

The Role of Nursing in Palliative Care with Oncology Patients in Terminal State: Literature Review

O Papel da Enfermagem em Cuidados Paliativos com Pacientes Oncológico em Estado Terminal: Revisão de Literatura

El Rol de la Enfermería en los Cuidados Paliativos con Pacientes Oncológicos en Estado Terminal: Revisión de la Literatura

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RESUMO

Objetivo: identificar o papel da enfermagem em Cuidados Paliativos aos pacientes oncológicos em estado terminal, com base na literatura recente. **Método:** A revisão integrativa realizada neste trabalho visou efetuar uma análise do tema de interesse para a área de enfermagem. A partir das bases de dados da SciELO, LILACS e BVS. A busca foi realizada entre setembro de 2021 e maio de 2022, sendo selecionados os artigos disponíveis na íntegra, em português e formato original, o ano de publicação compreende os anos de 2014 a 2021. **Resultados:** Apontam os sentimentos vividos pela equipe de enfermagem e multidisciplinar bem como as dificuldades enfrentadas por esses profissionais, e a deficiência na formação desses profissionais além dos sentimentos envolvidos tanto na família como nos profissionais e como lidam com a terminalidade. **Conclusão:** Existe a necessidade de uma visão mais ampla sobre Cuidados Paliativos com início ainda na graduação até as atividades desenvolvidas nos Cuidados Paliativos, a sobrecarga de trabalho enfreada por esses profissionais, e o aspecto psicológico devido ao sentimento experimentado por eles no processo de morte. **Descritores:** Cuidados Paliativos, Pacientes Terminais, Conforto do paciente e Família, Paciente Oncológicos

ABSTRACT

Objective: to identify the role of nursing in palliative care for terminally ill cancer patients based on recent literature. **Method:** an integrative review carried out in this work aimed at an analysis of the topic of interest in the nursing area. From the SciELO, LILACS and BVS databases. The study was carried out between September 2021 and May 2022, with the selection of articles available in full, in Portuguese and in original format, the year of publication comprises the years of search from 2014 to 2021. **Results:** They point out the feelings experienced by the nursing team and multidisciplinary, as well as difficulties faced by these professionals, and deficient in the training of these professionals in addition to feelings involved both in the family and in the professionals and how they deal with terminality. **Conclusion:** There is a need for a broader view of Palliative Care starting at graduation until the activities developed in Palliative Care, the overload of work enfreada by these professionals, and the psychological aspect due to the feeling experienced by them in the process of death. **Descriptors:** Palliative Care, Terminal Patients, Patient and Family Comfort, Oncology Patients.

RESUMEN

Objetivo: identificar el papel de la enfermería en los cuidados paliativos para pacientes con cáncer en estado terminal, a partir de la literatura reciente. **Método:** La revisión integradora realizada en este estudio tuvo como objetivo realizar un análisis del tema de interés para el área de enfermería. De las bases de datos de SciELO, LILACS y BVS. La búsqueda se realizó entre septiembre de 2021 y mayo de 2022, y se seleccionaron los artículos disponibles en su totalidad, en portugués y en formato original, el año de publicación comprende los años 2014 a 2021. **Resultados:** Indican los sentimientos experimentados por el equipo de enfermería y multidisciplinario, así como las dificultades a las que se enfrentan estos profesionales, y la deficiencia en la formación de estos profesionales, además de los sentimientos involucrados tanto en la familia como en los profesionales y cómo tratan la terminalidad. **Conclusión:** Existe la necesidad de una visión más amplia de los Cuidados Paliativos desde la graduación hasta las actividades desarrolladas en Cuidados Paliativos, la sobrecarga de trabajo enfreada por parte de estos profesionales, y el aspecto psicológico debido al sentimiento experimentado por ellos en el proceso de muerte. **Descriptores:** Cuidados paliativos, Pacientes terminales, Comodidad del paciente y la familia, Paciente con cáncer.

Introduction

Cancer is a word used to define a group of more than 100 types of pathologies of malignant origin that have in common the disordered growth of cells, which has the ability to invade adjacent tissues or organs from a distance. Multiplying rapidly, these cells tend to be quite aggressive and uncontrollable, causing the formation of tumors, which are capable of spreading to different regions of the human body. There are different types of cancer that configure various types of cells in the body. They are called carcinomas, when they start in epithelial tissues, such as skin or mucous membranes, and sarcomas, when they originate from connective tissues, such as cartilage, bones and muscles¹.

The incidence, morbidity and mortality rate in the hospital environment are control measures for epidemiological surveillance, which allow analyzing both the occurrence, distribution and development of diseases. Allowing to know the epidemiological profile of different types of cancer, contributing to possible changes in the scenario and creating elements that can guide Cancer Surveillance actions for the efficient and effective planning of cancer prevention and control programs in Brazil, these indicators are known mainly in cancer registries and in the Mortality Information System of the Ministry of Health (SIM/MS)².

According to the National Cancer Institute (INCA), in 2020, there was an incidence of 309,750 cases of cancer in the male population, the first cause being prostate cancer, with 65,840 new cases (29.2% of the total), with 121,686 deaths, and the first cause of death was cancer of the trachea, bronchi and lung, which killed 16,733 (13.8%); in the female population there was an incidence of 316,280 cases and the first cause is breast cancer, with 66,280 new cases, which is also the first cause of death in this population, with 18,068 (16.4%) deaths, out of a total of 110,334 deaths in women in Brazil^{1,2}.

Palliative Care translates the assistance provided by a multidisciplinary team, which aims to improve and give quality of life to the person and their family members through a life-threatening disease, through the prevention and relief of suffering, through early identification, impeccable assessment and treatment of pain and other symptoms of physical, psychological, social and spiritual characteristics³.

Its philosophy is care and its objective is to provide quality of life for individuals and family members in the presence of the disease and in natural processes of life and death. Family were practiced by people aged between 25 and 75, and most were female. Regarding the degree of kinship, children stand out, followed by husbands and wives, and the others were partners, mother, sister, brother and father. It is possible to observe the multiple feelings experienced that were inherent to the human being who lives with changes in the environment and in the family composition, mainly resulting from the process of human finitude. A common phenomenon for family members of end-of-life patients is anticipatory grief.⁴

Another perspective is that of nurses who work in Primary Health Care (PHC) which makes it possible to highlight the challenges faced as well as their attributions and contributions related to Palliative Care in the Family Health Strategy (ESF). Where the vast majority of PHC health professionals have already had contact and have already provided care, or care for cancer and palliative

patients, which indicates a great demand for patients who need this care in PHC. The main problem or main factor being the lack of knowledge and insecurity in the application of Palliative Care, in general by professionals in the scope of primary health care⁵.

On the other hand, it is possible to understand knowledge from the individual perceptions of nursing professionals. Among the difficulties highlighted by nurses, aspects related to professional training were highlighted, given the lack of preparation to deal with situations that reflect the complexity of the human being in the dying process, as well as the insufficiency of material and human resources. , in addition to the absence of an adequate physical structure, which will favor quality, individualized and humanized care by health professionals³.

In the multidisciplinary team, each health professional is responsible for the development of care actions that aim to cover the patient as a whole. The role of nurses is highlighted, due to the dynamics of their work, which is focused on care, valuing the health team, in the institution and, above all, with the patient/family, and is responsible for multiple relationships and interactions that are developed in its field of activity. Thus, being the nursing professional who remains present 24 hours a day in the provision of care and hospitalization, which allows the identification and direction of actions that can meet people's needs, assuming the family as a unit of care, following principles of Palliative Care⁵.

This study aims to identify the role of nursing in Palliative Care for terminally ill cancer patients, based on recent literature. In view of this, it is relevant to analyze the literature on the subject of Palliative Care and a reflection on what is the role of nursing in the care of patients who are in a terminal state, and this study may offer resources to identify the role of nursing, as well as as its performance in Palliative Care with terminal cancer patients.

Method

The integrative review carried out in this work aimed to carry out an analysis of the topic of interest to the area of nursing, which makes it possible to establish general conclusions about it and point out some gaps that can be filled with new studies on the subject. In the first phase, the guiding research question was constituted. Thus, the structured question was: What is the role of the nursing team in Palliative Care for terminally ill cancer patients?

For the second phase, a search strategy was used using the Descriptors in Health Sciences (DeCS): "Palliative Care", "Terminal Patients", "Patient Comfort" and "Family", in the Scientific Electronic Library electronic databases. Online (SciELO) and Scientific and Technical Literature from Latin America and the Caribbean (LILACS), and the Virtual Health Library (BVS), for complementary research.

It was refined, contemplating the third phase of the research, with the application of the inclusion criteria previously established in the search strategy: articles published online, between the years 2014 and 2021; available in Portuguese and in full; studies in the format of original articles from diverse scientific productions. In the fourth phase, the summaries of the retrieved studies

were critically read, excluding duplicates and those whose objective, results or conclusion did not discuss Palliative Care performed by the nursing team.

The literature search resulted in a total of 114 articles captured and, of these, 32 were in SCIELO, 37 in LILACS and 45 articles in the VHL. The number of occurrences was reduced by applying the inclusion and exclusion filters: in SCIELO, 05 studies were retrieved (50%); in LILACS, 01 (10%); and in the VHL, 04 (40%). The final sample consisted of 10 articles.

Results e Discussion

To facilitate the understanding of the works that make up the final sample, identification variables were extracted, such as: title, authors, objectives, method applied and conclusion of the work. It was intended with the instrument, in addition to forming a database, mapping relevant points, integrating data and characterizing the reviewed sample. In Table 1, information about the 10 articles contained in this integrative review was organized.

Table 1. Distribution of articles according to title, author, objective, method, conclusion and year of publication. Brasília (DF), Brasil, 2022.

Nº	Title	Author	Objective	Method	Conclusion	Year
1º	Social representations of comfort for relatives of patients in palliative care in intensive care	Perão OF, Nascimento ERP, Padilhab MICS, Lazzarib DD, Hermidad PMV, Kerstena MAC	Knowing the social representations of comfort for family members of patients in Palliative Care in intensive care	A descriptive, qualitative study, the theoretical framework adopted was Social Representations. Participants were 30 relatives of patients hospitalized in an intensive care unit in Palliative Care. Data were collected through semi-structured individual interviews, organized and analyzed using the Collective Subject Discourse technique.	The social representations about the comfort of family members of patients hospitalized in an intensive care unit in Palliative Care are identified by the feelings of family members during the visit, communication, and the humanized care applied by nursing professionals to patients in palliative therapy.	2021
2º	Conceptions, challenges and skills of nurses in palliative care in primary health care	Melo CM, Sangoi KM, Kochhann JK, Hesler LZ, Fontana RT.	Identify knowledge, skills and challenges faced by nurses working in Family Health Strategies about Palliative Care	Qualitative exploratory study carried out in the second half of 2018 with 24 nurses working in 24 municipalities in Rio Grande do Sul. Data collection was carried out through an online questionnaire and analyzed by thematic analysis.	It is believed that it will help municipal health managers to perceive Palliative Care as strategies in the feasibility, conduct and implementation of innovative care proposals based on the precepts of this practice, enabling proactive actions to users	2021
3º	Palliative care for the elderly in intensive care: the view of the nursing team	Queiroz TA, Ribeiro ACM, Guedes MVC, Coutinho DTR, Galiza FT, Freitas MC.	To know the meaning of Palliative Care for the elderly for the nursing team and to identify how the interactions between the family and the elderly occur in the intensive care unit.	Descriptive research, carried out in the intensive care unit of a public hospital in Fortaleza-Ceará-Brazil. Sample composed of 58 professionals from the nursing team. Data collection was carried out in the second half of 2015 through a semi-structured and recorded interview.	As the study showed, the team is knowledgeable about Palliative Care and recognizes the family as a link between professional and elderly. It is also considered that intensive care is not an appropriate environment for Palliative Ca.	2018

4°	The nurse's attention to the patient in palliative care	Picollo DP, Fachini M.	Identify the role of nurses in Palliative Care, list the main competencies of the professional to become able to work in Palliative Care and verify the importance of the multidisciplinary team in Palliative Care	It is a review of the bibliography of an integrative nature, where a search was carried out in a database of studies with a theme relevant to the guiding question. Subsequently, the answers found were organized in a synoptic table so that the visualization and interpretation of the results	Controlling pain and suffering, as well as offering quality of life, are fundamental points in the provision of Palliative Care. It is clear that integrative research opens gaps for further discussions in relation to the data found, which serve as a starting point for further studies.	2018
5°	Oncological home care: perception of family members/care givers about palliative care	Oliveira MBP, Souza NR, Bushatsky M, Dâmaso BFR, Bezerra DM Brito JA.	To know the perception of the family member/caregiver of patients diagnosed with terminal cancer in home care on Palliative Care.	Descriptive research, with a qualitative approach, carried out with six family caregivers of patients who receive home care in exclusive Palliative Care, provided by the Palliative Care Unit of a referral hospital. Data were collected through semi-structured interviews analyzed in the light of Bardin's Content Analysis.	It was possible to rescue the importance of Palliative Care at home as a possibility to minimize the impact of suffering with the disease and ensure dignity in the dying process.	2017
6°	Palliative care: view of nurses in a teaching hospital	Oliveira MC, Gelbcke FL, Rosa LM, Vargas ALV, Reis JBG	To identify whether there is an insertion of the concept and principles of Palliative Care defined by the World Health Organization in the work of nurses in Medical Clinic Units and in the Palliative Care and Pain Control Commission of a Teaching Hospital in the Southern Region of Brazil	Qualitative research with data collection through semi-structured interviews with 22 nurses, submitted to the content analysis technique.	The principles of the Palliative Care philosophy are partially embedded in the professionals' practice. There is a demand for academic and in-service training.	2016
7°	Experience of multiprofessional residency in social work and oncology palliative care	Frossard AGS, Silva ECS	Train technical, scientific and political leaders to qualify the line of care for people with cancer, aiming at the promotion, protection and recovery of health based on interprofessional collaboration	This is a descriptive and exploratory study, based on Marxian critical theory, of the experience report type, considering the authors' experiences with Palliative Care related to the implementation of the Multiprofessional Residency with an emphasis on cancerology.	The recording of impressions and strategies that worked or that did not work during the implementation of the Multiprofessional Residency in Health allowed us to think about what has already been done and what can be improved.	2016
8°	Palliative care in high complexity care in oncology: nurses' perception	Silva MM, Santanda NGM, Santos MC, Cirilo JD, Barrocas DLR, Moreira MC	To identify the difficulties faced in the provision of assistance to hospitalized people in the context of Palliative Care in a High Complexity Assistance Center in Oncology in the state of Rio de Janeiro, in the nurses' perception; and discuss	Descriptive research, with a qualitative approach. It was approved by the Research Ethics Committee of the institution. Thirteen nurses were interviewed. Data were subjected to thematic analysis.	The study warns about the need for effective changes to care for these people, who depend on a collective effort to qualify the practice and carry out new research.	2015

			strategies to better qualify nursing care in this context.			
9º	Family participation in cancer palliative care in the hospital context: nurses' perspective	Silva MM, Lima LS	The objective was to understand the nurses' perspective on the family's participation in oncological Palliative Care hospitalization and to analyze the nursing care strategies to meet their needs.	Descriptive, qualitative research, carried out at the National Cancer Institute, between January and March 2013, with 17 nurses. Elements of the Roy Adaptation Model were used to interpret the results.	The results contribute to the promotion of adaptation and family integrity to balance dependent and independent behaviors, aiming at quality of life and comfort. New studies are necessary due to the challenges of the specialty.	2014
10º	Perceptions of family members of people with cancer about musical encounters during anticancer treatment	SilvaVA, Marconl SS, Sales CA	To reveal the perception of family members accompanying patients living with cancer and anticancer treatment in a support house, where musical meetings are used as a treatment method.	A qualitative phenomenological study, structured in the Heideggerian existential analysis.	It was found that the encounter mediated by music can provide accompanying family members with a moment of existential introspection, which lead them to a transcendental experience in facing their existential condition, inciting the expression of subjectivities and the unveiling of their existential/spiritual needs.	2014

Through the selection of articles, it is notable that the nursing team has knowledge about Palliative Care, however strategies to improve the quality of care provided to terminal cancer patients should be discussed. According to the guiding question and content relevance, based on the selected sample, three categories were highlighted for discussion: Nursing's perception of Palliative Care with cancer patients and the end of life; The patient's and family's perception of Palliative Care and the finitude of life; and the difficulties faced by nursing professionals in Palliative Care and terminality.

The perception of nursing on Palliative Care with cancer patients and the end of life.

Palliative Care is a citizen's right. It is focused on the management of complex functional and symptomatic demands, with the aim of promoting changes in the way of caring for patients with diseases with no therapeutic chance of cure. This model of care suggests breaking the traditional focus that emphasizes the disease and starting to focus on comprehensive care, with active participation of the patient and family in decision-making. The nursing professional contributes significantly to the excellence of Palliative Care, but he does not develop care alone, for this this type of care involves a multidisciplinary team composed of a doctor, nurse, a nursing assistant and/or technician, community health agent. , due to the need for comprehensive care, since these are interconnected and are of great importance for quality care provided to the patient.⁶

It was possible to observe that the nursing professional experiences a feeling of impotence in the face of human finitude, which makes him often feel like a failure and incompetent, since he does not obtain a cure as a final result of

the work. It is understood that a good preparation of the entire multidisciplinary team is essential to serve the patient and/or family well, since the safety transmitted by it can directly influence the outcome of the treatment. On the other hand, creating a bond increases the patient's trust in the multidisciplinary team, making the situation less painful for both parties, welcoming the family and the patient should be a fundamental characteristic of nursing⁷.

The nurse has the ability to listen and interpret the exposed needs, as well as those that remain unspoken, according to each situation, which makes the nursing professionals pass to transmit safety to the patient and the family with the creation of a bond of care, thus facilitating the work, in order to make it more humanized. When referring to the humanization of care, it is highlighted that the dissemination of this practice in different contexts is still below what is necessary. Dehumanized care is a reality in many health care settings, including the hospital environment.^{3,8}

It is worth noting that not following the principles of Palliative Care, and performing therapies that are not necessary at this stage of the disease, can be considered as dehumanized practices, since they contribute to the suffering of people and their families, as well as to the appreciation of the physical aspects to the detriment of the holistic care of the human being in the process of death. Humanized care is a premise that must be disseminated among peers, reflected in an action of respect for others in any relationship, built on communication and a helping relationship. Nursing, as well as the principles of Palliative Care, carries with it solidarity and respect for the patient and aims to give these patients with no possibility of cure the right to have their autonomy and dignity preserved. It is worth mentioning that when the patient perceives humanized care, he can externalize his desires and feelings throughout the process of finitude, being able to reach a "good death"³.

The patient's and family's perception of Palliative Care and the finitude of life

Nursing believes that the presence of the family is essential in palliative patient care, especially when the family member shows interest in caring. Thus, their presence contributes to the collection of information related to the patient, in addition to representing an opportunity for their training through the possibility of home care. The participatory family member is an ally of the nursing team in terms of contributing to the operationalization of the nursing process, in addition to providing information or supporting care actions⁴.

With regard to previously hospitalized patients, the experiences of hospitalization bring up the mixture of various feelings such as anguish, loneliness, fear in the face of the new reality. Which are inherent to the patient who experiences these changes, mainly due to the process of the finitude of life. Anticipatory grief is a common phenomenon for family members of end-of-life patients⁵.

The grief experienced in this case differs from that resulting from a sudden loss, for its slow and gradual form, depending simply on time, and the fact that the person to whom the cause of grief refers is still alive, it seems that at all times are currently experiencing experiences of loss, abandonment and the desire to give up. Bereavement, in this way, causes changes in the situations experienced, making the process painful, difficult and slow. Taking care of family members in

these conditions requires a lot of dedication, especially on the part of the family member who assumes the role of caregiver, which can generate physical and emotional overload, related to the time spent in this care and the inherent difficulties^{5,9}.

It is essential to unite Palliative Care with the proposal of more humanized care as an act of respect and solidarity. The importance of support and clear communication between health professionals and the family of the patient who will be included in the Palliative Care therapy is highlighted, as this contact is essential for the quality of the service, highlighting the importance of establishing links between the team and the caregiver/family member, creating a relationship of trust between those involved. The fact that family members feel accompanied, and see that they are not alone, leads most caregivers to show more peaceful feelings¹⁰.

Difficulties faced by nursing professionals in Palliative Care and terminality

One of the difficulties faced by nurses in Palliative Care with regard to human finitude, in most cases, is related to the existence of deficient training in academic curricula, especially in relation to communication and relief of symptoms, such as pain. It was evidenced that in Brazil there is a gap, especially in Medicine and Nursing courses, since learning about Palliative Care is touched on questions such as death, pain or oncology. It is worth highlighting the need and importance of training in Palliative Care, with knowledge and skills to care for people at the end of their lives. There is a great lack of preparation on the part of professionals from different areas in how to deal with situations that are imminent and irreversible, of death and the process of dying¹¹.

Another difficulty is in the management of nursing care, with regard to the establishment of priorities in care, taking into account the variation in the profile of the people who are assisted in the medical clinic, as well as the treatment objectives, ending up prioritizing the cases in that there is a possibility of cure to the detriment in cases of palliative patients⁶.

Work overload, in addition to the shortage of human resources in the nursing category, as well as the absence of a multidisciplinary team to meet the needs of these people, in addition to the lack of material resources, are these difficulties that limit the practice of care. This can lead to the distancing of the professional nurse from direct care to the person/patient, with the need to expand continuing education to reaffirm Palliative Care as well as the Systematization of Nursing Care^{6, 12}.

With regard to the intensive care environment, it is noted that it makes it difficult to carry out Palliative Care with quality. Due to technological devices, noise and the environment, as well as visiting hours or lack of privacy, among other factors, which go against palliative conditions and contribute to inadequate care under these conditions, in addition to deviating from the recovery proposal. even when under severe conditions. This reinforces the need for nursing professionals to be attentive to the needs of patients, in their most diverse forms of illness, and can contribute to relieving the suffering of family members and loved ones, resulting in improved quality of life^{4,13}.

Different barriers are pointed out when it comes to Palliative Care, among them, the daily practice of the multidisciplinary team, especially nursing,

regarding Palliative Care, due to the non-real appropriation of the meaning of the word and working in an environment with objectives that do not match with palliation, which generates conflicts. At other times, it was possible to perceive the difficulty of consensus in the actions of the multiprofessional team, regarding the performance of a procedure not bringing benefits to the person in Palliative Care¹³.

Conclusion

Finally, as previously described, Palliative Care should be focused on promoting the patient's quality of life, as well as the process of death, treating it in an integral way, involving physical aspects as well as symptoms and psychological aspects in the care. The nursing professional contributes significantly to Palliative Care, along with the multidisciplinary team. It is noteworthy that humanized care can provoke in the patient the desire to externalize their feelings and feelings throughout the process of their finitude.

It is worth highlighting the importance of family participation in the Palliative Care routine. The participatory family member is an ally of the nursing team. We can also highlight the feelings involved, such as anguish and the experience of anticipated grief and the feeling of abandonment and abandonment in the face of the new reality, it is extremely important that care is humanized and prioritizes respect and solidarity. There is support and clear communication from health professionals with the patient's family so that he does not feel alone, and psychological support is fundamental to the family and the patient.

There are several difficulties experienced by the nursing team, from the need for a broader view of Palliative Care starting at graduation to the activities developed for this care. In addition to the work overload faced by these professionals, there is also the psychological aspect, the feeling of importance related to work due to the death process of their patients. It is important to develop continuing education on the topic of Palliative Care and psychological support for patient and family health professionals to improve and provide quality assistance to terminally ill patients.

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