundancy and / or repetition and thus considering unproductive to persist with the collection.<sup>8</sup>

Data collection was performed in September and October 2018, through a semi-structured script composed of two parts. The first included sociodemographic data (age, gender, length of professional practice, title and weekly workday); and the second part addressed four questions concerning PC. The interviews were recorded and transcribed in full and

later analyzed from the steps proposed by Bardin, which were organized around pre-analysis with the exploration of the material, coding, inference, and ending the interpretation of the results.<sup>9</sup>

The identity of the participants was preserved through the use of an interview code starting with the letter E, accompanied by a cardinal number (1, 2, 3 ...), obeying the chronology in which the interviews took place. The research respected what is recommended in Resolution No. 466/2012<sup>10</sup>, of the National Health Council, which regulates research involving human beings, being approved by the Research Ethics Committee of the University Center of João Pessoa - UNIPÊ / PB under the CAAE: 94923118.6.0000.5176 and the Consent Report: 2,901,544 on September 18, 2018.

## RESULTS

The study included 12 nurses, with an average age of 38.4 years, ranging from 25 to 62 years. Of these, nine (75%) were female. The length of professional practice ranged from 01 to 20 years with an average of six years and seven months.

Regarding the title, seven (58.3%) nurses have only graduation, four are specialists (33.3%) and one (8.4%) holds the title of master. Of the 12 nurses interviewed, four (33.3%) have more than one job, while eight (66.7%) work in only one hospital. The weekly workload ranged from 30 to 70 hours.

From the transcription and content analysis of the research corpus, three categories emerged: Perceptions about what palliative care is; relevant points to consider when performing palliative care; The management of pain in palliative care.

### Category I- Perceptions about what palliative care is

According to the interviewees' perception, PC is associated with the idea of caring for patients in an unlikely cure context, providing pain relief and comfort to both the patient and their families.

*It is to provide an end that is not in great pain. (E1)*

*It is the care provided. Comprehensive care, with a holistic view, by a multidisciplinary and interdisciplinary team and is dedicated to the patient and family. (E4)*

*Care based on care provided to patients with a life-threatening disease. With any life threatening illness, from the diagnosis stage to the grief stage, which should also be performed with the family. (E10)*

*Taking care of the patient when he has a chronic disease, a disease that has no cure, we will take care of his pain, he will heal the spiritual side. We will take care of the family, right? (E12)*

Nurses bring the issue of comprehensiveness in the care process, and that in order to reach issues inherent to the family and the dimension of spirituality, the action of an interdisciplinary team is necessary.

Given this situation, nurses must be prepared to deal with spiritual issues and attend not only the patient who needs their care, but also their family. However, although the fulfillment of spiritual needs are indispensable for the integral care of the patient, it is often observed that this lack of care, which can be minimized through training of professionals.

### Category II- Relevant points to consider when performing palliative care.

In category II, nurses emphasize that in patient care should be promoted comfort actions, providing a pleasant and welcoming environment that offers attention, love, affection, spiritual and psychological support.

*Drug treatment, with bed comfort, a change of position and a word of comfort, a handshake and attention. This with family members too. (E4)*

*Love, attention, affection, this is paramount in palliative care, must always exist, and it is better than an injection. (E9)*

*Patient comfort, information for the patient and family, pain control, psychological support. (E11)*

Nurses are concerned with providing nursing care to patients in PC prioritizing the promotion of comfort in order to minimize physical, psychological and spiritual pain, believing that with terminality the patient needs to feel welcomed and loved, not just for your family but also by the staff that accompanies you throughout the terminality process.

*We have to be trained as well and always be up to date in relation to palliative care. (E2)*

*Most professionals are not prepared to deal with palliative care, since most institutions, they teach students in the health area, in the sense of healing, in the curative model. (E4)*

*It is important to further qualify professionals in palliative care. (E5)*

With the increasingly demanding and competitive job market, there is a need for qualified professionals prepared to work in PC, this makes the professional has a profile that envisions a constant practice in search of qualification and improvement of scientific technical knowledge, however, recognizing the value of the emotional and social dimensions important in human relationships.

### Category III- The management of pain in palliative care.

In category III, nurses emphasize the importance of pharmacological measures combined with non-pharmacological measures in relation to pain management in PC.

*We mix medications to the point of not letting that patient feel pain, for example, he takes: dimorf, takes tramal and dipyrone. (E3)*

*Sometimes you may have pain in your soul, so you can approach that person and ask: how was your day? How was your afternoon, do you need something? Give a smile, a hug that sometimes relieves much more than a certain medication. (E8)*

*Use of medication is also a measure of comfort, such as promoting a clean, airy, comfortable environment and performing some procedures that can be done to minimize pain and suffering. (E10)*

*It can be the pharmacological, the psychological. It can also be the welcoming of the patient, when he arrives at the hospital, and also the welcoming of the family, whether in simple care, or simple information, this helps a lot, right? (E12)*

Pain was a relevant theme in this study, revealing the concern and importance given by nursing professionals.

## DISCUSSION

Despite efforts related to prevention, promotion of individual and collective health, the aging of the Brazilian population has been added to challenges for the exercise of subjectivity beyond an effective exercise of ethics and human solidarity. The increase in chronic health problems, when combined with the increased demand for health services, brings with it an increase in the expectation of work efficiency and effectiveness.<sup>11</sup>

Based on the management of clinical symptoms, the PC seeks to recognize the necessary balance between the strategies used to prolong life, paying attention to the possibility of higher quality, with the issues inherent to comfort in relation to terminality, both for the patient and family.<sup>12</sup>

Another important aspect in patient care in PC refers to the emotional changes that affect patients and families during the disease process. Emotional difficulties arise, and bring together various feelings, especially during the diagnosis phase and are directly related to the coping capacity of each patient and may last until the end of the disease care. Patients and relatives sometimes seek faith and religion for refuge strategies to face the most critical phases of the terminality process.<sup>13</sup>

Considering the family and the patient as a care unit reiterates the need for empathy and great sensitivity on the part of the nurse. It is noteworthy that the care dedicated to the patient should reflect the attention given to the family, since family members share the suffering of their relative.<sup>14</sup>

Welcoming and guiding the family are crucial points and contribute the necessary support to strengthen and be able to stay with your loved one in facing the intense demands and feelings that arise in the terminality process. When the terminology impossible to cure is assumed, one may come to the wrong conclusion that there is nothing else to do to promote the patient's quality of life in the face of treatment, however care must remain with the patient and their family since the diagnosis extends after death and in the mourning phase.<sup>15</sup>

Among the relevant points for performing PC, we highlight the promotion of comfort, which should be offered individually according to the needs of each patient, in order to provide a pleasant, welcoming environment, thus generating physical, spiritual and psychological well-being, also stimulating the presence of family members with the patient and demonstration of affection, concern and compassion on the part of professionals.<sup>16</sup>

In the interdisciplinary team, the work of the psychology professional contributes greatly, with interventions aimed at minimizing suffering, in the elaboration of eventual emotional sequelae resulting from this process, in the promotion of humanization, providing effective communication, active, comprehensive and reflexive listening, facilitating relationships between team - patient - family, as well as better adherence to treatment. Therefore, the nurse should ask the help of this and other professionals whenever deemed necessary.<sup>17</sup>

In this way it guarantees the integral reception and assistance to patients and their families where each professional has his or her role. Thus, interdisciplinarity proposes to contemplate a vision that allows integrality based on the dialogue between the various areas of knowledge. Interdisciplinarity does not propose the annihilation of specializations, but as a unit of reciprocity between different knowledge, without privileging one specialty and / or category over another.<sup>18</sup>

Aiming at comprehensiveness in care, questions about spirituality have been pointed out for providing conditions of physical and emotional well-being to terminally ill patients in this perspective, the relief of physical and psychological symptoms is observed as it promotes the reduction of anxiety as well as the reduction of anxiety. hopelessness. This care is given within the interdisciplinary team to the chaplain, who provides religious and spiritual services to the sick in hospitals to alleviate the physical, emotional, and spiritual suffering of terminally ill people.<sup>19</sup>

In order for the skills and competences to care for patients with life-threatening illnesses to be achieved, a paradigm shift in the still fragmented, Cartesian and reductionist vocational training is indispensable. The principles and foundations that define the formation of nurses present in the National Curriculum Guidelines of the Undergraduate



Nursing Course (DCNEnf) determine that the Higher Education Institutions should train qualified professionals with general skills, with a generalist, humanist, and reflective critical eye.<sup>20</sup>

With regard to the training of these professionals, it is still possible to find large gaps in terms of academic education, since the curriculum offered in most courses does not have some important disciplines for the formation of future nurses, such as those aimed at the PC, maintaining a conservative formation. On the other hand, there is an increase in the offer of courses and postgraduate studies *latu sensu* which has configured a necessary advance.<sup>21</sup>

With regard to pain management, Cicely Saunders, nurse, doctor and social worker elaborated the concept of total pain. He dedicated his life to patients who could not be cured, and from the perspective that when it was no longer possible to cure, it was possible to take care, aiming to keep the patient free of pain. He stressed that pain could not be interpreted solely from the prism of the physical dimension, but should consider the emotional, social and spiritual aspects as these aspects also influence pain expressions in the face of terminality.<sup>6</sup>

Pain is the main and most complex symptom found in patients with CP. Pain control should not be approached in isolation nor should it be ignored as it is a right and in this context a duty of professionals. Creating pain reduction strategies should be seen as a priority as being the fifth vital sign significantly affects patients' quality of life and requires both preventive care and appropriate treatment as it is known that the adoption of effective practices have the ability to reduce pain from 80% to 90 %.<sup>22</sup>

The World Health Organization has standardized pharmacological analgesia by introducing the three-step Analgesic Ladder, which recommends the use of drugs based on pain intensity. A fourth step has been included where in addition to classic analgesics it is possible to perform minimally invasive procedures in cases of pain that is difficult to control.<sup>23</sup>

For management, it is emphasized that adequate pain relief will be directly related to the choice of more effective analgesia methods where pharmacological therapy considers opioid agents as one of the most significant groups for control, as they are capable of inhibiting pain genesis and conduction of the painful stimulus. Pain management should be one of the priorities as it contributes to patient comfort and dignity and to achieve this goal depends on an expanded assessment based on multidisciplinary interventions. Regarding non-pharmacological therapeutic measures, they represent techniques that are used simultaneously with conventional treatments, especially relaxation, acupuncture, yoga and acupuncture techniques.<sup>24</sup>

The PC present as objectives of a care methodology to achieve improvements in the quality of life of patients and their families in coping with problems arising from treatments or life threatening disease itself. In this sense, it is important for nursing professionals and health staff to identify early efficiently and effectively assess and properly

manage pain and other possible physical, psychosocial and spiritual problems.<sup>25</sup>

## CONCLUSIONS

This study sought to contribute to the analysis of nurses' perception of their experiences on PC where nurses refer objectively and recognize the need for differentiated care, permeated by the principles of humanization, multidisciplinary work, enabling the appreciation of quality life, comfort, pain control, and family interaction.

They highlighted the performance of comfort measures and the promotion of pain control and relief through pharmacological and non-pharmacological methods, which in the meantime may contribute to the quality of life, in addition to recognizing that the process of dying with dignity should consider Patient's opinions inherent to the phase he experiences as it involves limitations, moments of anguish and fears. Among non-pharmacological measures, there was emphasis on lovingness, attention, affection, smiles, hugs, and psychological support. It is also mentioned that the care should not only contemplate the patient, but the family as a unit of care and that this attention should occur from the diagnosis until the grieving phase.

Through this research, it is expected to collaborate for the accomplishment of future studies besides investigations about the professionals formation in order to broaden the discussions about the PC. As it is a research carried out in only one institution, it can emphasize the need to carry out new studies in order to evaluate the quality of care as well as the need for continuing education in specialized services.

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Received in: 03/02/2019

Required revisions: 01/08/2019

Approved in: 14/10/2019

Published in: 30/03/2020

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Disclosure: The authors claim to have no conflict of interest.