







Families experiencing palliative care for hospitalized children with cancer: an integrative review

Familiares vivenciando cuidados paliativos de crianças com câncer hospitalizadas: uma revisão integrativa

Familiares vivenciando cuidados paliativos de niños hospitalizados con cáncer: una revisión integradora

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ABSTRACT

Objective: to examine production of knowledge on families' experience of palliative care for children with cancer hospitalized in an intensive care center and discuss the role of nursing in assisting the family of the child in palliative cancer care. **Method:** this integrative review was conducted on PubMed, LILACS, Scopus, SciELO and CINAHL between January and March 2020. **Results:** from the sample of 13 articles, two categories originated: The impact of palliative cancer care for children on family dynamics and multiprofessional care, especially by nurses, for the family of the child with cancer. **Conclusion:** the studies revealed the national and international panorama of palliative care for children with cancer and the breakdown of physical, social, psychological, and financial family dynamics, characterizing the period as stressful and painful. Nurses establish therapeutic approaches aimed at promoting quality of life for children in palliative care and their families. **Descriptors:** Child; Family; Cancer; Palliative Care; Intensive Care Units.

RESUMO

Objetivo: analisar a produção do conhecimento sobre a experiência da família acerca dos cuidados paliativos da criança com câncer hospitalizada na unidade de terapia intensiva e discutir o papel da enfermagem no atendimento à família da criança com câncer frente aos cuidados paliativos. **Método:** revisão integrativa realizada na PUBMED, LILACS, SCOPUS, SCIELO e CINAHL entre janeiro e março de 2020. **Resultados:** a amostra foi composta por 13 artigos, originando duas categorias: O impacto do cuidado paliativo da criança com câncer na dinâmica familiar e o cuidado multiprofissional, em especial dos enfermeiros, à família da criança com câncer. **Conclusão:** os estudos revelaram o panorama nacional e internacional dos cuidados paliativos à criança com câncer e a desestruturação da dinâmica familiar nos aspectos físicos, sociais, psicológicos, e financeiros, caracterizando o período como estressante e doloroso. Os enfermeiros estabelecem condutas terapêuticas objetivando promover qualidade de vida para crianças em cuidados paliativos e seus familiares. **Descritores:** Criança; Família; Câncer; Cuidados Paliativos; Unidades de Terapia Intensiva.

RESUMEN

Objetivo: analizar la producción de conocimiento sobre la experiencia familiar en los cuidados paliativos de niños con cáncer, hospitalizados en la unidad de cuidados intensivos, y discutir el papel de la enfermería en la asistencia a la familia del niño con cáncer frente a los cuidados paliativos. **Método:** Revisión integradora realizada en PUBMED, LILACS, SCOPUS, SCIELO y CINAHL entre enero y marzo de 2020. **Resultados:** La muestra estuvo conformada por 13 artículos, originando dos categorías: El impacto de los cuidados paliativos para niños con cáncer en la dinámica familiar y los cuidados multiprofesionales, especialmente de las enfermeras, a la familia del niño con cáncer. **Conclusión:** Los estudios revelaron el panorama nacional e internacional de los cuidados paliativos para niños con cáncer y la ruptura de la dinámica familiar en aspectos físicos, sociales, psicológicos y económicos, caracterizándolo como un período estresante y doloroso. Las enfermeras establecen enfoques terapéuticos dirigidos a promover la calidad de vida de los niños en cuidados paliativos y sus familias. **Descritores:** Niño; Familia; Cáncer; Cuidados Paliativos; Unidades de Cuidados Intensivos.

INTRODUCTION

Childhood cancer corresponds to a group of several diseases having in common the proliferation of abnormal cells and that can occur at any place of the organism. The most frequent tumors in childhood and adolescence are leukemias, central nervous tumors, and lymphomas. In addition, tumors such as neuroblastoma, Wilms tumor, retinoblastoma, germinative tumors, osteosarcoma, and sarcoma also stand out¹.

It is expected that the number of new cases of cancer in children and adolescents in Brazil for each year of the 2020-2022 triennium will be 4,310 among boys and 4,150 among girls. These values correspond to estimated risks of 137.87 new cases per million in the male gender and of 139.04 per million for the female gender².

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Consequently, cancer is the disease that most kills children and adolescents, being the second cause of death in this age group, only behind accidents and violent deaths. In Brazil, in 2017 there were 1,467 deaths due to all the tumors in children and adolescents for the male gender, with an estimated risk of 44.46/million. For the female gender, there were 1,086 deaths (34.30/million)^{1,2}.

The diagnosis and experience with cancer represent a long path to be taken by children or adolescents and by their families, with several impacts on their everyday life, considering the early and late consequences of the treatment. The different therapeutic modalities in the field of Oncology offered new chances of cure to children and adolescents, opening them the doors to new life perspectives³.

Consequently, when the disease is diagnosed early, there are great chances for treatment and cure. However, delays in the diagnosis can impair treatment, thus evolving to exclusive palliative care.

The World Health Organization (WHO) defines palliative care as an approach aimed at improving patients' and families' quality of life, provided through prevention and relief of suffering, as well as through early identification, proper assessment and treatment of pain and of other physical, psychosocial, and spiritual problems. This definition was reformulated years later, stating that palliative care must be initiated from the time of disease diagnosis and last throughout the children's life, until their death and afterwards⁴.

Palliative care consists of a differentiated care approach focused on the care of children with terminal cancer, addressing the importance of palliative care, incorporated into the daily Nursing care provided to these children from diagnosis to their death, based on holistic care to the children's physical, psychological, social, and spiritual aspects⁵.

Therefore, the purpose of care in this context is not seeking the cure for the neoplasm, but rather offering interdisciplinary care in order to provide support, information, and comfort to patients with a life-threatening disease and their family members. Currently, it is estimated that 20 million people/year, 6% of them being children, would have an indication for palliative care⁶.

However, during hospitalizations, children are likely to require admission to an Intensive Care Unit (ICU) and, in this unit, health professionals occupy different positions and play different roles, participating in the care of a patient at life risk and/or with imminent death. In these cases, different outcomes are admitted, in which the patient may recover or, in other cases, merely prolong the patient's life^{7,8}.

Family dysfunction resulting from intensive care hospitalization is experienced by all family members and can be intensified by uncertainties that accompany critical and emerging changes in the child's health. In this scenario, a series of sources of stress can be identified, including insecurity related to the intensive care environment, which involves alarms, equipment and communication with the team, as well as the roles of caregiver, the child's condition and changes resulting from the disease⁹, mainly when the child is under exclusive palliative care in the ICU.

In the scientific literature, there are several studies highlighting the benefits of family participation in the care of hospitalized children. However, the experiences of relatives of children with cancer under exclusive palliative care in the oncology ICU have not gained visibility in the literature yet. This study is justified by the complexity of this theme, added to the scarcity in terms of literature and research.

Therefore, this theme is important to the extent that palliative care emerges as a basic condition for patients with cancer to regain respect and dignity, mainly considering the ICU environment, because this sector receives severe patients who are often about to die.

This study adopted the following objectives: to analyze the production of knowledge on the family's experience with palliative care of children with cancer hospitalized in the ICU and to discuss the role of Nursing in the care of families of children with cancer in view of palliative care.

METHOD

This is an integrative literature review with the purpose of gathering findings of studies developed with different methodologies, allowing the reviewers to perform an analysis and synthesis of the primary data in a systematic and rigorous manner¹⁰.

The development of this review included six stages, namely: 1) elaboration of the the research question; 2) literature search of primary studies, based on inclusion and exclusion criteria; 3) organization of the pre-selected studies (data extraction from the studies); 4) critical analysis of the selected studies; 5) synthesis of the results; and 6) presentation of the integrative review¹¹.

The PICO¹² (Population: children/cancer/family; Intervention: Palliative Care; Context: hospitalization in the intensive care unit) mnemonic strategy was used to elaborate the research question. After using the strategy described, it was possible to elaborate the following guiding question: What is the production of knowledge on the family's experience regarding palliative care of children with cancer hospitalized in the ICU and the role of Nursing in the care of families of children with cancer in view of palliative care?

Article selection was conducted from January to March 2020 by consulting the following electronic databases: PUBMED (National Library of Medicine), LILACS (*Literatura Latino-Americana e do Caribe em Ciências da Saúde*), SCIELO (Scientific Electronic Library Online), SCOPUS (SciVerse Scopus) and CINAHL (Cumulative Index to Nursing and Allied Health Literature). The terminology used for the searches was based on the Medical Subject Headings (MESH) and on the Descriptors in Health Sciences (*Descritores em Ciências da Saúde*, DECS). The controlled descriptors of the PICO¹² element were crossed using the Boolean operator AND, resulting in the following crossing, based on the PICO strategy¹². P = *Criança/child* AND *câncer/neoplasm* AND *família/Family*; I = *Cuidados paliativos/palliative care*; Co = *Centro de terapia intensiva/intensive care unit*.

The inclusion criteria were the following: publications from 2015 to 2020, full articles available for access, productions in English, Spanish, and Portuguese that involved relatives of pre-school children, school children, and adolescents with cancer hospitalized under palliative care, conducted by researchers in the health area and presenting a contextualization related to the topic under study. The following publications were excluded: those addressing neonates and breastfeeding infants, duplicates, and those not meeting inclusion criteria, as well as integrative review articles, opinion articles, editorials, theses, and dissertations.

The selection of studies was initially made by reading the titles and abstracts, based on the inclusion criteria, totaling 222 articles. Of these, 28 publications were considered potentially eligible and selected for full reading and 13 were included in the final sample of this integrative review.

The PRISMA methodology was chosen to systematize the process of inclusion of the studies. Article selection is presented in a flowchart (Figure 1).

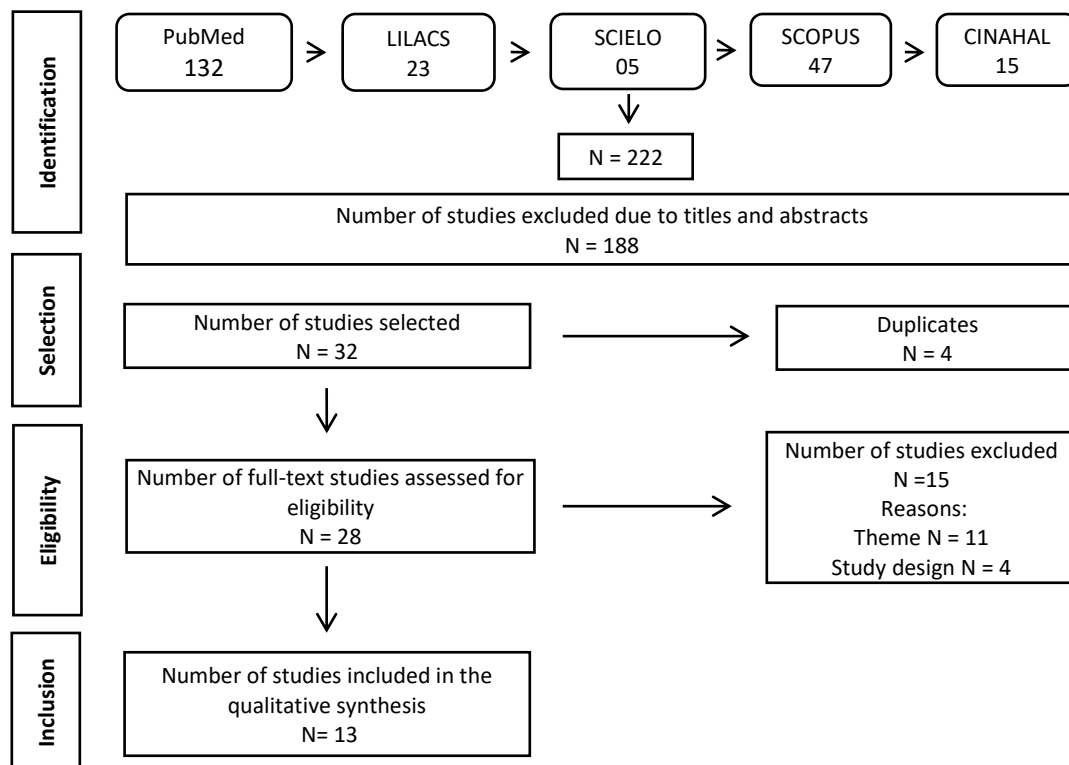


FIGURA 1: Fluxo de seleção dos artigos de revisão, segundo o PRISMA. Rio de Janeiro, Brasil, 2020.

RESULTS

The synthesis of the articles was grouped in Figures 2 and 3, referring to the characterization by title, year, place, database, objectives, study method/participants and contributions.

Title	Year, Place, Database	Objectives	Methodology/ Participants	Contributions
<i>Vivências de mães de crianças com câncer em cuidados paliativos mediante diagnóstico, tratamento e apoio familiar</i> ¹⁵ .	2020 Brazil LILACS	To investigate the experience of mothers of children with cancer in palliative care about diagnosis and treatment.	Qualitative study N=10 mothers	Emphasizing that palliative care needs to be comprehensively introduced in the assistance provided in Pediatric Oncology.
Parent perspectives of receiving early information about palliative and end-of-life care options from their child's pediatric providers ¹⁶	2019 United States PUBMED	To describe the parents' perspectives about receiving early palliative care.	Qualitative study N=10 parents	Encouraging the parents in relation to expected realistic goals for the condition and care of their children in palliative care.
Predictors of location of death for children with cancer enrolled on a palliative care service ¹⁷	2018 United States CINHAL	To preventively identify subgroups of patients at higher risk of dying in the PICU.	Retrospective cohort study N=321	Promoting interventions directed to at-risk subgroups, improving the care provided to children with cancer and their families in the PICU.
<i>Experiências de mães de crianças com câncer em cuidados paliativos</i> ¹⁸ .	2018 Brazil LILACS	To understand experiences of mothers of children with cancer in palliative care.	Qualitative study N=20	Contributing for the construction of a new perspective about the experience of the mothers of children with cancer.
Patients' and parents' views regarding supportive care in childhood cancer ¹⁹ .	2017 Amsterdam PUBMED	To investigate the support care actions that patients and parents consider as most important.	Qualitative study N=29	Improving the support care actions and the development of guidelines incorporating the patients' preferences and those of their family members.
Coping with the diagnosis and hospitalization of a child with childhood cancer ²¹	2015 Brazil SCOPUS	To find out how the family members cope with the hospitalization of their child with cancer.	Qualitative study N=10	Providing subsidies for the Nursing care to these population.
<i>A experiência da família da criança e/ou adolescente em cuidados paliativos: flutuando entre a esperança e a desesperança em um mundo transformado pelas perdas</i> ²³ .	2015 Brazil SCIELO	To understand the experience of the families of children and/or adolescents in palliative care.	Qualitative study, with Symbolic Interactionism as its theoretical framework N=15	To contribute to the recognition of the suffering of the family, by nurses, in the trajectory of palliative care, and in its coping with issues of grief and death.

FIGURE 2: Characterization according to the categories found. The impact of palliative care provided to children with cancer in the family dynamics. Rio de Janeiro, RJ, Brazil, 2020.

After reading the articles' abstracts, the final sample comprised 13 publications: 7 (54%) from international journals and 5 (46%) from national journals. The analysis of the articles enabled to identify two categories that encompassed the following: The impact of palliative care provided to children with cancer on the family dynamics and the care provided by the multiprofessional team, especially nurses, to families of children with cancer in view of palliative care.

Title	Year, Place, Database	Objectives	Methodology/ Participants	Contributions
The experience of providing end of life care at a children's hospice: a qualitative study ²⁰ .	2017 Northern Ireland PUBMED	To explore the experiences of the care team members who provide end-of-life assistance.	Qualitative study N=12	Improving the experience of the care team with the family of children in palliative care in an acute setting.
<i>Cuidados paliativos em oncologia pediátrica: Percepções, saberes e práticas na perspectiva da equipe multiprofissional</i> ²² .	2015 Brazil LILACS	To find out the perceptions, knowledge and practices of the multi-professional team in the care provided to children in palliative care.	Qualitative study N=9	Emphasizing that, in teaching and research, sharing experiences now also includes the multi-professional team.
<i>A experiência da família da criança e/ou adolescente em cuidados paliativos: flutuando entre a esperança e a desesperança em um mundo transformado pelas perdas</i> ²³ .	2015 Brazil SCIELO	To understand the experience of the families of children and/or adolescents in palliative care.	Qualitative study, with Symbolic Interactionism as its theoretical framework N=15	Acknowledging the suffering of families throughout palliative care and, subsequently, when coping with grief issues.
<i>Criança com câncer em processo de morrer e sua família: Enfrentamento da equipe de Enfermagem</i> ²⁴ .	2015 Brazil LILACS	To describe the specificities of the Nursing care provided to children with cancer and their families in the dying process.	Qualitative study N=6	Contributing in the training of the team about palliative care, the dying process, death and grief.
Caring for pediatric patients' families at the child's end of life ²⁵ .	2015 United States CINHAL	To describe a grief program designed to ease permanent communication with grieving families.	Qualitative case study N=1	Promoting practical strategies that allow nurses to communicate with the family of a child in the dying process.
Palliative care in pediatric patients with hematologic malignancies ²⁶ .	2015 United States PUBMED	To understand the barriers and benefits of integrating palliative care of children with hematologic malignancies.	Qualitative study N=01	Acknowledging the need to pay attention to the management of symptoms, spiritual and emotional suffering, and empathy with the family members.
Parents' experience with a dying child with cancer in palliative care ²⁷ .	2015 Slovakia SCOPUS	To clarify and analyze the experience of parents with treatment failure and death of their children with cancer.	Qualitative study N=5	Helping nurses and other health professionals to better understand the questions of the parents' perspective about treatment failure.

FIGURE 3: Characterization according to the categories found. The impact of palliative care provided to children with cancer on the family dynamics. Rio de Janeiro, RJ, Brazil, 2020.

DISCUSSION

The impact of palliative care provided to children with cancer on the family dynamics

In articles¹⁴⁻²¹ it was evidenced that the families go through conflicting moments when faced with the cancer diagnosis of their children, as well as the evolution to exclusive palliative care. They try to adapt to the new health-disease condition of their child under palliative care, which can be mostly represented by feelings of hope, despair, guilt, denial, anger, and fear of death. This information was extracted from the aforementioned articles and will be described in this discussion.

The experience begins with the devastation of family life, characterized by the information that the child and/or adolescent was diagnosed with cancer and evolved to palliative care. This treatment modality exposes the family to a new reality: the existing drug treatment is not sufficient to prevent or control disease progression²⁰.

In this sense, the impact on the family is related to long hospitalization times, frequent readmissions, aggressive therapy, difficulty separating from the family, limitations to understand the diagnosis, anguish, pain and suffering. The difficulties in playing this role represent coping situations experienced by the family members in this process of adapting to the disease and to the possible grief from the child's death²⁷.

When facing the experience of having a child under palliative care, although the feeling of loss is present throughout the course of the disease, it tends to be actually acknowledged only after death, when the unique relationship with the child is lost, which is perceived as vital for those who experience it. Coping with these feelings in advance is difficult and frightening for parents of children at an end-of-life phase²⁸.

In this context, acknowledging palliative care is not an easy task for the family, since they are required to cope with uncertainties and apprehension regarding the future and the possibility of death²⁰.

The care provided by the multiprofessional team, especially nurses, to families of children with cancer in view of palliative care

A number of studies²²⁻²⁶ show how the multiprofessional team, especially nurses, works together with the same purpose of providing dignified and humanized assistance to children with cancer under palliative care, prioritizing the family as an integral component of this treatment modality.

Given the complexity of the assistance provided in Pediatric Oncology, the importance of a multi-professional health team stands out. As a member of this team, Nursing is present in the different care stages: from prevention, diagnosis and extended treatments to palliative care²⁹. This care is enhanced in the face of the cancer diagnosis with no therapeutic possibilities. The nurse becomes a reference for the support to the children and adolescents, as well as to their families, to face the terminal phase and, consequently, death³⁰.

Therefore, the approach of the interdisciplinary team in pediatric cancer represents the basis for much of modern oncology and future progress. It is an area of oncology that has achieved remarkable results, with therapeutic advances leading to increased survival rates for some types of cancer, but it also poses devastating challenges when some pediatric tumors remain incurable¹⁷.

Acknowledging the conceptions related to the implementation of palliative care and to the process of finitude would provide nurses with a better understanding of their values and beliefs about this process, which would make them feel prepared to deal with patients and family members who are experiencing this situation³¹.

Therefore, professionals working in pediatric oncology initially face an important change in the focus of care. These professionals, who are prepared to deal with the concept of health, start to work with the concept of progressing disease. The desired cure starts to make way to the pursuit of quality of life^{5,32}.

Thus, the same team that experiences the ambivalences of its professional praxis also manages to understand the importance of their performance in these times of suffering and feels gratified to be able to ensure that children live a decent life up to their death²⁸.

The assistance model generally adopted in the ICUs, which is based on interventionism and on a curative logic, hampers care in all its dimensions, that is, meeting the patients' various needs, regardless of the life phase they are going through. From the perspective of terminality, the use of the most sophisticated resources to maintain life will not be enough for these patients^{8,33}.

Within this context, palliative care comes into play, which, although scarcely used in ICU patients in terminal phases, is considered as a study target, especially the criteria for its application. Consequently, acceptance of death becomes important, interpreting it as a natural event, without neglecting respect towards the patients' autonomy and non-maleficence^{9,34}.

As an indispensable part of the multidisciplinary team in pediatric oncology, the Nursing is in charge of several roles in its routine context, being present from the beginning, when the diagnosis is made, and also participating in the children's and families' disorders. Thus, nurses are able to understand and have a broad view of all their needs^{35,36}.

Study limitations

As a study limitation, it is believed that the time frame used in the search strategy may have contributed to the exclusion of research studies on the theme published either before or after this period. In addition to that, even resorting to different databases to find articles that addressed exclusive palliative care in the intensive care unit, it was not possible to identify any. In this sense, it is shown that there is a knowledge gap on this theme.

CONCLUSION

According to the categories found, it was possible to identify that the theme of *palliative care* has been gaining prominence in the teaching and health practices, both in the national and international scopes. In this context, all the individuals involved in the care process, family and multidisciplinary team, seek to somehow minimize the suffering and

anguish caused by advanced disease. In this respect, Nursing care aims to promote quality of life for children under palliative care during the time they have left, as well as for their families.

Therefore, support care gain increased importance in the development of guidelines that incorporate shared decision-making, with the involvement of the family and multiprofessional team in the care of children under palliative care.

Hence, situations of crisis are expected to generate changes in the role of the relatives, who are challenged to accept and cope with the fact that their child is under palliative care and with imminent death, and of nurses, who acknowledge that the child's treatment must be comprehensive, individualized, humanized, and based on honest communication.

It is also worth highlighting the scarcity of productions of knowledge on palliative care provided to children with cancer in ICUs, pointing to the need of new studies on such a relevant topic for nurses working in the direct care of this population.

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