



THE EXPERIENCES OF INFORMAL CAREGIVERS CARING FOR PATIENTS UNDERGOING ONCOLOGIC PALLIATIVE TREATMENT: AN INTEGRATIVE REVIEW

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ABSTRACT

Objective: to collate, synthesize, and integrate the literature around the experiences of informal caregivers providing care to patients undergoing palliative cancer treatment. **Method:** an integrative literature review using the methodology proposed by Ganong. The searches were carried out through the Medical Literature Analysis and Retrieval System Online (MEDLINE) and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. The search strategy was composed of terms from the Medical Subject Headings (MeSH) and their versions in English and Portuguese. After formulating the search strategy, it was reviewed by a specialist in systematic reviews to ensure rigor. **Results:** twenty-four articles were selected, and they addressed aspects related to the importance of caring for the loved one, challenges faced, resources used, and coping with the process of death and dying. **Conclusion:** this review brings evidence of the lack of support and resources faced by informal caregivers of palliative cancer patients. Also, it highlights the need for more research on this topic since all studies mentioned the lack of research in this field.

Keywords: Caregivers. Palliative care. Neoplasms. Death. Experiences.

INTRODUCTION

Cancer is a major public health issue and the main cause of death world wide⁽¹⁻²⁾. In 2018, the number of people living with cancer around the world was 18.1 million and, in 2040, this number is expected to reach 29.5 million⁽³⁾. The most recent predictions foresee that between the years 2020-2022 Brazil will have 625 thousand new cases of cancer⁽²⁾. However, the cancer diagnosis often occurs at an advanced stage of the disease, decreasing chances of treatment and cure, as well as increasing the probability of the patient requiring palliative care⁽⁴⁾.

Every year, around 40 million people world wide need palliative care and almost 14 million of these people have cancer⁽¹⁾. According to the World Health Organization, palliative care can be defined as the assistance provided by a multidisciplinary team to prevent and reduce the suffering of patients and families living with a life-threatening illness⁽⁵⁾. The purpose of palliative care is to improve the patients' quality of life, however, patients in palliative care are not necessarily in the final and incurable stage of the disease, and treatments to cure, improve or

prevent the progression of the disease can be done during this process⁽⁴⁾. Furthermore, besides palliative care be provided by an interdisciplinary team, it can and should also be provided together with family members and/or formal and informal caregivers⁽⁶⁾.

Informal caregivers are defined as someone who provide care to a patient and usually do not have specific education for this task, just as they usually do not get paid for this activity. The most common types of informal caregivers are parents, spouses, friends, and neighbors of people in need of care⁽⁷⁾. In contrast, formal caregivers are people who usually have some level of education in the healthcare field and get paid to assist patient, such as nurses and personal support workers⁽⁸⁾.

In the cancer illness, both the patient and family members face conflicts when dealing with the disease, the diagnosis and treatment⁽⁹⁻¹⁰⁾. Currently, it is known that cancer can affect the lives of informal caregivers as much as it affects the patient. However, the role and needs of these caregivers are often ignored and/or overlooked by professionals and the health care system⁽⁷⁾. In this study, when mentioning the term caregivers,

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we will consider only informal caregivers. Studies investigating the perception of informal caregivers related to the process of caring for a patient undergoing palliative treatment for cancer highlighted that those caregivers face physical, emotional, and financial barriers during the process⁽¹¹⁻¹³⁾. However, although there are reports about this topic in the literature, there is still a lack of studies that group and synthesize this data to produce evidence that is complete and comprehensive enough to promote changes in practice.

Additionally, healthcare professionals need to understand the perspectives and feelings of caregivers related to caring for a person undergoing palliative cancer treatment. Because, only upon a clear understanding of the roles and experiences of caregivers that health professionals will be able to provide adequate support and assistance to this population. Also, this understanding can help to promote a more comprehensive care between health professionals and informal caregivers, benefiting everyone involved in the process.

In this study, we will consider the phenomenological view around the concept experience, which is the aspects related to people's perspectives, in this case the caregivers, produced from the knowledge acquired from their experiences and observations while caring for a person undergoing palliative cancer treatment⁽¹⁴⁾. Therefore, the objective of this study is to collate, synthesize and integrate the literature about the experiences of informal caregivers providing care to patients undergoing palliative cancer treatment.

METHOD

In this study, we used the integrative review framework for nursing research proposed by Ganong⁽¹⁵⁾. This approach consists of six steps: selecting hypotheses or questions for the abstract, exemplifying, representing the characteristics of the primary research, analyzing the findings, interpreting the results, and reporting the review. To elaborate the research question of this integrative review, we used the PICo strategy (acronym for population, phenomena of interest, context)⁽¹⁶⁾ and we defined as the research question: what is known about the experiences of informal

caregivers caring for a person undergoing palliative cancer treatment? In that question, informal caregivers are the population, experience is the phenomenon of interest, and the act of caring for a person undergoing palliative cancer treatment is the context. To answer this question, the following sub-questions were also explored: what are the challenges faced by informal caregivers when caring for a person undergoing palliative cancer treatment? What are the sources of support and comfort used by informal caregivers to help them to care for a person undergoing palliative cancer treatment?

Inclusion and Exclusion Criteria

In this study, we used the time frame of January 2014 - January 2020 for two main reasons: to retrieve more current references on the topic of interest; and considering that, in 2014, the first global resolution on palliative care occurred (World Health Assembly resolution 67.19), where the WHO and the Member States were urged to improve access to palliative care as a key component of health systems, this with an emphasis on primary health care and community/home-based care⁽¹⁷⁾. The inclusion criteria included qualitative studies, once it is a study about experiences, and articles that addressed any aspects related to the experiences or perceptions of informal caregivers who are in the care process for a patient undergoing palliative cancer treatment. Also, duplicate articles were excluded if they appeared in more than one database.

Search Strategy

The search was conducted in two databases: Medical Literature Analysis and Retrieval System Online (MEDLINE) and Cumulative Index to Nursing and Allied Health Literature (CINAHL). For the search strategy, terms in English and Portuguese from Medical Subject Headings (MeSH) were selected, which were: experience, palliative care, caregiver, cancer, and neoplasms. Different combinations were performed and for the crossing of the descriptors the Boolean operators AND and OR were applied until the best search strategy could be selected. A librarian specialized in systematic

literature reviews reviewed and approved the search strategies employed in this research presented in Chart 1.

Chart 1. Combination of Search Strategies, Kingston, Ontario, Canada, 2020

MEDLINE	1. Experience.af. 2. Palliative care.af. 3. Caregiver.af. 4. (cancer or neoplasms).af. 5. 1 and 2 and 3 and 4 6. Limit to year and language Total results: 122
CINAHL	1. Experience.af. 2. Palliative care.af. 3. Caregiver.af. 4. (cancer or neoplasms).af. 5. 1 and 2 and 3 and 4 6. Limit to year and language 7. Total results: 115

Source: elaborated by authors.

Study Selection

The studies found in the search strategy performed were imported to EndNote® and the duplicates were removed. After that, the citations were imported into a reference management software (Convidence®). The titles and abstracts were first assessed for eligibility against the inclusion criteria and subsequently the full texts were assessed. Articles that were not available online were requested by the Interlibrary Loan.

Data Analysis and Presentation

For data collection, a data extraction tool was created to obtain the main characteristics of the studies. The tool included aspects related to the type of study, proposed methodology, sample and instruments, main categories, and level of evidence according to the Joanna Briggs Institute. The data extracted was assessed through a content analysis approach to find a consensus across the records and then summarized and synthesized to report in integrative review. The findings are explored through a narrative summary followed by a descriptive numerical summary to address and answer the purpose of this review.

A total of 237 articles were initially found in the selected databases, 122 through MEDLINE and 115 from CINAHL. After excluding duplicates, 148 studies were screened, 24 of which met the inclusion criteria and were selected for this review. Details related to the searching process and studies selection can be found in the PRISMA-ScR flowchart, Figure 1. The data from the 24 studies selected was collected according to the data extraction instrument, and a short version of the instrument and the main characteristics of the articles can be found in Table 2.

Regarding the level of evidence of the studies according to the Joanna Briggs Institute⁽¹⁹⁾, one article⁽²⁰⁾ was considered as level 2, which is a qualitative synthesis or mixed methods; and the remaining articles were level 3, which means that each was a single qualitative study⁽¹⁹⁾. Related to the qualitative methods, 22 used semi-structured or open interviews as data collection techniques, which were conducted in person, by phone or through online support chat, and only a study⁽²¹⁾ did not include any type of interview as it was a case study report. Narrative photographic method was used in one study⁽²²⁾ and the use of field notes was only mentioned in two studies^(23,24).

RESULTS

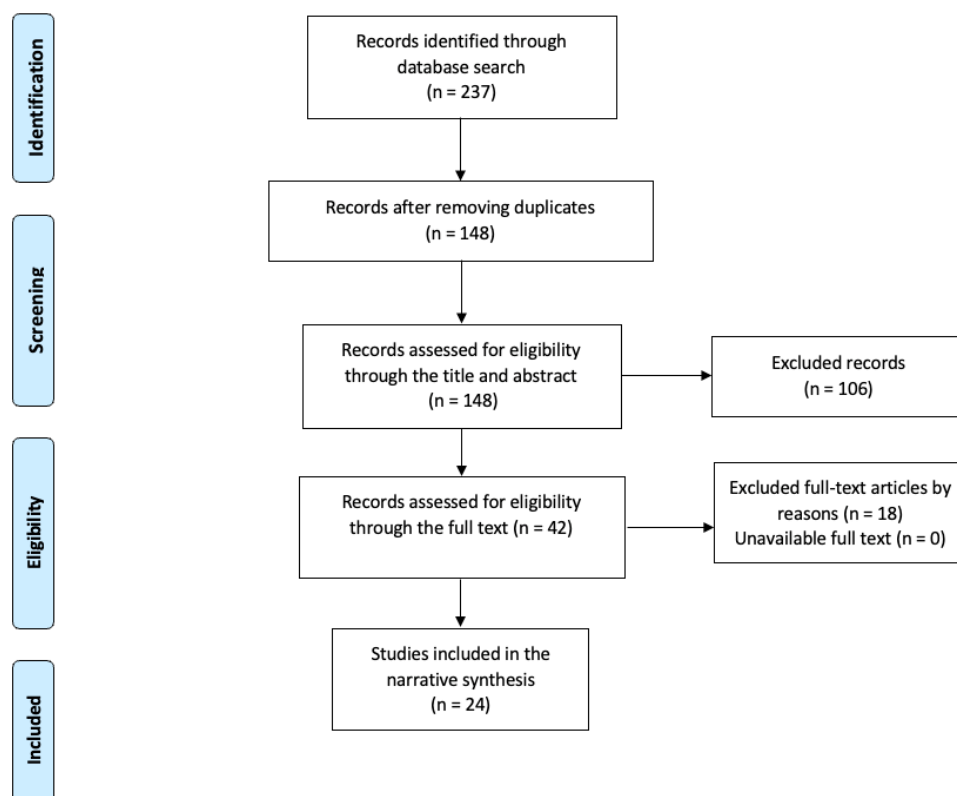


Figure 1. Article selection process according to PRISMA-ScR⁽¹⁸⁾. Kingston, Ontario, Canada, 2020

Although the choice of the methods was congruent with the purpose of the articles in all studies selected, there was a lack of description related to the methodology used. This because seven articles did not explicitly expose the specific methodology used^(21,22,24-28). Saturation related to data collection was mentioned by 12 articles, and only four^(24,26,29,30) clearly stated why saturation was reached according to their criteria. In the other eight articles, the authors mention that saturation was reached without further or satisfactory explanations^(27,28,31-36). Also, approval by an ethics committee was not mentioned in eight of the studies^(20-22,34,37-40).

The results from the thematic analysis conducted gave origin to the following categories according to the findings: the importance of caring for the loved one; challenges faced; resources used; and coping with the process of death and dying.

Regarding the significance of caring for the loved one, this category refers to the feelings expressed by the caregivers related to the reasons and the importance of caring for a close

and dear person, and this category was found in 13 studies^(20-22, 26, 28, 30, 33, 35-37, 40-42). Results in this category highlighted that caregivers face different feelings that led them to caring for a person, the main one being the intention to pay back the patient through care for everything the patient has done for the caregiver in the past. Caregivers recognize that the act of caring is complex and exhausting, but for them, providing care to someone they love is more important^(20-22,26,28,30, 33,35-37,40-42).

Regarding the challenges faced, this category refers to the different obstacles that caregivers commonly face while caring for a person undergoing palliative cancer treatment, and this category was observed in 19 studies^(20-22, 24-26, 29-33, 35, 37-41, 43, 44). Caregivers mentioned different challenges, but the most common were the physical, emotional, and financial challenges, as well as the lack of support from the health system and professionals. Such demands led many caregivers to experience a feeling of fatigue and exhaustion^(20-22,24-26,29-33,35,37-41,43,44).

Chart 2. Selection of articles according to the identification of authors/year and objective. Kingston, Ontario, Canada, 2020.

Authors and year of publication	Objective
Applebaum AJ, Kulikowski JR, Breitbart W (2015).	Describe the application of a care plan to the unique experience of caregivers of patients with advanced cancer
Borland R, Glackin M, Jordan J (2014).	Explore the partners' understandings and experiences in relation to caring for a loved one with a terminal illness, with a particular focus on the role of the hospice nurse specialist
Cacciatore J, Thieleman K, Lieber AS, Blood C, Goldman R (2017).	Assess parents' perceptions of their experiences with health professionals (health care providers) before and after the death of their children in different contexts and geographic locations
Francis LE, Kypriotakis G, O'Toole EE, Rose JH. Cancer (2016).	This study is based on the life course theory to argue that the strains of cancer caregiving and bereavement are modified by the age of the patient
Hannon B, Swami N, Rodin G, Pope A, Zimmermann C (2017).	Determine, from the participant's perspective, the experience of receiving early palliative care and elements of that care
Harrop E, Byrne A, Nelson A (2014).	Explore the information and support needs of family caregivers, as perceived by caregivers and the nursing team
Kristanti MS, Effendy C, Utarini A, Vernooij-Dassen M, Engels Y (2019).	Explore and model experiences of family caregivers of cancer patients in Indonesia performing care tasks
Kristanti MS, Engels Y, Effendy C, Astuti, Utarini A, Vernooij-Dassen M. Comparison (2018).	Describe and compare the experiences of families and caregivers of people with cancer and dementia in Indonesia and explore the role of their social health in these experiences
Lee HT, Melia KM, Yao CA, Lin CJ, Chiu TY, Hu WY (2014).	Explore caregivers' experiences and needs when providing hospice home care to their terminally ill elderly patients with cancer in Taiwan for 1 year.
Levy K, Grant PC, Tenzek KE, Depner RM, Pailler ME, Beupin LK (2019).	Analyze the narratives collected during Photographs of Meaning Program to improve clinical and community knowledge of life as a Photographs of Meaning Program for pediatric palliative caregivers
Lima LES, Santana ME, Correa Júnior AJS, Vasconcelos EV (2019).	Describe the experience of family caregivers of cancer patients in palliative care and analyze the implications for nursing care
Male DA, Fergus KD, Stephen JE (2015).	Explore the experience of caring for a loved one with advanced cancer by means of participant-determined communication, using interactive, text-based transcripts from synchronous online support groups
McPherson CJ, Hadjistavropoulos T, Devereaux A, Lobchuk MM. (2014).	Explore and describe the roles and perspectives of elderly patients with advanced cancer and their family caregivers in pain management at home
Meeker MA, Waldrop DP, Schneider J, Case AA (2014).	Investigate how patients with advanced diseases and their primary caregivers experienced and responded to health care needs and decision-making and how some dyads turned into comfort-focused care
Mosher CE, Ott MA, Hanna N, Jalal SI, Champion VL (2015).	Identify strategies to deal with various physical and psychological symptoms among patients with advanced symptomatic lung cancer and their main family caregivers
Norton SA, Wittink MN, Duberstein PR, Prigerson HG, Stanek S, Epstein RM (2019).	Describe family caregivers' perspectives of the final month of life of patients with advanced cancer, particularly whether and how chemotherapy was discontinued and the effect of clinical decision-making on family caregivers' perceptions of the patient's experience of care at the end of life
Quinoa-Salanova C, Porta-Sales J, Monforte-Royo C, Edo-Gual M (2019).	Achieve a deeper understanding of the lived experience of individuals who are the primary caregiver of a relative with multiple myeloma and shed light on their needs
Robinson CA, Bottorff JL, McFee E, Bissell LJ, Fyles G (2017).	Describe the experiences of bereaved family caregivers whose terminally ill family members with advanced cancer were successful in achieving a desired home death
Robinson JE, Huskey D, Schwartz J, Weaver MS (2019).	Explore the paternal roles, responsibilities, strengths, challenges, personal growth, and support needs of fathers of children with brain tumors receiving new palliative care consultations
Rocio L, Rojas EA, Gonzalez MC, Carreno S, Diana C, Gomez O (2017).	Describe the experiences of the caregiver-family dyad during the transition from hospital to home at a National Cancer Institute in Colombia
Selman LE, Beynon T, Radcliffe E, Whittaker S, Orlowska D, Child F et al. (2015).	Describe the impact of cutaneous T-cell lymphoma on family members and how they cope and adjust, to inform support services
Sherman DW, McGuire DB, Free D, Cheon JY (2014).	Understand the experience of family caregivers of patients with advanced pancreatic cancer
Vale JMM, Neto ACM, Santos LMS, Santana E (2019).	Analyze how health education is developed by the nurse to the family caregiver of the sick in palliative oncology home care
Wijnhoven MN, Terpstra WE, Van Rossem R, Haazer C, Gunnink-Boonstra N, Sonke GS et al (2015)	Examine the experiences of bereaved relatives from the time of diagnosis of incurable cancer to death, with specific emphasis on their role in decision-making (end of life) about chemotherapy

Source: data collected by the authors.

Related to the resources used, this category addresses the different resources that are often

used by caregivers throughout the care process, and this category was mentioned in 17 studies⁽²⁰⁻

22,24,26-35,37-39). Among the different resources used, the most mentioned were religion, hope and spirituality. The use of such resources helped caregivers to face challenges and provide a better care for the patient^(20-22,24,26-35,37-39).

Lastly, the category on coping with the process of death and dying, which refers to the feelings experienced about the continuous possibility of death, was found in 17 studies^(20-25,30-33,35-39,41,44). Caregivers face different feelings related to the death, but all referred to this process as challenging. However, while some caregivers referred to the death as something sad and devastating, others saw that as a relief that would release the patient from all the pain and suffering^(20-25, 30-33,35-39,41,44).

DISCUSSION

Being a caregiver involves a lot of work, both physically and mentally, and one of the biggest motivators for caregivers is the importance of taking care of someone they love^(20-22,26,28,30, 33,35-37,40-42). Even with the challenges faced while caring for a person undergoing palliative cancer treatment, caregivers often mentioned the positive aspects, such as intensity of moments, feelings of contentment, connection, and happiness. These feelings were of tenacity accompanied by a sense of obligation 'payback' because often the patient was the mother or spouse of the caregiver. As the patient had done a lot for the caregiver while he/she was healthy, the caregiver felt that it was his/her duty to take care of the patient. Furthermore, caregivers also mentioned that caring for their sick loved one was a way to demonstrate protection, compassion, gratitude and trust^(20-22,26,28,30,33,35-37,40-42).

Taking care of patients undergoing palliative cancer treatment can be very difficult and involves several challenges^(20-22,24-26,29-33,35,37-41,43,44). The excessive demands placed on caregivers for physical, emotional and financial support can create a stressful situation labelled Caregiver Burden (CB), also known as caregiver overload or exhaustion. Besides the CB negatively influencing the caregivers' lives, it can also affect the quality of the care provided to the patient⁽⁴³⁾. CB was a frequent finding among the articles, and it was mentioned in more than half of the articles^(21,22,24,26,28-30,32,33,35,38,40,41).

Another challenge frequently mentioned was the lack of support received by caregivers. It was not uncommon for caregivers to face a situation where they were the main responsible care provider for a patient, but they had not received any instructions about how to provide the necessary care. This lack of information on how to provide adequate care was emphasized as an important stressor for caregivers^(20,25,26,30,31,35,37,41,44).

The authors from all studies in this literature review mentioned the lack of support faced by caregivers. Besides the lack of knowledge and support experienced by caregivers, another challenge, and probably the greatest of all, was the feeling of powerlessness and helplessness. This refers to the situation faced by caregivers when they see their loved one suffering mentally and physically unable to offer specialized assistance to improve the condition^(20,21,29,32,33,37,39,41,44).

Due to all the challenges faced by caregivers, studies highlighted the need for supportive resources. Among the resources cited in the articles, hope, religion and spirituality were the most often mentioned. Caregivers referred to the constant effort of hoping the patient will get better, and even in the final stages of the disease they were still hoping for a miracle. Furthermore, they mentioned the pain faced when the hope is taken away from them, and suggested that health care professionals need to balance honesty and hope when talking with the family^(20-22,24,26,30-35,37).

Spirituality and religion are distinct, yet they can be easily confounded. Spirituality was frequently cited among caregivers, and it can be defined as the connection with something bigger than one self; it involves search for the life's meaning, one's soul and inner self^(21,26,28,29,31,35,38,39). Religion was also frequently mentioned by caregivers, and it can be defined as a set of beliefs and faith in God and the origin of the world^(20-22,26-29,35). Spirituality and religion were mentioned as a source of relief for caregivers, because even if the worst happened and the patient died, they still believed in something better. On the other hand, having a loved one going through such a difficult process made some of the caregivers to question the existence and veracity of religion and spirituality.

When debating about palliative care of cancer patients, death is an unrelenting possibility. Caregivers often mentioned the difficult process of seeing a loved one deteriorating towards the process of death and dying. This was a difficult process, as they needed to be prepared to lose someone they loved while trying to keep a positive attitude towards the patient. However, some caregivers also mentioned death as a relief because it would release their loved one from all suffering and agony^(21,23-25,32,33,35-38,41,44).

Furthermore, fear was often mentioned by caregivers, especially when death was unavoidable, and they needed to go through this process. Most caregivers also said that their major fear related to the process of death and dying was not death itself, but the loneliness they would face after their loved one had gone^(20,22,24,30,31,32,39,41).

We emphasize as limitations of this study the fact that only articles published between 2014 and 2020 were included. Moreover, the fact that the search and data collection was carried out in Canada may have resulted in an omission of articles published in Portuguese.

CONCLUSION

Through this study it was possible to synthesize the current literature of what is known about the experiences of caregivers in the process of caring for a person undergoing palliative cancer treatment. Informal caregivers feel a great responsibility in the process of care, however, they often face a lack of support from

health professionals and system. This lack of support combined with other stressors, such as witnessing the suffering of a loved person, feelings of helplessness and excessive pressure, can lead caregivers to develop CB. Although there are strategies that caregivers rely on to face the process of having a close person undergoing palliative care, such as hope, religion and spirituality, these are not enough to assure their well-being.

Thus, the findings from this review have important implications for the health and disease process in a nursing perspective. As informal caregivers play an important role for the patient, they should receive more support, including education, from health professionals and institutions. The current situation experienced by these caregivers can negatively affect them, as well as patients and healthcare services, as the lack of adequate care can increase complications related to healthcare. Furthermore, the results from this review highlighted that caregivers believe that health professionals should make more effort to balance honesty and hope when talking to the family. This evidence should work as an instrument for health professionals to better prepare themselves to meet the demands of this population and, consequently, improve the care provided to patients undergoing palliative cancer treatment. Also, further studies in this field are required to better understand the needs of this specific population as all the studies reviewed mentioned the lack of research in this field.

AS EXPERIÊNCIAS DE CUIDADORES INFORMAIS DE PACIENTES EM TRATAMENTO ONCOLÓGICO PALIATIVO: UMA REVISÃO INTEGRATIVA

RESUMO

Objetivo: agrupar, sintetizar e integrar a literatura acerca das experiências de cuidadores informais que prestam cuidados a pacientes oncológicos em tratamento paliativo. **Método:** revisão integrativa de literatura usando a metodologia proposta por Ganong. As buscas foram realizadas nas bases de dados *Medical Literature Analysis and Retrieval System Online* (MEDLINE) e *Cumulative Index to Nursing and Allied Health Literature* (CINAHL). A estratégia de busca foi composta por termos do Medical Subject Headings (MeSH) e suas versões em inglês e português. Após formulada a estratégia de busca, a mesma foi revisada por uma especialista em revisões sistemáticas para garantir rigorosidade. **Resultados:** vinte e quatro artigos foram selecionados, e abordavam aspectos referentes a importância de cuidar do ente querido, desafios enfrentados, e recursos utilizados durante o processo morte e morrer. **Conclusão:** esta revisão traz evidência da falta de suporte e recursos enfrentados por cuidadores informais de pacientes oncológicos paliativos. Assim como, demonstra a necessidade de novas pesquisas sobre esse tópico já que todos os estudos mencionaram a falta de pesquisa nessa área.

Palavras-chave: Cuidadores. Cuidados paliativos. Neoplasias. Morte. Experiências.

LAS EXPERIENCIAS DE LOS CUIDADORES INFORMALES DE PACIENTES EN TRATAMIENTO ONCOLÓGICO PALIATIVO: UNA REVISIÓN INTEGRADORA

RESUMEN

Objetivo: agrupar, sintetizar e integrar la literatura acerca de las experiencias de cuidadores informales que prestan cuidados a pacientes oncológicos en tratamiento paliativo. **Método:** revisión integradora de literatura utilizando la metodología propuesta por Ganong. Las búsquedas fueron realizadas en las bases de datos *Medical Literature Analysis and Retrieval System Online* (MEDLINE) y *Cumulative Index to Nursing and Allied Health Literature* (CINAHL). La estrategia de busca fue compuesta por términos del *Medical Subject Headings* (MeSH) y sus versiones en inglés y portugués. Tras formulada la estrategia de busca, esta ha sido revisada por un experto en revisiones sistemáticas para garantizar rigurosidad. **Resultados:** veinticuatro artículos fueron seleccionados, y trataban aspectos referentes a la importancia de cuidar a la persona querida, retos enfrentados, y recursos utilizados durante el proceso muerte y morir. **Conclusión:** esta revisión pone de manifiesto la falta de soporte y recursos enfrentados por cuidadores informales de pacientes oncológicos paliativos. Demostrando también la necesidad de nuevas investigaciones sobre este tópico puesto que todos los estudios relataron la falta de investigación en este ámbito.

Palabras clave: Braquiterapia. Enfermería. Neoplasias de los Genitales Femeninos. Dolor.

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