

Needs of Family Caregivers and the Role of Nurses in Oncological Palliative Care: Integrative Literature Review

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Necessidades de Familiares Cuidadores e Atuação do Enfermeiro nos Cuidados Paliativos Oncológicos: Revisão Integrativa da Literatura

Necesidades de los Cuidadores Familiares y Papel de las Enfermeras en los Cuidados Paliativos Oncológicos: Revisión Integradora de la Literatura

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ABSTRACT

Introduction: The family caregiver of a cancer patient plays an important role in providing care, it is essential that health professionals act effectively in face of their needs and difficulties in promoting the development of caring skills. The study provides significant contributions for enhanced nursing care in order to strengthen the relationship between theory and practice. **Objective:** Identify the main needs of family caregivers of cancer patients in palliative care and the role of nurses in meeting these needs. **Method:** Integrative literature review with articles published in Portuguese, English and Spanish at the databases PubMed, BDENF, LILACS, SciELO. **Results:** The final sample consisted of 27 articles divided into two categories: 1) The transition to care – care needs and skills of family caregivers; 2) Nurse's role in the transition of the family caregiver. It has been shown that family caregivers have innumerable needs in view of their new role, with nurses being primarily responsible for offering this support, helping them to master these skills. **Conclusion:** Scientific evidence demonstrates that nurses must understand the experiences and needs of family caregivers in face of several situations experienced in their working journey, and provide information and guidance that favors the decision-making process.

Key words: Palliative Care; Nursing Care; Needs Assessment; Nurse's Role; Oncology Nursing.

RESUMO

Introdução: O familiar cuidador de um paciente oncológico exerce papel importante na assistência, sendo fundamental que os profissionais de saúde atuem efetivamente diante de suas necessidades e dificuldades, a fim de promover o desenvolvimento das competências de cuidado. O estudo fornece contribuições significativas para uma melhor fundamentação da assistência em enfermagem, com o intuito de aprimorar a relação entre teoria e a prática. **Objetivo:** Identificar as principais necessidades dos familiares cuidadores de pacientes oncológicos em cuidados paliativos e o papel do enfermeiro frente a essas necessidades. **Método:** Revisão integrativa da literatura com artigos publicados em português, inglês e espanhol nas bases de dados PubMed, BDENF, LILACS e SciELO. **Resultados:** A amostra final foi composta por 27 artigos, divididos em duas categorias: 1) A transição para o cuidar – necessidades e habilidades dos familiares cuidadores; 2) Atuação do enfermeiro diante da transição do familiar cuidador. Foi demonstrado que os familiares cuidadores precisam se ajustar às demandas geradas pelo novo papel, sendo os enfermeiros os principais responsáveis por oferecer esse suporte, auxiliando-os a desenvolver e dominar as respectivas habilidades. **Conclusão:** As evidências científicas demonstram que o enfermeiro deve compreender as experiências e necessidades dos familiares cuidadores diante de inúmeras situações vivenciadas em sua trajetória no cuidado, e fornecer informações e orientações que favoreçam o processo de tomada de decisão. **Palavras-chave:** Cuidados Paliativos; Cuidados de Enfermagem; Avaliação das Necessidades; Papel do Profissional de Enfermagem; Enfermagem Oncológica.

RESUMEN

Introducción: El cuidador familiar del paciente con cáncer juega un papel importante en el cuidado, siendo fundamental que los profesionales de la salud actúen eficazmente ante sus necesidades y dificultades para promover el desarrollo de habilidades de cuidado. El estudio proporciona aportes significativos para una mejor fundamentación de la atención de enfermería, con el objetivo de mejorar la relación entre teoría y práctica. **Objetivo:** Identificar las principales necesidades de los cuidadores familiares de pacientes oncológicos en cuidados paliativos y el papel de las enfermeras en la satisfacción de estas necesidades. **Método:** Revisión integradora, realizada en las siguientes bases de datos PubMed, BDENF, LILACS, SciELO, de artículos publicados en inglés, portugués y español. **Resultados:** La muestra final estuvo compuesta por 27 artículos, divididos en dos categorías: 1) La transición al cuidado – necesidades de cuidado y habilidades de los cuidadores familiares; 2) El papel del enfermero en la transición del cuidador familiar. Se demostró que los cuidadores familiares tienen numerosas necesidades de cara a su nuevo rol, siendo las enfermeras las principales responsables de ofrecer este apoyo, ayudándoles a desarrollar el dominio de las habilidades. **Conclusión:** La evidencia científica demuestra que el enfermero debe comprender las experiencias y necesidades de los cuidadores familiares ante numerosas situaciones vividas en su recorrido asistencial, y brindar información y orientación que favorezcan el proceso de toma de decisiones. **Palabras clave:** Cuidados Paliativos; Atención de Enfermería; Evaluación de Necesidades; Rol de la Enfermera; Enfermería Oncológica.

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INTRODUCTION

The significant rise in cancer cases and their chronic effects motivated the need to consider new assistant modalities to promote appropriate care to the population. With technological and scientific advancements and improvements to diagnosis and treatment, the number of cancer survivors is increasingly higher¹.

Cancer diagnosis, as well as the hospitalization process, results in a series of repercussions, triggering changes in the whole family dynamic, including changes in the daily life and acquisition of new social roles². Thus, the patient's family is considered to experience a transition period, in which they will have to exercise a new role as a family caregiver (FC). In this context, the approach of palliative care becomes relevant for its ability to promote better quality of life to patients diagnosed with life-threatening illnesses, such as malign neoplasms, and their families³.

Given the relevancy of this theme, the transitions theory by Afaf Meleis⁴ has been selected as the theoretical framework for the present study. This includes four central concepts: i) the nature of transitions; ii) the conditions of transitions; iii) the response patterns; and iv) the nursing interventions. The conceptualization of transition is strongly influenced by the nursing assistance, positively influencing processes through a broader view, with prevention, therapeutic promotion and intervention⁵.

Nurses are professionals who directly work in care, being used to witnessing situations of pain, death and hopelessness of patients and their families in their final life stage⁶. The FC, on the other hand, plays an important role in assistance, making it essential for the health professional to establish a positive relationship with the caregiver to influence the development of care skills⁷.

Assisting the FCs involves observation and addressing their needs in this new social role, aiming to prepare and provide them with a foundation to cope with their new routine^{8,9} as the protagonist of care.

Advances in Medicine significantly improved the prognosis of oncological patients, who often require prolonged care, in which the family starts to play an essential role during hospitalization and after the patient is discharged, returning to their home.

Thus, by identifying the needs and skills of family caregivers during the process of care, it becomes possible to develop strategies that favor family engagement within assistance, strengthening bonds, and effective communication, so the FC can provide safer and better-quality care to their sick family member.

The study provides significant contributions for enhanced nursing care to bring theory and practice closer together. Thus, this research aims to identify the main

needs of family caregivers of cancer patients in palliative care and the role of nurses in meeting these needs.

METHOD

Integrative review, method that summarizes the existing empirical or theoretical literature to provide a broader understanding of a particular phenomenon¹⁰. The review was elaborated following six steps proposed by Mendes, Silveira and Galvão¹¹: i) theme identification and selection of the research question; ii) determination of inclusion and exclusion criteria for sample selection; iii) identification of pre-selected and selected studies; iv) categorization; v) analysis and interpretation of results; and vi) presentation of review.

To help identify the key topics and formulate the guiding question, the PICo acronym was used, in which "P" refers to the study population (family caregivers); "I", to the studied intervention or variable of interest (nursing role); and "Co", to the context (oncological palliative care). To guide the research, the following question was elaborated: "What is the role of nursing, given the needs of family caregivers of oncological patients in palliative care?"

The searches were performed in May and July 2023, in the following databases: National Library of Medicine (PubMed), *Base de dados de Enfermagem (BDENF)*, *Literatura Latino-Americano e do Caribe de Informação em Ciências da Saúde (LILACS)*, Scientific Electronic Library Online (SciELO), using the following *Descritores em Ciências da Saúde/Medical Subject Headings (DeCSMeSH)*: "Neoplasms", "nursing care", "palliative care", "family caregivers" and "health care needs assessment" in the English, Spanish and Portuguese languages, using the Boolean operators "AND" and "OR", adopted for the search strategy (Chart 1), following inclusion and exclusion criteria.

The inclusion criteria were complete articles available for free in the English, Portuguese and Spanish languages, published over the last 10 years (2013-2023), that match the study objective and research question, delimiting the search to oncological palliative care in adult individuals. The exclusion criteria were articles that did not match the theme or objective of the research, articles about pediatric palliative care, incomplete studies and/or unavailable for free; literature or bibliographical reviews and other publications such as technical manuals, monographs, theses and dissertations.

Later, to help collecting and presenting data, a chart was elaborated to simplify, summarize, and organize the findings, validated by Ursi¹², containing the following information: title, year/country, type of study, objectives, sample size and main results (Chart 2).

Chart 1. Databases and search strategies. Belém (PA), Brazil, 2023

Databases	Search strategies
BDENF	(<i>cuidados de enfermagem</i>) AND (<i>neoplasias</i>) AND (<i>cuidados paliativos</i>) AND (<i>familiares cuidadores</i>) OR (<i>avaliação das necessidades de cuidados de saúde</i>) AND (<i>cuidadores familiares</i>)
LILACS	(<i>cuidados de enfermagem</i>) AND (<i>neoplasias</i>) AND (<i>cuidadores familiares</i>) AND (<i>cuidados paliativos</i>) OR (<i>avaliação das necessidades de cuidados de saúde</i>) AND (<i>cuidadores familiares</i>)
SciELO	(<i>avaliação das necessidades de cuidados de saúde</i>) OR (<i>cuidados de enfermagem</i>) AND (<i>cuidados paliativos</i>) AND (<i>familiar cuidador</i>)
MEDLINE/ PubMed	(<i>nursing care</i>) AND (<i>needs assessment</i>) AND (<i>palliative care</i>) AND (<i>family caregivers</i>)

RESULTS

The initial screening found 388 productions in the four databases. The inclusion and exclusion criteria removed 279 productions. Furthermore, 109 articles were assessed regarding eligibility, which excluded other 47 duplicated articles. A total of 62 articles were submitted to title and abstract reading to verify if they matched the guiding question and research objective, resulting in the exclusion of 38 articles due to theme incompatibility. The final sample consisted of 24 studies (Figure 1).

The flowchart showing the publication selection journey followed the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) recommendation model¹³ (Figure 1).

The final sample consisted of 24 articles, of which 17 (70.8%) were found in PubMed, four (16.6%) in BDENF, three in LILACS. No articles were sampled from the SciELO database. Regarding language, 16 articles were published in English, seven in Portuguese and one in Spanish (Chart 2)¹⁴⁻³⁷.

Regarding the themes, the manuscripts show issues related to the family caregiver needs when caring for an oncological patient. Emotional and financial needs, lack or difficulty of access to palliative care, in addition to lack of information on cancer and its treatments, lack of formal training through health education, and lack of support to practical care activities, so that family caregivers can develop such care skills with quality. The role of nurses is also seen as the main link in communication between team-patient-family, and responsible for promoting health

education, involving family caregivers in care planning and decision-making.

DISCUSSION

THE TRANSITION TO CARE – CARE NEEDS AND SKILLS OF FAMILY CAREGIVERS

After the diagnosis of a serious and life-threatening disease, the family deals with fears and insecurities, in addition to the need of readapting the functional structure so it can fully address the needs of the ill family member^{3,38}. According to Meleis⁴, when playing new roles, people go through a transition processes. At this point, the family caregiver (FC) role emerges. According to theory⁴, FCs experience a situational transition, as it includes events that promote shifts or redefinition of the person's roles.

By recognizing that FCs are an essential component of care, it becomes imperative to investigate the issues and needs presented by them. The needs will be analyzed through the Meleis⁴ theory, considering the conditioning factors of transition and nursing therapeutics.

The transition conditions can be related to inhibiting or facilitating factors of transition, encompassing the challenges in the care process, the personal experiences, of the society and community they are inserted in, permeated by the nursing therapeutics, which are nurse actions in care that focus on preventing unhealthy transitions, promoting well-being perception⁴.

The role of the FC of an oncological patient in palliative care demands the performance of multiple tasks, including symptom management, medication administration, care coordination, domestic chores, and providing emotional and physical support to patients, according to findings from most studies.

These actions are inherent to the transition properties⁴, such as awareness/perception of the new role, involvement or commitment, and changes perceived after the transition to the caregiver role. To Meleis et al.⁴, the awareness level influences the commitment to care and vice-versa. The more aware the FC is of their beloved one's prognosis, the more they will get involved in the job of care.

As to the challenges and difficulties faced by FCs, studies show they can be tense about the burden of caring for someone highly dependent of their support, and need adequate training and education to improve practical and emotional care skills, including communication skills, symptom management, patient skin care and nutrition^{16,17,22-24,28-32,35,36}, medication administration, and wound care^{17,19,23,24,27-31,34,35}. Skills intimately related to self-efficacy and better decision-making.



Chart 2. Chart summarizing the distribution of selected articles by title, year/country, type of study, objectives, sample size and main results, 2023

Title	Year/Country	Type of study	Objectives	Sample size	Main Results
<i>Exploring the support needs of family caregivers of patients with brain cancer using the CSNAT: a comparative study with other cancer groups¹⁴</i>	2015/ Australia	Stepped wedge cluster trial	Compare the profile and differences in well-being results of family caregivers of people with brain cancer and people with other types of cancer that have participated in the CSNAT intervention and assess CSNAT viability as an intervention for identifying and approaching the support needs of family caregivers of people with brain cancer in home palliative care	500 patients with cancer diagnosis and 29 caregivers of patients with primary brain cancer	The Carer Support Needs Assessment Tool (CSNAT) may help health professionals in adapting their support to the individualized and exclusive needs of family caregivers of patients with brain cancer, highlighting the importance of recognizing and validating the role of the caregiver, providing emotional and practical support
<i>Nursing team actions from the perspective of families of patients under palliative care¹⁵</i>	2016/ Brazil	Descriptive exploratory	Understand the perception of families on the nursing team care actions towards patients in palliative care	17 family caregivers of patients in palliative care	The nursing professional should include families in the specific care plan to understand how they experience the life and death process and deal with the challenges of care
<i>Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being¹⁶</i>	2016/ USA	Randomized controlled trial	Examine the effects of an enhanced training protocol for caregivers (Enhanced-CT) that taught caregivers knowledges and skills to manage patients' symptoms and strategies to manage their own psychic suffering.	10 nurses	The intervention significantly improved the self-efficacy of caregivers in dealing with cancer symptoms and stress in patients, as well as their preparedness for care
<i>Caregiver activation and home hospice nurse communication in advanced cancer care¹⁷</i>	2017/ USA	Prospective observational	Analyze the caregiver activation during home palliative care for patients with advanced cancer	45 palliative care nurses, 60 patients and 60 family caregivers	The caregivers play a fundamental role in end-of-life home care, and it is important to meet their needs to ensure they provide high quality care
<i>Educational booklet for patients in palliative care and their families: construction strategies¹⁸</i>	2017/ Brazil	Descriptive	Elaborate an educational booklet for patients in oncological palliative care and their families	30 oncological patients in palliative care, 30 family members and 50 health professionals	Communication, information and education in health are the foundation of palliative care. The production of educational materials is key to improve the quality of teaching-learning and assistance communication, intensifying guidance and information relayed by the professional to the patient and their family
<i>The family as a member of palliative care assistance¹⁹</i>	2018/ Brazil	Descriptive exploratory	Analyze the perception of nurses on family participation in palliative care assistance	10 nurses	A family intervention is needed from a cultural approach to care, respecting their values and beliefs, fostering improvements in communication and relaying of information between professional-patient-family
<i>Factors associated with family caregivers' confidence in future surrogate decision making for persons with cancer²⁰</i>	2018/USA	Cross-sectional	Identify a precise set of modifiable intra-personal and social factors associated with confidence to make future surrogate decisions	294 family caregivers	Social and intra-personal support may be an important factor in encouraging the caregiver to feel more confident about making medical and life maintenance decisions for the patient

to be continued



Chart 2. continuation

Title	Year/Country	Type of study	Objectives	Sample size	Main Results
<i>Informal caregiver challenges for advanced cancer patients during end-of-life care in Johannesburg, South Africa and distinctions based on place of death²¹</i>	2018/South Africa	Retrospective cohort	To better understand the challenges of informal end of life care in South Africa, both at home and at hospitalization units	174 patients and 174 caregivers	Skill training interventions may improve caregivers' self-efficacy and physical function and reduce suffering and anxiety
<i>Validation of a technology for self-care of family caregivers of cancer patients in home-based palliative care²²</i>	2019/Brazil	Methodological	Validate the content of a booklet designed to support the self-care of family caregivers of cancer patients in home-based palliative care	11 expert judges, including nurses and judges from other fields	Educational technologies are important tools to cope with the transformations that happen in the family context, providing essential information based on actual needs and promoting better acceptance of treatment and change
<i>Assessment of caregiving burden of family caregivers of advanced cancer patients and their satisfaction with the dedicated inpatient palliative care provided to their patients: a cross-sectional study from a tertiary care centre in South Asia²³</i>	2019/India	Cross-sectional	Assess the burden over the caregiver and the satisfaction of family caregivers of advanced cancer patients with the palliative care services provided in a dedicated inpatient palliative care unit of a tertiary care center in India, South Asia	211 family caregivers	The importance of a broad and customized care plan, in which nurses can perform a fundamental role in supporting family caregivers and providing quality palliative care, regularly assessing the care load
<i>Family caregiver descriptions of stopping chemotherapy and end-of-life transitions²⁴</i>	2019/USA	Descriptive exploratory	Describe perspectives of family caregivers on advanced cancer patients' last month of life, particularly if and how chemotherapy was discontinued and the effect of clinical decision-making on the perception of family caregivers on the patient's end of life care experience	92 family caregivers	Caregivers can offer better care to patients if they have access to clear and precise information about what to expect during the final stages of the illness, and if they have a clear palliative care plan
<i>Self-care of the caregiver of the sick in adequate palliative oncological home care²⁵</i>	2019/Brazil	Descriptive	Understand the self-care needs of family caregivers when caring for the sick in oncological home palliative care and propose strategies so these caregivers can perform self-care	10 family caregivers	The Nursing role is seen as a promoter of health restoration in people, stimulating the implementation of assistance and educational practices that value self-care, aiding the whole multi-professional team in the care unit
<i>What do family caregivers know about palliative care? Results from a national survey²⁶</i>	2019/USA	Exploratory	Verify the level of knowledge on palliative care among USA family caregivers and describe the demographic variation in awareness and perceptions of palliative care	45 palliative care nurses, 60 patients and 60 family caregivers	Recommends that renewed efforts of public announcements are needed to clarify palliative care services using a patient and family-centered approach
<i>Needs assessment for Turkish family caregivers of older persons with cancer²⁷</i>	2019/Turkey	Descriptive exploratory	Assess the needs and obtain suggestions that may inform the adaptation of early palliative care model based on ENABLE (Educate, Nurture, Advise Before Life Ends) evidence for Turkish family caregivers of elderly people with cancer	25 caregivers and 25 patients	Highlights the importance of providing psychosocial and educational support to family caregivers, in which the nursing team can build a relationship of trust with them, involving them in the decision-making process regarding the care to their beloved ones

to be continued



Quadro 2. continuation

Title	Year/Country	Type of study	Objectives	Sample size	Main Results
<i>Family/caregiver's perspective on chronic pain in palliative care patients</i> ²⁸	2019/Costa Rica	Descriptive exploratory	Understand the family/caregiver perspective on coping with their palliative care family member's chronic pain	9 family caregivers	Highlights the importance of communication as a support therapeutic resource in pain crisis and the need for raising awareness of health professionals towards improving the under-treatment of chronic pain
<i>Increasing preparedness for caregiving and death in family caregivers of patients with severe illness who are cared for at home —study protocol for a web-based intervention</i> ²⁹	2020/Sweden	Intervention/descriptive	Describe a study protocol that approaches if web-based interventions can be used in the context of palliative care to promote preparedness of family caregivers for care and death	200 family caregivers	The health professionals can support cancer caregivers in several ways, including by providing information and resources on patient care, emotional and psychological support, liaising with support groups and coordinating care with other members of the health team
<i>Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana</i> ³⁰	2020/Ghana	Phenomenological	Explore and describe the motivations and experiences of care among family caregivers of patients that live with advanced breast cancer	15 family caregivers	Family caregivers play an important role in the care of patients with advanced breast cancer. They need adequate training and support, such as adequate information and resources to help them effectively perform their care activities
<i>The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: a multi-country qualitative study</i> ³¹	2021/ Nigeria, Uganda, and Zimbabwe	Multinational cross-sectional	Understand the role, impact and support of informal caregivers of patients with advanced cancer when interacting with palliative care services in Nigeria, Uganda, and Zimbabwe	15 informal caregivers	Digital interventions can improve communication between patients and caregiving providers, as well as the need for training and education for informal caregivers, the importance of financial and emotional support in providing palliative care
<i>eTRIO trial: study protocol of a randomised controlled trial of online education modules to facilitate effective family caregiver involvement in oncology</i> ³²	2021/Australia	Randomized controlled trial	Describe a randomized clinical trial that assesses the combined efficacy of new online education modules on communication with caregivers for: (1) oncological doctors (eTRIO) and (2) patients with cancer and caregivers (eTRIO-pc)	30 health professionals (oncological doctors and nurses and/or hematologists) and 270 patients and caregivers divided in 2 groups (control and intervention)	The development of an evidence-based online learning program divided in two modules (clinical and patient/caregiver) can improve involvement and management of caregivers in the context of cancer
<i>Factors associated with carer psychological and physical health during end-of-life caregiving: an observational analysis of a population-based post-bereavement survey of carers of people with cancer</i> ³³	2021/England	Retrospective cross-sectional	The objective of this study was to test for the first time the potential impact of a broad set of variables that can be observed in the caregiver's health while providing end of life care, within a population-based sample of caregivers	1,504 family caregivers	As intervenções para apoiar os familiares cuidadores devem abordar as necessidades específicas dos cuidadores, como fornecer cuidados de alívio, aconselhamento e outros serviços de suporte. Além disso, as intervenções devem se concentrar na manutenção de outras atividades e no relaxamento para ajudar a reduzir a carga de cuidado
<i>Priorities to improve cancer caregiving: report of a caregiver stakeholder workshop</i> ³⁴	2021/USA	Descriptive exploratory	Summarize caregivers' recommendations for investigation and clinical priorities in cancer care	15 informal caregivers	Recommends integrating the caregiver as a healthcare provider to the patient, with a focus on the health and well-being of caregivers and interventions that reduce caregiver stress, such as peer mentoring programs

to be continued



Quadro 2. continuation

Title	Year/Country	Type of study	Objectives	Sample size	Main Results
<i>The self-care practices of family caregivers of persons with poor prognosis cancer: differences by varying levels of caregiver well-being and preparedness³⁵</i>	2021/USA	Cross-sectional	Describe the specific self-care practices of family caregivers of individuals with advanced cancer and determine its association with caregiver well-being and preparedness for care	294 family caregivers	Healthcare providers and support services to family caregivers should shift the focus from illness and overload to health and well-being
<i>Care of family members of people with malignant neoplastic wounds at home³⁶</i>	2022/Brazil	Descriptive exploratory	Understand how caregivers of people with malignant neoplastic wounds perform home care	7 family caregivers	Family caregivers experience suffering, discrimination and the feeling of care insecurity. They need support from health services and professionals, far beyond practical/technical procedures, understanding the importance of welcoming, empathy, and respect
<i>An exploration of family caregivers' health care needs when caring for patients with cancer in the resource-challenged context of west java, Indonesia³⁷</i>	2023/Indonesia	Cross-sectional	Determine the needs of family caregivers when providing informal care to family members with cancer in the context of scarce resources in West Java, Indonesia	220 family caregivers	Reinforces the autonomy of the oncological nurse in the outpatient services and the emerging needs through remote or home visits

The new role triggers informational, emotional, psychological, practical, and effective communication needs to deal with care-related stress and requests^{19,23,24,27-31,34,37}. These personal needs, if properly addressed, can be considered facilitating factors for transition⁴, understanding the influence they cause in skill mastery and thus providing a healthy transition.

The findings point to a lack of adequate preparation and training to improve FCs skills that can negatively impact their own well-being and the care skill, causing an emotional and physical overload^{14,21,23,31-33,35} and a lack of effective communication with the health team^{23,24}. Factors that can inhibit a transition, since, according to Meleis et al.⁴, the more prepared and informed is the caregiver, the greater their care skill, facilitating the transition experience and influencing it in a healthy way.

As to the conditioning factors to community and society⁴, studies show the need for social order and intrapersonal support^{20,27,30,37}, access to quality health resources and palliative care services^{17,24,26,32,33}, as well as homecare programs^{16,17,30,32,37} to support FCs, conditions that can facilitate the transition process. Moreover, studies highlight the importance of government social intervention programs²⁴, local community and religious leaders' involvement in providing palliative care and support to caregivers³¹.

According to Dionne-Odom, Ornstein, and Kent²⁶, FCs play a critical role in providing daily healthcare and performing other tasks, from diagnosis to end of life. This is in line with the narrative revision study³⁹, which analyzed the needs and skills of FCs of patients with thoracic cancer.

Among the study's main points³⁹ is the importance of integrating early palliative care to the treatment, with the goal of managing challenges associated to the illness, improving quality of life of patients and caregivers, since palliative care is not limited to only end of life care⁴⁰, but should be integrated to the treatment approach from the diagnosis stage due to its ability to promote well-being and quality of life.

Thus, preparedness and knowledge during transition and the use of strategies that can help throughout the process tend to facilitate the care experience in the context of oncological palliative care⁴¹. Identifying the effects and impacts of these needs in the transition to care is essential to the assistance provided by nurses, since being aware of this helps to perfect skills and improve the care provided and thus favor a better quality of life to patients and their FCs.

To summarize, a healthy transition occurs when individuals demonstrate they have mastered the care skills needed in their new role. According to Meleis et al.⁴, such mastery is the combination of pre-existing skills with skills acquired from experiences during the transition to care. Or even, being unhealthy or ineffective, when it is marked by difficulty in understanding the role, without the mastery to manage the new condition appropriately.

Thus, nurses are facilitators of a healthy transition process with a key role in the first moments of care, since it is less likely that FCs master care skills at the early stages of dealing with their beloved one's illness⁴¹. With that in mind, the next category approaches the role of nurses in face of the hereby demonstrated needs.



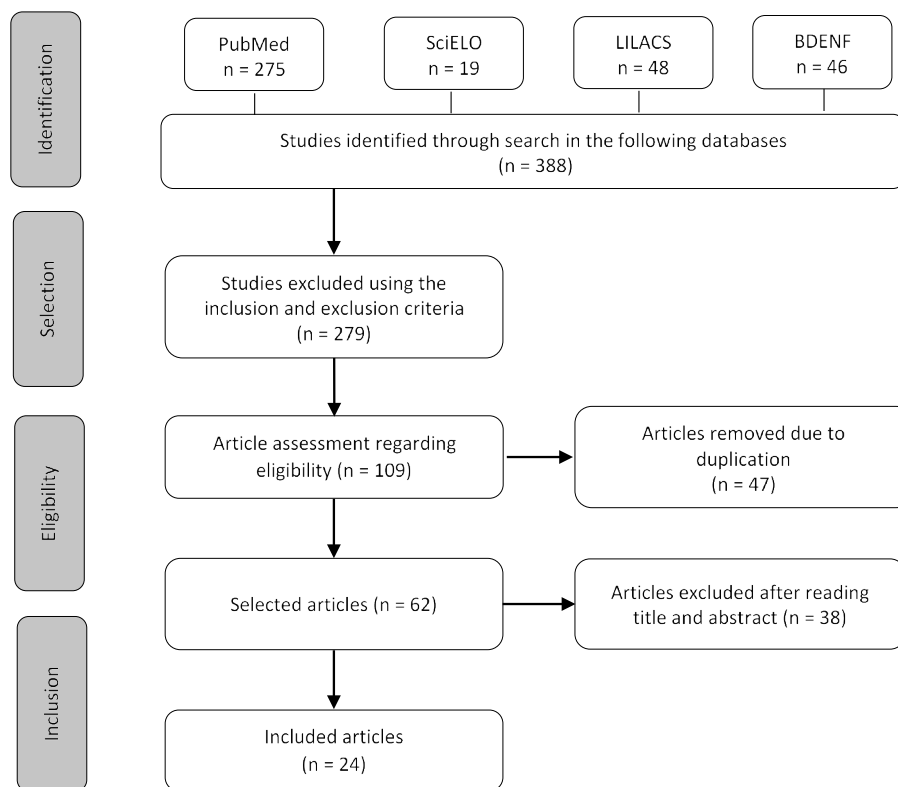


Figure 1. Flowchart of articles search and selection in the databases. Belém (PA), Brazil, 2023

Source: Adapted from PRISMA¹³.

NURSE ACTION IN FACE OF THE FAMILY CAREGIVER'S NEEDS

The nursing therapeutics⁴² can be understood as activities and actions performed by nurses with the objective of facilitating the transition process and, thus, reaching a better health condition and greater well-being. To Schumacher and Meleis⁴³, nursing interventions directed to FCs develop the honing of skills and provide support when needed. That way, nursing therapeutics should focus on preventing unhealthy transitions, promoting well-being perception and guidance needed for caregivers to master their new role⁴¹.

Studies show that nurses need to be aware of the needs and concerns of caregivers in providing quality and effective care^{17,23}, and offer interventions, such as education on the daily care practice, counseling, and referral to support services when needed^{30,33}. Nurses are also helpful in teaching technical procedures related to the daily needs, promoting active listening¹⁵, providing strategies for managing FCs' stress^{16,17,23,24,32-35}, and improving communication skills^{14,17,23,24,28,29,31,32}.

Acknowledging the experiences lived by FCs is one of the pillars of the transition theory⁴, which attributes to the nurses the responsibility of developing interventions that address the needs of caregivers in the transition process. By focusing their practice on the person and their actual needs, which should contemplate physical, psychological,

and spiritual aspects of the FC, nurses can influence the transition processes⁴¹.

Within palliative care, there are principles that govern the approach, one of them being "offer a support system to help families cope with grief during the patient's illness"⁴⁴, with a focus on the presented needs. Such principle reflects the importance of identifying needs and clearing doubts of these FCs, so they can assertively care for their beloved ones and find strategies to cope with grief, as reinforced by the studies in this review^{17,21,29,33}.

This is in line with the study conducted in Indonesia²⁰, which points to development of palliative care interventions led by nurses to address the needs of FCs of patients with cancer in several areas. The study suggests that "oncological nurses can offer appointments in the outpatient, train the family, monitor progress and emerging needs through remote or home visits"²⁰, with the goal of promoting better quality of life, respecting the needs and skills of patients and FCs.

Other findings⁴⁵ suggest that nursing interventions have beneficial effects on FCs of cancer patients, playing a key role in improving preparedness from a holistic perspective. Providing training and guidance involves them in the decision-making process regarding care of their beloved ones, helping caregivers to make informed decisions^{20,27,32,35}.

Most studies suggest providing information and education on practical care, illness pathology, most common symptoms, prognosis and treatment options, symptom management, including knowledge on non-pharmacological therapies for pain relief, medication control, to reduce complications arising from the evolution of the illness, skin care, personal hygiene, nutrition and hydration^{14-18,21-24,27-33,38}.

An integrative review⁴⁶ showed that clear and objective information is one of the main support tools health professionals can offer to families in the hospitalization period to facilitate their understanding on the health condition of the patient. Thus, the communication with patients and their families should have such attributes and be sympathetic, always respecting people's autonomy, valuing their beliefs and values, aiming to understand their difficulties and needs for adapting to new situations that generate instability.

Such guidance needs to be easily understood, given that health education favors safe care, thus facilitating the transition to the new caregiver role. In this sense, educational technologies emerge as important tools that help these professionals provide information, which in turn promotes better adherence to safe practices and behavior changes, as shown by studies^{18,22}. To Varela et al.¹⁸, the use of educational technologies aimed at addressing the actual needs of this family member's new condition as a caregiver allows for better quality of teaching-learning and communication in healthcare.

Reinforcing the findings by Alavariza et al.²⁹ and Grande et al.³³, lack of communication and understanding between patients, caregivers, and professionals may lead to inadequate treatment decisions and to a decrease in quality of life for patients and FCs.

Thus, there is a growing need for encouraging patients and FCs to adopt practices that can provide integral and humanized care, considering the whole context the patient is inserted and how their family dynamics play out. By promoting integral and welcoming assistance to the patient and their family, with humanized practices and effective communication, the nurse acting in palliative care helps these family caregivers cope with the challenges that are intrinsic to caring.

Therefore, it is up to the nurses to acknowledge the importance of family caregivers and provide adequate support and training to help them deal with the challenges of caring for oncological patients in palliative care, helping to provide that care through preparation and support, access to resources and practical and psychosocial services, and integrating early palliative care to the treatment plan.

The limitations of this study include the number of databases selected for research, which does not, however,

interfere in the obtained results, given the number of articles selected for discussion. Therefore, adding other databases and combinations of descriptors to future studies will increase the chances of surfacing new findings with greater evidence levels and new contributions to the scientific communication.

CONCLUSION

By experiencing the transition to the role of caregiver of an oncological patient, family members are faced with feelings of fear, anguish, and suffering. This triggers changes in the whole family dynamic, in addition to the need for readjusting their role in society and acquiring care skills. Their needs have diverse natures, such as informational, practical, emotional, and psychological, reinforcing the importance of the nurse's role in this theme, as a facilitator of the transition process.

The present study showed that nurses must understand the experiences and needs of family caregivers in face of the many situations experienced in their care journey, providing information and guidance that facilitate the decision-making process in care, in which both patient and family caregiver receive assistance that promotes well-being and better quality of life, as advocated by palliative care.

The use of a theoretical model for understanding results allowed for a deeper discussion on such an important theme within oncological palliative care, enabling recognition of the nurse's role through a holistic view of the process of caring, as well as strengthening the debate in the scientific community, improving the relationship between theory and practice. The identification of transition facilitating and inhibiting factors may serve as foundation for planning nursing interventions that promote integral and humanized care towards family caregivers.

Other studies may better unravel such nursing interventions performed in palliative oncological assistance, with the goal of identifying the best alternatives that may convey information and prepare for the acquisition of new care skills, favoring a care plan according to the actual needs of family caregivers that involve the stages of diagnosis, hospital discharge and end of life care and, finally, grief.

CONTRIBUTIONS

Ana Carolina de Sousa Gomes Moraes has substantially contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Mary Elizabeth de Santana has contributed to the wording



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DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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