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## Palliative care in oncology from a nursing perspective: unveiling knowledge and practices

Cuidados paliativos na oncologia sob a óptica da enfermagem: desvelando saberes e práticas

Cuidados paliativos en oncología desde la perspectiva de enfermería: desvelando conocimientos y prácticas

#### **ABSTRACT**

Objectives: to identify nursing professionals' knowledge of palliative care and demonstrate the assistance provided to people experiencing cancer. Method: descriptive study with a qualitative approach, conducted with 20 nursing professionals who worked in a High Complexity Oncology Unit. An open-ended interview script was used to collect data. From the analysis, as proposed by Bardin, two thematic categories emerged. Results: nursing professionals understood that palliative care is directed to patients in a more advanced stage of the disease with the purpose of alleviating suffering and providing well-being. In care practice, they emphasized important care and procedures to promote comfort, but also emphasized the importance of offering affection and attention. Final considerations: training health professionals and addressing palliative care in Nursing schools are essential for effective and quality care.

**Descriptors:** Neoplasms; Nursing; Palliative care; Oncology nursing.

#### **RESUMO**

Objetivos: Identificar o conhecimento dos profissionais de enfermagem sobre os cuidados paliativos e demonstrar a assistência prestada à pessoa que vivencia uma doença oncológica. **Método:** Estudo descritivo de abordagem qualitativa, realizado com 20 profissionais de enfermagem que atuavam em uma Unidade de Alta Complexidade em Oncologia. Para coleta dos dados, foi utilizado um roteiro de entrevista aberta. Da análise, conforme proposto por Bardin, emergiram duas categorias temáticas. Resultados: Os profissionais de enfermagem compreenderam que os cuidados paliativos são direcionados aos pacientes em um estágio mais avançado da doença com a finalidade de amenizar o sofrimento e proporcionar bem-estar. Na prática assistencial, ressaltaram cuidados e procedimentos importantes para promoção do conforto, mas também destacam a importância de oferecer carinho e atenção. Considerações finais: São imprescindíveis a capacitação dos profissionais de saúde e a abordagem dos cuidados paliativos nas escolas de enfermagem para uma assistência efetiva e de qualidade.

Descritores: Neoplasias; Enfermagem; Cuidados paliativos; Enfermagem oncológica.

#### **RESUMEN**

Objetivo: Identificar el conocimiento de los profesionales de enfermería sobre los cuidados paliativos y demostrar la asistencia brindada a las personas que padecen cáncer. Método: Estudio descriptivo con enfoque cualitativo, realizado con 20 profesionales de enfermería que laboraban en una Unidad de Oncología de Alta Complejidad. Se utilizó un guión de entrevista abierta para recopilar los datos. Del análisis propuesto por Bardin surgieron dos categorías temáticas. Resultados: Los profesionales de enfermería entendieron que los cuidados paliativos están dirigidos a pacientes en un estadio más avanzado de la enfermedad con el objetivo de aliviar el sufrimiento y brindar bienestar. En la práctica del cuidado, destacaron importantes cuidados y procedimientos para promover el confort, pero también resaltaron la importancia de ofrecer afecto y atención. Consideraciones finales: Es fundamental formar profesionales de la salud y abordar los cuidados paliativos en las Escuelas de Enfermería para una atención eficaz y de calidad.

Descriptores: Neoplasias; Enfermería; Cuidados paliativos; Enfermería oncológica.

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#### INTRODUCTION

Cancer, considered a global public health problem, is one of the most prevalent causes of death before the age of 70. impacting both life expectancy and quality of life. It is estimated that 28.4 million new cases of cancer worldwide will occur in 2040, representing a 47% increase compared to  $2020^{(1)}$ .

Given the growing number of people affected by cancer and, at the same time, technological and scientific advances that increase life expectancy, the implementation of Palliative Care (PC) becomes an important strategy for improving quality of life and reducing the number of unnecessary hospitalizations(2).

PC understands the actions to relieve pain, suffering, and other symptoms when patients face illnesses or other health conditions that threaten or limit life expectancy<sup>(3)</sup>. Provided by a multidisciplinary team, they aim to improve the quality of life of the sick individual and their family through an approach that considers psychosocial, physical, and spiritual symptoms<sup>(2)</sup>. When started early, they improve quality of life, reducing rates of anxiety, depression, and other symptoms of stress, and increasing coping strategies, compared to traditional care focused on the disease cure<sup>(4)</sup>.

This approach is based on the premise of humanized measures aimed at patients with no possibility of cure and who are terminally ill, from the diagnosis of the disease to the final stage of life. The aim is to provide individualized care to the sick person and their family, managing symptoms and preventing suffering, with the intention of promoting greater comfort and well-being<sup>(5)</sup>. In cancer treatment, disease-modifying therapy should be simultaneous with PC throughout the therapeutic trajectory, and not only at the end of life. However, there is a cultural stigma that equates PC with end-of-life care, which contributes to impairments in the quality of life and death of many patients, with repercussions on the physical and emotional health of the family. It should be noted that referrals are often late or non-existent, so few receive quality PC(6).

Faced with the difficult journey of coping with an incurable disease such as cancer, Nursing plays an important role in providing care that offers dignity to the patient and their family. Professionals' knowledge of PC in oncology should be based on promoting the comfort of people with cancer, aiming at their well-being, with the relief of symptoms such as pain in its broadest sense, which encompasses physical, emotional, spiritual, and social components, based on the concept established by the World Health Organization (WHO). Personal hygiene care, dressings, and emotional support, which extends to the family, are also noteworthy<sup>(7)</sup>.

The care plan should include actions that promote a better quality of life, seeking to address the individual's unique needs from the moment a life-threatening disease is diagnosed<sup>(8)</sup>. Nursing care should prioritize the patient's needs, whether physical, emotional, social, or spiritual, and when this is not possible, request the assistance of the multidisciplinary team. However, for this to be possible, it is essential that professionals understand the objective of PC and their principles, so that they can offer care that moves away from the interventionist and curative model<sup>(9)</sup>

Based on what has been presented, it is important to identify the knowledge of healthcare professionals to develop professional training strategies in this area, based on the knowledge gaps presented, in addition to offering quality care based on the principles and philosophy of PC. The knowledge of nursing professionals on the concept of PC, what their indication consists of, when to start this approach, and the possibilities for nursing interventions can directly interfere with the care provided. Furthermore, it is worth noting the insignificant number of publications in the national literature on the subject in the field of Nursing<sup>(9,10)</sup>.

Given the above, the following questions arise: What do nursing professionals know about palliative care? What nursing care does the team provide based on their knowledge of palliative care? Thus, this study aims to identify nursing professionals' knowledge of PC and demonstrate the assistance provided to people experiencing an oncological disease.

#### **METHODOLOGY**

This is a descriptive, exploratory study with a qualitative approach, considering the criteria of the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>(11)</sup>.

The setting was a hospital considered a High Complexity Oncology Unit (Unacon) located in a municipality in the Zona da Mata Mineira region, which provides services to the Unified Health System (UHS) in partnership with the private sector, in a ratio of 80% to 20% respectively, covering patients from areas of the Zona da Mata Mineira and Sul Fluminense regions. At the public level, it offers care exclusively to oncological patients, providing hospitalization, exams, surgeries, treatments such as radiotherapy, chemotherapy, brachytherapy, and iodine therapy, prevention,

and diagnosis. As for private care, it provides outpatient services and other medical specialties. In total, the hospital has a team of 23 nurses and 104 nursing technicians, with four inpatient units, including two UHS wards, one private ward, and one pediatric ward. Contact with the hospital was established through conversations and meetings with the nurse responsible for the institution.

Twenty interviews were conducted with nursing staff members, who were selected for convenience. It was observed that professionals were often reluctant to respond to the interview after learning what the topic would be, and some refused to respond. The inclusion criteria established were: nursing professionals of both sexes who work in direct care for people with cancer, on day and night shifts. Those with less than six months of experience in the field and those who work in care but are returning from leave or training after a period of absence of more than two years were excluded.

An open-ended interview script was used to collect data, with participant characterization and the following guiding questions: What do you understand about palliative care? How do you provide palliative care in your practice when caring for people with cancer and their families? The researcher responsible for data collection was a nursing student in the early stages of her scientific career, who received guidance, training, and supervision from a researcher with experience in qualitative studies.

To provide a comfortable environment, the data for this study was collected at the workplace itself. A private space was sought so that participants would feel comfortable expressing their feelings and

sharing their experiences without other people around.

The interviews were recorded using a smartphone and subsequently transcribed manually in full, maintaining the reliability of the information relevant to the analysis. The transcribed material was not returned to the participants. The average duration was approximately seven minutes. Data collection was interrupted when the phenomenon under investigation was revealed in its multiple dimensions, enabling the necessary depth and scope to be achieved in the process of understanding<sup>(12)</sup>.

No software was used for deductive analysis. The content was analyzed in three phases, as proposed by Bardin: pre--analysis, in which the material was organized and analyzed, following the rules of exhaustiveness, representativeness, homogeneity, and relevance. Next, the researched material was explored and studied in greater depth, adopting the procedures of coding, classification, and categorization. Finally, the results were interpreted by inference and interpretation of the data<sup>(13)</sup>. Subsequently, literature relevant to the topic was used as a theoretical framework for data interpretation.

The research was conducted after approval by the Research Ethics Committee, under Opinion No. 6,185,356, and upon signature of the Free and Informed Consent Term (FICT) by the participants. To preserve confidentiality, the research subjects were identified with an alphanumeric code, represented by the letter "N" with no differentiation between nursing technicians and nurses, followed by a number corresponding to the chronological order of the meetings.

#### **RESULTS**

Twenty professionals aged between 21 and 64 participated in this study, with 14 (70%) aged between 20 and 40. Analyzing the professional category, 12 were nursing technicians (60%) and eight were nurses (40%), with two (25%) having postgraduate degrees.

The length of training varied between 4 and 25 years, with 10 professionals having trained for 3 to 9 years (50%) and 10 (50%) having trained for more than 10 years. Regarding the length of experience in oncology, 12 (60%) responded that they had worked in the field for 2 to 5 years and eight (40%) responded that they had worked for more than 6 years. It should be noted that the length of time working at the institution was the same as the length of time working in oncology for all participants.

Two thematic categories emerged from the data analysis: nursing staff knowledge about palliative care and the care of health needs in the context of palliative care.

## Nursing staff's knowledge of palliative care

Participants understood PC as care focused on individuals who are very debilitated, in a more advanced stage of the disease, at the end of life, when they no longer respond to various forms of treatment. Some expressed that PC is an option for those who no longer have treatment alternatives, only basic care:

[...] when you're already at a very advanced stage of the disease, close to death (N1).

[...] a very debilitated patient in the terminal phase [...] is someone who is already in a more advanced state and no longer has a treatment that can be expected to cure them, right? (N3).

- [...] we only do the basic necessary care to sustain life (N10).
- [...] is a patient who is already terminally ill with the disease progressing, and no longer has treatment (N16).

On the other hand, there have been statements that PC are indicated for anyone diagnosed with an incurable disease, and are not exclusive to oncological diseases. The meaning of palliative is not always linked to death:

- [...] every person who has been diagnosed with a disease that may not have a cure [...] it's not just in oncological diagnosis (N1).
- [...] when we talk about palliative care, we understand that the patient is going to die, but that is not always the case (N20).

The understanding was that PC aim to provide comfort, pain relief, hygiene, dignity, and respect for patients, seeking to alleviate suffering and provide well-being until the moment of death through humanized care. Participants emphasized that invasive measures should be avoided in this approach:

- [...] care to alleviate pain, alleviate the suffering of patients (N3).
- [...] Everything is aimed at patient comfort, because in palliative care we avoid invasive measures (N14).
- [...] it's when we try to comfort the patient [...] to give comfort, whether through words, affection, or jokes. If they feel pain, go there and medicate them (N17).

The comfort and warmth of the family were highlighted by some participants as an integral part of the PC:

[...] it is a humanized approach to caring for family members, encouraging interaction between the family and the pa-

tient (N16).

[...] Palliative care is about bringing comfort to the patient and their family. (N20).

# Nursing care in the context of palliative care

Participants revealed that they seek, through nursing care, to understand what the main demand is, with a view to the individual's well-being:

- [...] we also try to talk to them a lot, so we can understand what their main demand is (N2).
- [...] to understand their complaints (N5).

Certain nursing care and technical procedures are important for symptom control, comfort, and well-being. Participants discussed changing positions, water compresses, hydration, punctures, medication, wound dressing, hypodermoclysis, oxygen therapy, and hygiene practices aimed at patient comfort:

- [...] changing position, if the person needs to, feels the need; warm or cold compresses; changing dressings too; assessing the best time [...] is to think about the best dressing to be able to control the symptoms of that wound well, among other things more focused on the symptoms themselves (N1).
- [...] there are some types of treatment, for example, when the patient no longer has access, they give up hypodermoclysis (N7).
- [...] it's the medications, the oxygen, to give the patient peace of mind (N9).
- [...] It's the bath, you know [...] the care, medications, diapers, everything the patient needs at that moment (N11).

Participants described pain as the most common symptom among individu-

als in PC, which is managed with morphine and sedation. The staff always seeks to control pain, but they emphasized that it is not always physical:

- [...] is to try as much as possible to control that person's pain, which is not always physical pain (N1).
- [...] palliative patients are usually already in pain, so if there is medication to relieve the pain, it has to be given (N5).
- [...] Explain what is being done, be attentive to pain, [...] if there is pain, we medicate (N16).

They also emphasized that through conversation, they welcome and convey information, aiming to provide security and peace of mind to the patient. Nursing care involves offering affection, giving attention, encouraging, and being there for the person experiencing PC:

- [...] The first thing is to be empathetic, give them plenty of information so they feel more relaxed and secure [...] information is essential (N2).
  - [...] we have to welcome them (N5).
- [...] treating them with kindness and attention (N5).
- [...] We pay attention [...] encourage them not to get discouraged, we always have to work on that emotional side too, which is quite demanding (N12).

Some participants emphasized the need to welcome and talk openly with the family, make visiting hours more flexible, and, if necessary, refer them to the hospital psychologist. There was an understanding that family members need psychological support, but this need for patient care was not highlighted:

[...] for family members, we rely on the psychologist, right? We nurses end up acting as psychologists too, providing all the psychological support to family members [...] comfort measures for the patient themselves, and the psychological aspect for those accompanying them, for family members (N9).

[...] We have a very frank conversation with the family, very open. The family is aware that this is end-of-life care, that the patient is at the end of their life, so we try to be flexible about allowing family members to visit (N10).

#### **DISCUSSION**

Based on the testimonials analyzed, it is clear that nursing professionals still need to be better informed and acquire knowledge about the objectives and principles that govern PC. Health indicators point to an increase in the number of people with cancer worldwide, highlighting the importance of knowledge about PC for healthcare professionals, especially nurses(14).

Palliative care is defined as active and comprehensive treatment that should be provided as early as possible to people diagnosed with life-threatening illnesses, aimed at improving quality of life, offering support to patients and their families, preventing suffering, and treating pain in its entirety, whether or not accompanied by curative treatment(15).

The nursing professionals interviewed understand that the purpose of PC is to improve quality of life for patients and their families, and that it is not a practice exclusive to oncology. However, they believe that this approach should only be chosen when all possibilities for curative treatment have been exhausted, and should be offered to a debilitated person at the end of life. They also relate PC to the patient's responsiveness to treatment and prognosis for disease cure. Similarly, in a study on nurses' perceptions of patient care in PC, there is still an association between this practice of care focused on terminal patients and its use when there is no longer any possibility of cure<sup>(16)</sup>.

Improving nursing knowledge about the indication and use of PC in oncology contributes to more effective and humanized care, to improve quality of life of the sick person<sup>(16)</sup>. There appears to be a deficiency in nursing professionals' training on this topic, which affects patients' quality of care. Added to this is the scarcity of scientific publications on the subject, making it even more difficult to share reliable information with professionals and students<sup>(10)</sup>.

It is therefore necessary for health and education institutions to offer continuing education to professionals in order to improve practices related to this type of care. Health training is an important tool for providing theoretical support to nursing professionals, which will contribute to the quality of life of people with cancer in the context of  $PC^{(17)}$ .

Nursing professionals associate PC with humanized patient care, emphasizing the importance of active listening, communication, and comfort(17). The results point to interventions such as changes in position, dressings, diaper changes, and personal hygiene, which aim to improve quality of life and provide dignity to the person, regardless of their prognosis. It is important to highlight that the psychological approach is also very important for people experiencing the impacts of cancer, in order to offer resources that help them cope<sup>(17)</sup>. In this study, participants did not comment on the psychologist's role in managing these aspects for the sick person, focusing only on the importance of this support for family members.

Family members experience feelings of fear, anguish, insecurity, and helplessness after a cancer diagnosis, which brings to the family and the patient the meaning of the finitude of life, promoting a reorganization of family dynamics. Based on the philosophy of PC, health professionals welcome these feelings and help in recognizing death as a stage of life to be experienced, which is a natural process for every human being<sup>(18)</sup>.

According to the Theory of Basic Human Needs, proposed by Wanda Horta, human beings need three main human dimensions, namely: psychobiological, psychosocial, and psychospiritual, which are in line with the philosophy of PC. It is observed that cancer patients are directly impacted in these three aspects, making it essential that nursing care be directed in an individualized manner, with a comprehensive approach based on the principles of humanization<sup>(19)</sup>. In this study, psychobiological needs are well addressed in the clinical practice of professionals; however, psychosocial and psychospiritual needs are often overlooked.

A study conducted in Hong Kong showed that emotional symptoms were more overwhelming than physical symptoms such as pain. Anxiety, lack of peace, and lack of information were more significant, followed by lack of energy, impaired mobility, and physical pain<sup>(18)</sup>. Thus, it is necessary to pay attention not only to physical pain, but to total pain, encompassing physical, social, psychological, and spiritual symptoms<sup>(20)</sup>.

It is noticeable that healthcare professionals still find it difficult to understand the extent of the total pain experienced by a person with PC, due to the diffi-

culty of expressing it in words. Given the complexity of cancer and multidimensional suffering, there needs to be ongoing assessment by professionals to structure a care plan that involves the biopsychosocial and spiritual aspects of the human being(20). The participants in this study recognize that the symptoms are not only physical, but nevertheless refer to physical pain as the most common.

Pain is seen by healthcare professionals as the most recurrent symptom and the one that causes the most suffering for people with cancer. Therefore, professionals prioritize pain control, taking measures to minimize pain and promote comfort, corroborating the findings of this study by showing that, in the presence of pain, analgesia is achieved through the use of morphine and even sedation. The use of drugs for the treatment of cancer pain is common for most patients hospitalized with cancer, whether analgesics or opioids; that is, pharmacological measures are prioritized, which is not in line with the concept of total pain<sup>(14)</sup>.

A study conducted with professionals in France showed that most participants agreed with palliative sedation, that is, deep and continuous sedation, maintained until death in end-of-life care for pain relief(21), but some still disagree with this action. According to Candido et al.(22), nurses recognize that palliative sedation is important for pain and suffering relief and for promoting comfort, tranquility, and a dignified end of life, but they understand that further discussion is needed to support this practice on the part of institutions.

In this sense, in order to address the subject holistically, it is worthwhile considering non-pharmacological measures for pain management, such as transcutaneous electrical nerve stimulation, which can be used not only against pain, but also against other physical symptoms, such as nausea and appetite loss(23); "pet day," which allows animals to visit hospitalized patients; or even music therapy, understanding that pain is multifactorial<sup>(24)</sup>.

A study that outlined the clinical-epidemiological profile of cancer patients referred to PC indicates that professionals avoid performing invasive procedures on patients who are in PC. When performed, the most common procedures are catheterization and punctures for laboratory tests, with the vast majority not undergoing life-sustaining measures<sup>(25)</sup>. This study corroborates these findings, in the sense of avoiding invasive measures aimed at comfort and relief from unnecessary suffering.

#### **FINAL CONSIDERATIONS**

The research conducted shows that nursing professionals need to better understand the concept of PC, their indications, and the necessary care. In terms of assistance, they aim to alleviate suffering and promote comfort and well-being, but they still prioritize biological aspects, such as pharmacological measures for pain relief, and make little mention of care options that address psychosocial and spiritual needs.

This study contributes to the field of nursing by pointing out gaps in knowledge that still need to be filled to provide quality care in accordance with the principles that guide PC, thereby improving healthcare practice. Nursing schools should discuss PC in their curriculum, at both the technical and undergraduate and graduate levels, in view of the aging population and the increase in people living with chronic and degenerative diseases, a scenario with prospects for continued growth.

By recognizing the need for further learning, it is possible to implement training and capacity building for healthcare professionals who work with patients in PC to provide effective, quality care that addresses all health needs, not just those related to the patient's body. The family and/or support network need to be included in the nursing care plan, given the repercussions of the loved one's illness and what this represents in the lives of family members.

The study's limitations are related to the choice of only one practice setting that primarily serves patients from the Unified Health System, in addition to reflecting the reality of only one geographic region of the country. However, the results found are similar to those of other studies.

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Data collection: KBW, ACPCP

Data analysis and interpretation: KBW, ACPCP

Manuscript writing: KBW, EMDF, ADGF, ADGF, ALSA, JBN, ACPCP

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