









NURSING CARE FOR CHILDREN WITH CANCER IN PALLIATIVE CARE: SCOPING REVIEW

ASSISTÊNCIA DE ENFERMAGEM À CRIANÇA COM CÂNCER EM CUIDADOS PALIATIVOS: SCOPING REVIEW

ATENCIÓN DE ENFERMERÍA A NIÑOS CON CÁNCER EN CUIDADOS PALIATIVOS: SCOPING REVIEW

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ABSTRACT

Objective: to map the scientific production disseminated in electronic databases regarding Nursing care for children with cancer in palliative care. Methods: a scoping review based on the method recommended by the Joanna Briggs Institute was carried out. The search for publications was carried out in six libraries and/or databases covering research from 2010 to 2020. Results: 34 articles that met the inclusion criteria were included. Most studies were published in 2014 in English, and Brazil was the country that stood out. The most prevalent themes of the studies referred to care strategies (mainly related to relieving suffering and therapeutic communication) and the difficulties experienced by Nursing professionals facing complex care (e.g., emotional distress and lack of preparation to deal with terminality). Conclusion: the evidence from the studies highlights the relevance of palliative care in promoting the quality of life of children with cancer and the challenges that need to be overcome so that it can be applied in practice. Hence, the data refer to the fact that, in order to affect the care, which is still being deficiently performed, the main strategies that must be implemented in health services by nurses are: pain control, family support, teamwork, and offering training for professionals. In view of the above, we hope that this mapping can subsidize new research in the sense that it is possible to shed more light on the field of study of palliative care.

Keywords: Neoplasms; Nursing Care; Palliative Care; Pediatrics; Review.

RESUMO

Objetivo: mapear a produção científica, disseminada em bases de dados eletrônicas, acerca da assistência de Enfermagem à criança com câncer em cuidados paliativos. Métodos: revisão do tipo Scoping Review fundamentada na metodologia recomendada pelo Instituto Joanna Briggs. As buscas das publicações foram realizadas em seis bibliotecas e/ou bases de dados contemplando estudos do período de 2010 a 2020. Resultados: foram incluídos 34 artigos que atenderam aos critérios de inclusão. A maior parte dos estudos foi publicada em 2014, no idioma inglês, sendo o Brasil o país que obteve destaque. As temáticas de maior prevalência apontadas pelos estudos se referiam às estratégias de atenção (principalmente relacionadas ao alívio do sofrimento e à comunicação terapêutica) e às dificuldades vivenciadas por profissionais de Enfermagem diante de um cuidado complexo (a exemplo do desgaste emocional e da falta de preparo para lidar com a terminalidade). Conclusão: as evidências dos estudos destacam a relevância dos cuidados paliativos na promoção da qualidade de vida de crianças com câncer e nos desafios que precisam ser superados, para que ocorra sua aplicação na prática. Assim, os dados referenciam que, para efetivar o cuidado, que ainda vem sendo realizado de forma deficitária, as principais estratégias que necessitam ser implementadas nos serviços de saúde por enfermeiros são: controle da dor, apoio à família, trabalho em equipe e oferta de treinamentos para os profissionais. Diante do exposto, espera-se que este mapeamento possa subsidiar novas pesquisas, no sentido de que seja possível compreender melhor o campo de estudo do cuidar paliativo.

Palavras-chave: Neoplasias; Cuidados de Enfermagem; Cuidados Paliativos; Pediatria; Revisão.

RESUMEN

Objetivo: mapear la producción científica, difundida en bases de datos electrónicas, sobre los cuidados de enfermería a niños con cáncer en cuidados paliativos. Métodos: revisión del tipo de Scoping Review, basado en la metodología recomendada por el Instituto Joanna Briggs. La búsqueda de publicaciones se realizó en seis bibliotecas y/o bases de datos, en el periodo comprendido entre 2010 y 2020. Resultados: se incluyeron 34 artículos que cumplían los criterios de inclusión. La mayoría de los estudios se publicaron en 2014, en inglés, y Brasil fue el país que se destacó. Los temas más frecuentes identificados por los estudios se refieren a las estrategias de atención (principalmente relacionadas con el alivio del sufrimiento y la comunicación terapéutica); y las dificultades experimentadas por los profesionales de enfermería que se enfrentan a una atención compleja (que implican angustia emocional y falta de preparación para afrontar la terminalidad). Conclusión: los datos de los estudios ponen de manifiesto la importancia de los cuidados paliativos para promover la calidad de vida de los niños con cáncer y los retos que hay que superar para que puedan aplicarse en la práctica. Así, para hacer efectivos los cuidados,

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que todavía se realizan de forma deficitaria, los datos hacen referencia a las principales estrategias que deben ser implementadas en los servicios sanitarios por parte de las enfermeras: el control del dolor, el apoyo a la familia, el trabajo en equipo y la formación de los profesionales. Teniendo en cuenta lo anterior, se espera que este mapeo pueda subvencionar nuevos estudios, de modo que se pueda comprender mejor el campo de estudio de los cuidados paliativos.

Palabras clave: Neoplasias; Atención de Enfermería; Cuidados Paliativos; Pediatría; Revisión.

INTRODUCTION

Care is the first gesture of existence, and it pervades and guides human interactions from birth to death. Care is constituted by practices and knowledge directed toward others, which is indispensable for maintaining the human species.¹ Within the scope of Nursing, care provides the patient's biopsychosocial and spiritual well-being through an empathic relationship, technical competence, and ethical responsibility, in addition to guiding the process of re-signifying the meaning of life in the presence of illness,² with emphasis on chronic diseases such as cancer. This pathology affects various age groups and is considered the leading cause of death by disease among children. Corroborating this conception, over 400,000 children are diagnosed with cancer worldwide every year.³

Childhood cancer is characterized as a pathology with high lethality and presents high proliferation rates and significant invasive character, since the nonspecific symptomatology prevents a closer look for early detection, hindering diagnosis and timely treatments. From the appearance of the most relevant warning signs and symptoms until the diagnosis is reached, it takes roughly three months.⁴

Considering that cure is not always possible in all cancer cases, the practice of pediatric palliative care as a form of support, comfort, and spiritual and psychosocial support is propitious. This care is characterized by a set of multidisciplinary practices that aim to ensure and promote quality of life and well-being for the child facing a life-threatening illness, as well as for his or her family members, to prevent and alleviate suffering.⁵

Palliative care seeks to provide humanized and integral care to meet the needs of patients. This care is provided by a multi-professional team, with a focus on Nursing, which must be qualified to provide individual care to the child and their family.⁶

Given this scenario, this study highlighted the complex nature and urgency of conducting new research that guides nurses to perform adequate and evidence-based palliative care, which is still being pointed out

as a research gap.⁷ The relevance of a deeper study of Nursing care for children with cancer in palliative care is undeniable to support nurses' clinical practice in this modality of care. Therefore, this study sought to map the scientific production disseminated in electronic databases regarding Nursing care for children with cancer in palliative care.

METHODOLOGY

This is a scoping review, which is a modality that aims to map key concepts of a defined area of knowledge through a comprehensive literature review; it seeks to provide a descriptive perspective of the evidence identified in the studies to specify and disseminate existing gaps in the theme explored.⁸

This scoping review followed the recommendations of the Joanna Briggs Institute Review Manual, starting with the following steps: 1) identifying the research question; 2) identifying relevant studies; 3) selecting studies; 4) data extraction; 5) data summarization and analysis.⁹

In addition, throughout the development of this study, the indications of the PRISMA Extension for Scoping Reviews (PRISMA-ScR) were employed. This instrument comprises the various structural parts of a manuscript and is arranged into seven domains (title, abstract, introduction, method, results, discussion, and funding) and 22 items.¹⁰

Identifying the research question

This study adopted the PCC strategy to elaborate the question and search strategy; the "P" refers to the population, the "C" to the main concept that one seeks to analyze, and the "C" is the context.⁷ Thus, the following guiding question emerged: "What are the scientific productions about Nursing care for children with cancer in palliative care?" In this context, "children with cancer" refers to the population, "Nursing care" corresponds to the concept, and "palliative care" to the research context.

Identifying the relevant studies

A preliminary search was conducted in the electronic library US National Library of Medicine (PubMed) to determine the most commonly used keywords and descriptors for indexing research related to the subject of interest.

Between October and December 2020, the search for records was conducted by two independent reviewers

responsible for screening and identifying relevant studies in the following electronic sources: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Latin American and Caribbean Literature in Health Sciences (LILACS), Scientific Electronic Library Online (SciELO), Scopus, and Web of Science (WOS).

From the search strategy employed in the selected databases, the Health Sciences Descriptors (DeCS) “palliative care,” “nursing,” “child,” and “cancer” — adopted from a translation of the Medical Subject Headings (MeSH): “palliative care,” “nursing,” “child,” and “cancer” — were operated using the Boolean ‘AND.’ They are the data listed in Figure 1 along with the identified and selected studies.

After determining the descriptors and creating the strategy (Figure 1), the search process was made operational in the selected libraries and/or databases. Developing the activity was facilitated through the accessibility to digital benefits available at the Portal de Periódicos CAPES, requiring a personalized and available browser to access it using a login.

Study selection

The search sources were limited to publications in English, Spanish, and Portuguese from January 2010 to April 2020, since this type of method was expanded and had remarkable growth in the area of health sciences during this interval.¹¹ Thus, after identifying studies from the databases, the documents were exported to the End-note® software; duplicate studies were excluded.

The selection process was based on a careful reading of the titles and abstracts of the studies obtained from the information sources, and studies that did not include the terms ‘palliative care’ and ‘nursing care’ were removed, in addition to those that were not accessible in their entirety. Then, the analysis of the full text was performed.

For the eligibility criteria, the research question was considered (i.e., scientific productions that approached Nursing

care as a strategy in providing palliative care to children with cancer). As for the exclusion criteria, the studies that contemplated health professionals other than nurses were removed. At this point, both review studies and primary studies were included (quantitative or qualitative), which met the inclusion criteria of the PCC mnemonic.

Data extraction

Data extraction was produced using a form generated by the authors and based on the recommendations of the Joanna Briggs Institute Reviewer’s Manual.⁹ The following data were extracted: authorship, year of publication, the country where the study was developed, the objective of the study, study design, population, and sample of the study, Nursing care used for children with cancer in palliative care, which were the main results and conclusions about this care.

The articles in the sample were divided equally between two reviewers for data extraction. The researchers reviewed and discussed the form before starting the data extraction. In addition, the authors tested the data extraction of a single selected study to ensure that there was a consistent interpretation of the data required. At the end of the process, the data were pooled in the Microsoft Office 2016 Excel software.

Data summarization and analysis

A mapping of the extent, nature, and general distribution of the included studies was prepared from the extracted content, which was compared for common findings so that the similarities and differences between them could be traced. The goal was to identify, in the findings, the recurring themes to later perform a descriptive analysis that would be consistent with the guiding question of this review.

Figure 1 - Electronic sources, search strategies, and identified/selected studies

Electronic Sources	Search strategy	Identified studies	Selected studies
CINAHL	palliative care AND nursing AND child AND cancer	135	13
LILACS	palliative care AND nursing AND child AND cancer	37	12
SciELO	palliative care AND nursing AND child AND cancer	09	01
Scopus	TITLE-ABS-KEY (palliative AND care AND nursing AND child AND cancer)	22	03
Web of Science	(palliative care) AND TOPIC: (nursing) AND TOPIC: (child) AND TOPIC: (cancer)	100	05

Source: Prepared by the author. João Pessoa, PB, Brazil, 2021.

We found that the studies covered two themes in greater prevalence: i) the main strategies of Nursing care directed to children with cancer in palliative care and their families, mainly concerning the relief of suffering and therapeutic communication; and ii) the challenges experienced by nurses in providing pediatric palliative care, including emotional distress and lack of preparation to deal with terminality.

RESULTS

As shown in Figure 2, 380 publications were found, of which 34 made up the final sample.

Characteristics of the studies

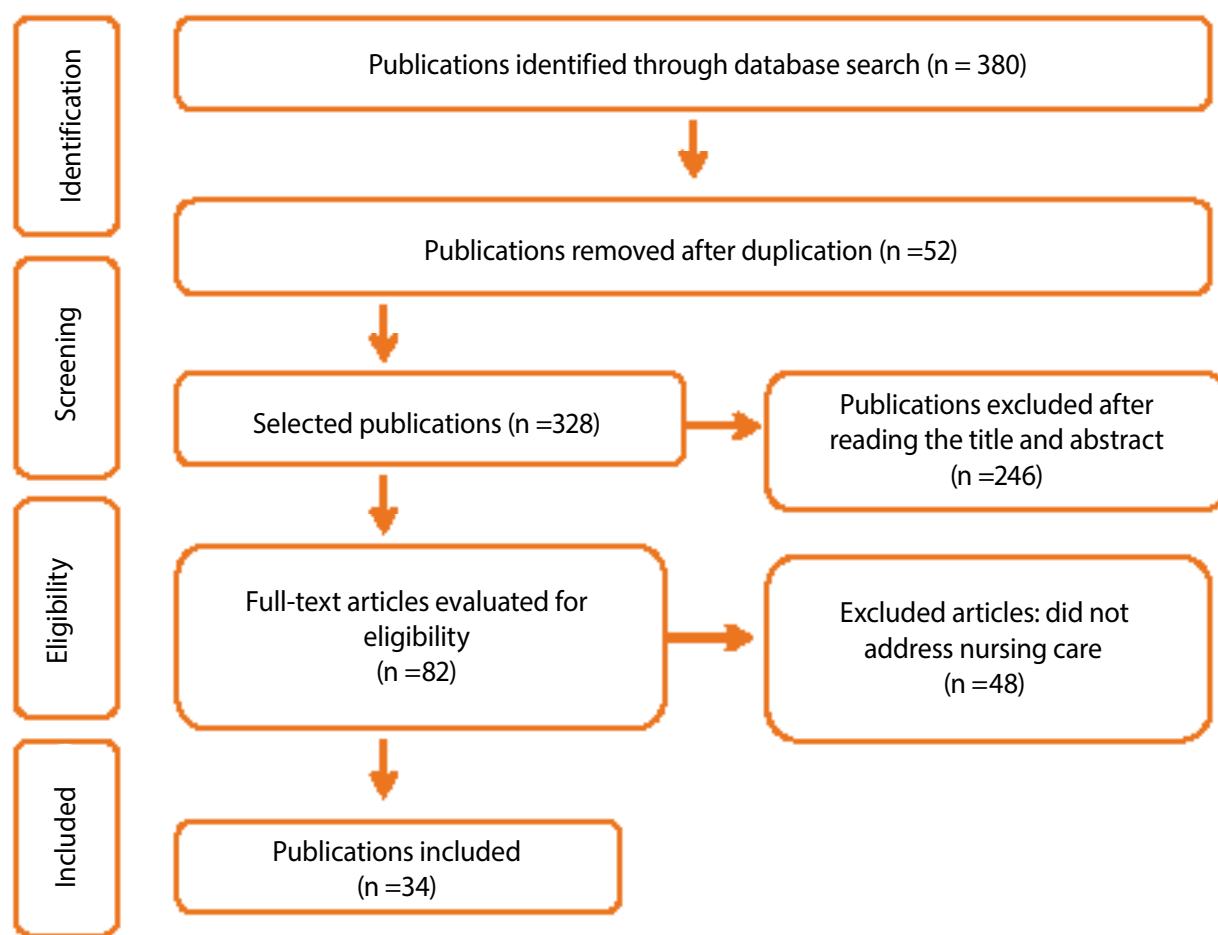


Figure 2 - Flow chart of the included studies
Source: PRISMA-ScR (adapted). João Pessoa, Brazil, 2021.

Most of the studies belonging to the sample were published in 2014 and in English, totaling 21 studies. As for the country, most of them were developed in Brazil (17 studies). Regarding the type of publication, 22 original research studies and 12 review studies were verified (Figure 3).

The most prevalent themes of the studies referred to care strategies, especially those related to the relief of suffering and therapeutic communication (22 studies),

and the difficulties experienced by Nursing professionals facing complex care, such as emotional distress and lack of preparation to deal with terminality (10 studies). Stricto sensu professionalization (2 studies) was also a significant theme.

Figure 2 lists the code for identifying the publications, the references of the publications, and the purpose of the studies.

Description of care strategies

Figure 3 - Characterization of the studies as to identification (code), publication references, and study objective

Code	Publication references	Purpose of the study
A1	Monteiro ACM, Rodrigues BMRD, Pacheco STA, Pimenta LS. A atuação do enfermeiro junto à criança com câncer: cuidados paliativos. Rev Enferm UERJ. 2014[cited 2021 Apr 16];22(6):778-83. Available from: http://dx.doi.org/10.12957/reuerj.2014.15665	To know the nurse's action in caring for children with cancer in palliative care
A2	Carmo SA, Oliveira ICS. Criança com câncer em processo de morrer e sua família: enfrentamento da equipe de Enfermagem. Rev Bras Cancerol. 2015[cited 2021 Apr 16];61(2):131-8. Available from: https://doi.org/10.32635/2176-9745.RBC.2015v61n2.300	To describe the specifics of Nursing care for children with cancer in the dying process and their families
A3	Costa TF, Ceolim MF. A Enfermagem nos cuidados paliativos à criança e adolescente com câncer: revisão integrativa da literatura. Rev Gaúch Enferm. 2010[cited 2021 Apr 16];31(4):776-84. Available from: https://doi.org/10.1590/S1983-14472010000400023	To identify actions of Nursing in palliative care for children and adolescents with cancer, considering the specificities of the disease and the death process
A4	Bernardo CM, Bernardo DM, Costa IA, Silva LR, Araujo WGP, Spezani RS. A importância dos cuidados paliativos prestados pelo enfermeiro à criança com câncer em estágio terminal. Rev Pesqui. 2014[cited 2021 Apr 16];6(3):1221-30. Available from: https://doi.org/10.9789/2175-5361.2014v6n3p1221	To reflect on the importance of palliative care provided by nurses to terminally ill children with cancer
A5	Afungchwi GM, Challinor J. Addressing childhood cancer in low-resource countries: current challenges, strategies, and recommendations. Oncol Nurs Forum. 2016[cited 2021 Apr 16];43(4):525-8. Available from: https://doi.org/10.1188/16.ONF.525-528	To describe challenges and provide strategies related to oncopediatrics in low- and middle-income countries
A6	Currie ER, McPeters SL, Mack JW. Closing the gap on pediatric palliative oncology disparities. Semin Oncol Nurs. 2018[cited 2021 Apr 16];34(3):294-302. Available from: https://doi.org/10.1016/j.soncn.2018.06.010	To describe pediatric palliative care (PPC) in oncology and its importance, as well as innovative strategies to improve access to PPC and implications for oncology Nursing practice
A7	Hendricks-Ferguson VL, Akard TF, Madden JR, Peters-Herron A, Levy R. Contributions of advanced practice nurses with a DNP degree during palliative and end-of-life care of children with cancer. J Pediatr Oncol Nurs. 2015[cited 2021 Apr 16];32(1):32-9. Available from: https://doi.org/10.1177/1043454214555195	To describe how the 8 elements and core competencies of the American Association of Colleges of Nursing can be used in doctoral studies in advanced practice Nursing in pediatric oncology settings
A8	Mandac C, Battista V. Contributions of palliative care to pediatric patient care. Semin Oncol Nurs. 2014[cited 2021 Apr 16];30(4):212-26. Available from: https://doi.org/10.1016/j.soncn.2014.08.003	To provide an overview of pediatric palliative care (PPC) as it pertains to children and families living with cancer disease
A9	Mutti CF, Padoin SMM, Paula CC, Souza IEO, Terra MG, Quintana AM. Cuidado de Enfermagem à criança que tem doença oncológica avançada: ser-com no cotidiano assistencial. Ciênc Cuid Saúde. 2012[cited 2021 Apr 16];11(1):113-20. Available from: https://doi.org/10.4025/cienccuidsaude.v11i1.18867	To understand the meaning, for Nursing staff, of caring for children who have cancer that no longer responds to curative treatments
A10	França JRFS, Costa SFG, Nóbrega MML, Lopes MEL. Cuidados paliativos à criança com câncer. Rev Enferm UERJ. 2013[cited 2021 Apr 16];21(6):779-84. Available from: https://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/12283/9562	To understand the existential experience of nurses in caring for children with cancer without therapeutic possibilities
A11	Santos GFATF, Batista PSS, Lima DRA, Oliveira ARM, Dias KCCO, Costa BHS. Cuidados Paliativos em Oncologia: Vivência de Enfermeiros ao Cuidar de Crianças em Fase Final da Vida. Rev Pesq Cuid Fundam online. 2020[cited 2021 Apr 16];12:689-95. Available from: https://doi.org/10.9789/2175-5361.rpcfo.v12.9463	To investigate nurses' experiences in caring for children with cancer in palliative care
A12	Mutti CF, Padoin SMM, Paula CC. Espacialidade do ser-profissional-de-Enfermagem no mundo do cuidado à criança que tem câncer. Esc Anna Nery Rev Enferm. 2012[cited 2021 Apr 16];16(3):493-9. Available from: https://doi.org/10.1590/S1414-81452012000300010	To understand the meaning, for the Nursing staff, of caring for children who have advanced oncologic disease, whose illness no longer responds to curative treatments

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Figure 3 - Characterization of the studies as to identification (code), publication references, and study objective

Code	Publication references	Purpose of the study
A13	Eshaghian-Dorcheh A, Zandi M, Rasouli M, Tahmasebi M, Esmailzadeh F. Evaluating the cost-effectiveness of home-based palliative care for children with special health care needs: a review study. <i>Inter J Pediatr</i> . 2020[cited 2021 Apr 16];8(11):12381-95. Available from: https://doi.org/10.22038/IJP.2020.45949.3745	To evaluate, based on a review of the literature, the cost-effectiveness of home-based palliative care for children with complex health needs
A14	França JRFS, Costa SFG, Lopes MEL, Nóbrega MML, Batista PSS, Oliveira RC. Experiência existencial de crianças com câncer sob cuidados paliativos. <i>Rev Bras Enferm</i> . 2018[cited 2021 Apr 16];71:1320-27. Available from: http://dx.doi.org/10.1590/0034-7167-2016-0493	To understand, in the light of Humanistic Nursing Theory, the existential experience of children with cancer under palliative care
A15	Semtchuck ALD, Genovesi FF, Santos JL. Los cuidados paliativos en oncología pediátrica: revisión integradora. <i>Rev Urug Enferm</i> . 2017[cited 2021 Apr 16];12(1):88-101. Available from: http://rue.fenf.edu.uy/index.php/rue/article/view/216/210	To verify, in the main databases of scientific literature, which are the evidences related to the child with cancer in palliative care, having a major focus on the Nursing team's action
A16	Hendricks-Ferguson VL, Sawin KJ, Montgomery K, Dupree C, Phillips-Salimi CR, Carr B, Haase JE. Novice nurses' experiences with palliative and end-of-life communication. <i>J Pediatr Oncol Nurs</i> . 2015[cited 2021 Apr 16];32(4):240-52. Available from: http://dx.doi.org/10.1177/1043454214555196	To understand the importance of effective nurse communication with family members of children with life-threatening illnesses
A17	Sousa ADRS, Silva LF, Paiva ED. Intervenções de Enfermagem nos cuidados paliativos em oncologia pediátrica: revisão integrativa. <i>Rev Bras Enferm</i> . 2019[cited 2021 Apr 16];72(2):556-66. Available from: http://dx.doi.org/10.1590/0034-7167-2018-0121	To identify, in the scientific productions, Nursing interventions in palliative care for children and adolescents with cancer
A18	Monteiro ACM, Rodrigues BMRD, Pacheco STA. O enfermeiro e o cuidar da criança com câncer sem possibilidade de cura atual. <i>Esc Anna Nery Rev Enferm</i> . 2012[cited 2021 Apr 16];16(4):741-6. Available from: https://doi.org/10.1590/S1414-81452012000400014	To analyze, in a comprehensive way, the nurse's care of the hospitalized child with an oncologic disease beyond the possibility of cure
A19	Ebadinejad Z, Fakhr-Movahedi A. palliative care in children with cancer. Iran: Challenges and Perspectives. <i>Pediatr Nurs</i> . 2019[cited 2021 Apr 16];45(4):205-6. Available from: https://doi.org/10.18502/ijpho.v9i1.296	To describe the challenges and prospects of promoting palliative care offered to children with cancer
A20	Rodrigues AJ, Bushatsky M, Viaro WD. Cuidados paliativos em crianças com câncer: revisão integrativa. <i>Rev Enferm UFPE online</i> . 2015[cited 2021 Apr 16];9(2):718-30. Available from: https://doi.org/10.5205/reuol.7028-60723-1-SM.0902201530	To analyze the production of knowledge about palliative care in children with cancer published by nurses
A21	Jantsch LB, Neves ET, Arrué AM, Pieszak GM, Gheller B. Palliative care in pediatric oncology: Nursing contributions. <i>Rev Enferm UFPE online</i> . 2012[cited 2021 Apr 16];6(7):1706-13. Available from: https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/7222	To analyze the trend in scientific production on palliative care in pediatric oncology
A22	Tubbs-Coolley HL, Santucci G, Kang TI, Feinstein JA, Hexen KR, Feudtner C. Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care. <i>J Palliat Med</i> . 2011[cited 2021 Apr 16];14(5):631-7. Available from: https://doi.org/10.1089/jpm.2010.0409	To describe nurses' ratings of the goals and problems of palliative care offered to pediatric patients in hospital units
A23	Newman AR, Haglung K, Rodgers CC. Pediatric oncology nurses' perceptions of prognosis-related communication. <i>Nurs Outlook</i> . 2019[cited 2021 Apr 16];67(1):101-14. Available from: https://doi.org/10.1016/j.outlook.2018.11.001	To investigate the experiences of pediatric oncology nurses regarding prognosis-related communication
A24	Foster TL, Lafond DA, Reggio C, Hinds PS. Pediatric palliative care in childhood cancer Nursing: from diagnosis to cure or end of life. <i>Seminars in oncology Nursing</i> . WB Saunders. 2010[cited 2021 Apr 16];26(4):205-21. Available from: https://doi.org/10.1016/j.soncn.2010.08.003	To increase the awareness of nurses and other healthcare professionals to the initiative of recent research to improve the lives and decrease the suffering of these children and their families
A25	Akard TF, Hendricks-Ferguson VL, Gilmer MJ. Pediatric palliative care Nursing. <i>Ann Palliat Med</i> . 2019[cited 2021 Apr 16];8(Suppl 1):S39-48. Available from: https://doi.org/10.21037/apm.2018.06.01	To describe selected components of pediatric palliative care at diagnosis of cure or end of life that combine to help nurses achieve goals of care for children with cancer and their families
A26	González-Castillo MG, Ramírez-Villegas RM. Proceso de enfermería en cuidados paliativos al paciente pediátrico con retinoblastoma bilateral. <i>Rev Enferm Inst Mex Seguro Soc</i> . 2014[cited 2021 Apr 16];22(3):145-52. Available from: https://www.medigraphic.com/pdfs/enfermeriaimss/eim-2014/eim143e.pdf	To implement and evaluate the Nursing process with a focus on palliative care in a pediatric patient with bilateral retinoblastoma

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Figure 3 - Characterization of the studies as to identification (code), publication references, and study objective

Code	Publication references	Purpose of the study
A27	Reis TLR, Paula CC, Potrich C, Padoin SMM, Bin A, Mutti CF, et al. Relações estabelecidas pelos profissionais de Enfermagem no cuidado às crianças com doença oncológica avançada. Aquichan. 2014[cited 2021 Apr 16];14(4):496-508. Available from: https://www.redalyc.org/pdf/741/74133057005.pdf	To understand the relationships established by professionals of the Nursing team in caring for children with advanced oncologic disease without therapeutic possibilities
A28	França JRFS, Costa SFG, Lopes MEL, Nóbrega MML, França ISX. The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory. Rev Latinoam Enferm. 2013[cited 2021 Apr 16];21(3):780-6. Available from: https://doi.org/10.1590/S0104-11692013000300018	To investigate and analyze communication in palliative care in pediatric oncology from the point of view of nurses, based on Humanistic Nursing Theory
A29	Albuquerque SV, Silva LF, Santos PM, Depianti JRB. The importance of playing for hospitalized children with cancer in palliative care. Rev Enferm UFPE online. 2016[cited 2021 Apr 16];10(3):1047-53. Available from: https://pesquisa.bvsalud.org/portal/resource/pt/bde-29622	To identify the importance of playing in the palliative care of hospitalized children with cancer in the perception of the Nursing team
A30	Docherty SL, Thaxton C, Allison C, Barfield RC, Tamburro RF. The Nursing dimension of providing palliative care to children and adolescents with cancer. Clin Med Insights Pediatr. 2012[cited 2021 Apr 16];6:75-88. Available from: https://doi.org/10.4137/CMPed.S8208	To review the impact of patient prognosis in palliative care
A31	Tringali D, Lauro-Grotto R, Papini M. The perspective of the Nursing staff on terminal sedation in pediatric onco-hematology: a phenomenologic-hermeneutic study. Palliat Support Care. 2013[cited 2021 Apr 16];11(6):465. Available from: https://doi.org/10.1017/S1478951512000867	To explore the subjective perspective on end-of-life practices in three different groups of pediatric onco-hematology nurses
A32	Soares VA, Silva LF, Cursino EG, Goes FGB. O uso do brincar pela equipe de Enfermagem no cuidado paliativo de crianças com câncer. Rev Gaúch Enferm. 2014[cited 2021 Apr 16];35(3):111-6. Available from: https://doi.org/10.1590/1983-1447.2014.03.43224	To describe how the Nursing team uses playing in the palliative care of children with cancer and analyze the facilities and difficulties of using play in this care
A33	Neilson SJ, Kai J, McArthur C, Greenfield S. Using social worlds theory to explore influences on community nurses' experiences of providing out of hours paediatric palliative care. J Res Nurs. 2013[cited 2021 Apr 16];18(5):443-56. Available from: https://doi.org/10.1177/1744987113491759	To explore the experiences of pediatric nurses in providing palliative care outside of working hours in the home setting of children with cancer
A34	Pearson HN. "You've only got one chance to get it right": children's cancer nurses' experiences of providing palliative care in the acute hospital setting. Issues Compr Pediatr Nurs. 2013[cited 2021 Apr 16];36(3):188-211. Available from: https://doi.org/10.3109/01460862.2013.797520	To understand the experiences of specialist childhood cancer nurses regarding the delivery of palliative care in the emergency department of the hospital setting

Source: Prepared by the author. João Pessoa, PB, Brazil, 2021.

The main strategies of Nursing care directed to children with cancer in palliative care and their families are listed in Figure 4; according to the analysis of the studies, this care extends to the caregiver. Strategies directed to nurses and care and educational managers in Nursing are also presented,

aiming to improve and strengthen the workers. To better demonstrate the evidence, we chose to subdivide the strategies into five categories, as shown below:

Figure 4 - Summary of strategies directed to the child with cancer in palliative care

Child-oriented strategies
Controlling signs and symptoms, especially pain ^{A2,A3,A4,A11,A18,A20,A22,A25,A27,A28,A30,A31}
Giving comfort, providing quality of life to the child ^{A1,A11,A16,A18,A20,A22,A27,A28}
Providing integrated care that meets the child's needs ^{A1,A2,A18,A20,A26,A28,A33}
Emphasizing playing and playful activities, such as drawing, painting, and music ^{A1,A3,A15,A17,A29,A32}
Individualized, personalized, and targeted care for every child ^{A1,A3,A4,A26}
Being closer to the child, available, and listening in a sensitive and interactive way ^{A1,A18,A22,A26,A28}
Respectful relationship with the cared for ^{A1,A2,A4}
Promoting a dignified death ^{A15,A27}

Continued...

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Figure 4 - Summary of strategies directed to the child with cancer in palliative care

Family-oriented strategies
Supporting the family by listening to them, getting to know their problems, and reassuring them, especially in the face of terminality ^{A1, A3, A11, A15, A16, A18, A20, A27, A31, A33}
The insertion of the family during the entire process of interaction between the team and the family, especially in decision-making ^{A1, A2, A3, A4}
Guide the family on how to proceed ^{A15, A18}
Strategies aimed at both children and their families
Informing and guiding, through a direct and intersubjective intercommunication with the family and the child, especially in critical conversations ^{A1, A3, A4, A10, A11, A15, A16, A20, A23, A24, A25, A30}
Using soft technologies, including touching, listening, and being sensitive and perceptive to the suffering of others, helping them with care and attention in carrying out their daily activities ^{A1, A2, A3, A16, A20, A27}
Achieving trust through a dialogical relationship with the child and their family ^{A2, A14, A15, A21, A24, A27, A31}
Providing spiritual, emotional, and religious support ^{A1, A11, A16, A24, A27}
Promoting meaningful and empathetic care based on frankness, warmth, attention, and hope ^{A6, A9, A12, A20}
Complementary therapies, such as massage, music therapy, hypnosis, and psychotherapy ^{A3, A17}
Minimizing social isolation and providing moments of privacy for affectionate relationships of the child with their parents and siblings ^{A4, A24}
Promoting a welcoming environment ^{A6, A24}
Strategies directed at nurses
Promoting advances and improvements in their assistance, with emphasis on interdisciplinary and multidisciplinary work ^{A3, A7, A8, A19, A25, A31, A33}
Developing and evaluating innovative evidence-based care models ^{A6, A7, A17, A19, A25}
Separating the professional and emotional dimensions and neutralization of feelings, especially in the face of death ^{A2, A12, A20, A26, A27}
Searching for advanced skills and current knowledge required for promoting quality care for children in palliative care ^{A6, A7, A8, A21, A25}
Strategies for Nursing managers
Offering specialization courses in palliative care ^{A4, A5, A34}
The need to establish means for psychological and emotional support for nurses ^{A4, A12, A15}
Providing continuing education for practicing nurses ^{A6, A25, A34}
Offering training for the professionals ^{A5, A19, A25}
Promoting spaces for reflection and moments in which professionals can express their anguish about terminality, thus learning to deal with and accept death ^{A3, A4}

Source: Prepared by the author. João Pessoa, PB, Brazil, 2021.

Description of the challenges experienced by nurses in providing pediatric palliative care

The main challenges that stood out in the studies regarding the daily routine of Nursing care for children with cancer in palliative care are listed in Figure 5. The aspects of life

and death of patients affected by this pathology were contemplated, as well as the suffering experienced by them and their families from the diagnosis until the restoration of health or finitude.

Figure 5 - The main challenges reported by nurses

Emotional scope
Difficulty in dealing with death and terminality ^{A2, A3, A4, A15, A16, A21, A27, A31}
Lack of preparation and emotional and psychological wear ^{A4, A16, A20, A21, A27, A33, A34}
Feelings of helplessness, exhaustion, fear, sadness, anguish, negativity, pity, and failure ^{A3, A4, A15, A20}
Involvement with the suffering of children and parents ^{A12, A24, A27}
Stressful environments ^{A7}
Children's fear of separation from their families in the face of the possibility of finitude ^{A14}
Communication/relationship scope
Perceived tension in discussions about palliative and end-of-life care among children, families, and other professionals ^{A16, A17, A19, A24}
Lack of knowledge of therapeutic communication techniques, especially when faced with bad news ^{A4, A11}

Continued...

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Figure 5 - The main challenges reported by nurses

Difficulty in playing with the child due to their physical condition, the resistance of some professionals, and the lack of time for carrying out this activity ^{A29,32}
Nurses are often not included in the process of communicating news ^{A23}
Fragile communication with children in the final stage of life ^{A10}
Knowledge scope
Lack of training for such a complex pathology ^{A1,A3,A5,A8,A9,A19,A27,A30,A33}
Few reliable and valid instruments for pediatric palliative care assistance ^{A8,A19,A29}
Unpreparedness due to lack of theoretical knowledge ^{A22,A34}
Difficulty in gauging the magnitude of physical, mental, and spiritual pain in this age group ^{A1,A18}
Care management scope
The necessity to promote quality care in pediatric palliative care management ^{A8,A19,A33,A34}
Socioeconomic disparities and vulnerabilities within pediatric palliative oncology ^{A6,A19,A25}
Working with complex families and parents who have different views on treatments and palliative care ^{A9,A27}
Hospitalization time ^{A13}
Impact on out-of-hours care, where nurses work overtime ^{A33}

Source: Prepared by the author. João Pessoa, PB, Brazil, 2021.

This context revealed the physical, psychological, and mental exhaustion of these professionals facing such complex care that demands advanced skills. The lack of training and validated instruments on pediatric palliative care was also reported as a major difficulty nurses face.

DISCUSSION

The analysis of the scientific production showed that, despite significant advances in recent years, palliative care practices in pediatrics have still been exercised incipiently. Research has stressed the importance of nurses promoting advances and improvements in their care, with visibility for interdisciplinary and multidisciplinary work;^{A3,A7,A8,A19,A25,A31,A33} development and evaluation of innovative and evidence-based care models;^{A6,A7,A17,A19,A25} separating the professional dimension from the emotional and neutralization of feelings, especially in the face of death;^{A2,A12,A20,A26,A27} and the search for advanced skills and current knowledge, primordial aspects of promoting quality care for children in palliative care.^{A6,A7,A8,A21,A25}

Nevertheless, there were strategies directed to the care and educational managers of the Nursing area aimed at improving and strengthening these professionals. Among such strategies, offering specialization courses in palliative care was identified,^{A4,A5,A34} the urgency of establishing means for the psychological and emotional monitoring of nurses,^{A4,A12,A15} promoting spaces for reflection and moments in which professionals can express their anguish about terminality, thus learning to deal with death and to accept it,^{A3,A4} the inclusion of

continuing education for the practice of nurses,^{A6,A25,A34} and offering training for professionals.^{A5,A19,A25}

Regarding the strategies directed to the child, there was a great concern in the studies^{A2,A3,A4,A11,A18,A20,A22,A25,A27,A28,A30,A31} regarding symptom control, especially regarding pain. It should be noted that during the diagnostic process of children with cancer, pain represents 78% of the symptoms investigated. The symptom is reduced to 25–58% during treatment. However, in the stage of finitude, pain is the main symptom, representing 90% of the patients' complaints.¹² What is more, in the context of palliative care, pain is classified as the fifth vital sign, significantly weakening the quality of life of the patient, which demands vigilance and effective treatment.¹³

A study^{A11} reported that in order to achieve pain relief, the interviewed nurses organized their care in two dimensions: pharmacological and non-pharmacological measures. Pharmacological measures are administered to minimize pain significantly. Appropriate pain management must be a priority in planning, and pain assessment and measurement are important. As for non-pharmacological measures, it is known that pain comprises dimensions beyond the sensory aspect, and it may be of a social, psychological, and emotional nature. They are vital for the patient's well-being, but, obviously, such measures do not replace treatment with analgesic medication. Therefore, corroborating this understanding, correlating these humanized measures with the treatment is pivotal as they have a remarkable role in pain control, providing relief from the symptom effectively.¹⁴ Among the non-pharmacological measures, some complementary

therapies, including massages, music therapy, hypnosis, and psychotherapy, were mentioned in the researched studies.^{A3,A17}

Some studies emphasized that nurses must provide comprehensive care that is individualized and directed to each child in order to meet their needs.^{A1,A3,A4,A11,A16,A18,A20,A22,A26,A27} through assistance permeated with strategies that seek to promote the child's comfort in the face of illness, providing relief from pain and comfort through words, physical contact, and psychological support, so that they can die with dignity.^{A1,A2,A4,A11,A15,A16,A18,A20,A22,A26,A27,A2} With this view, nurses must be closer to the child and make themselves available by listening sensitively and interactively;^{A1,A18,A22,A26,A28} this approach can happen more easily through playing.

It should be emphasized that the playroom is an important resource in treating children in palliative care; it can become a meeting place where pain and suffering can be minimized due to the joy aroused by distractions.^{A15} The playful and recreational activity sometimes encounters difficulties, such as the indisposition of some children, the medical orders to remain in bed, and the resistance of some professionals, which end up making the act of playing unfeasible.¹⁵

In addition to strategies directed to the child, the nurse must insert strategies directed to the family. The objective is to implement them during the whole care process, especially in decision-making,^{A1,A2,A3,A4} supporting, listening, and getting to knowing the problems to reassure them, particularly in the face of terminality.^{A1,A3,A11,A15,A16,A18,A20,A27,A33,A31}

It is necessary that nurses promote a welcoming environment^{A6,A24} and with the goal of minimizing social isolation; they must ensure moments of privacy for the child's affective relationships with their parents and siblings.^{A4,A24} Additionally, it is essential that the healthcare professional provide spiritual, emotional, and religious support as based on the philosophy of palliative care.^{A1,A11,A16,A24,A27}

One study found that nurses consider of utmost importance the insertion of the family as the protagonist in the care of the child in finitude, so that there is recognition that, in fact, there was a dignified death process.¹⁶ Meanwhile, valuing the presence of the family allows the child to remain connected with their loved ones throughout the disease process.¹⁷ Another study also demonstrated that Nursing care for children with cancer in palliative care should address strategies that seek to inform and guide the family and child through direct and intersubjective intercommunication, especially when conversations require decision-making.^{A1,A3,A4,A10,A11,A15,A16,A}

^{20,A23,A24,A25} In this context, nurses must use light elements in their care, such as touch and listening, in addition to being sensitive and perceptive to the suffering of others, helping them with affection and attention in carrying out their daily activities.^{A1,A2,A3,A16,A20,A27} For this to occur, it is salutary that Nursing care be based on trust, through a dialogical relationship with the child and their family,^{A2,A14,A15,A21,A24,A27,A31} in the search to promote meaningful and empathetic care.^{A6,A9,A12,A20}

The Nursing professional presents his/her own characteristic when caring for others, which includes not only children with cancer. When advocating a humanized conduct, as recommended by the philosophy of palliative care, the nurse is also committed to providing assistance based on the understanding of the family context, aiming to establish a transpersonal relationship of comfort and empathy.^{A19}

In the context of palliative care, the general challenges for promoting Nursing care are related to the care of the patient in the end-of-life phase, their families, and the multiprofessional team.^{A16,A17,A19,A24} in the perspective of transdisciplinarity. This underlines the urgency of updating the curricula of Nursing courses, continued education, permanent health education, and implementing clinical and therapeutic guidelines to improve the quality of palliative care.¹⁸

A Brazilian study developed at the Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA) listed the obstacles to assistance in pediatric palliative care. The following aspects were pointed out: inadequacy of the physical structure; insufficient human resources; fragmentation of the health services network; intersectoral gaps; lack of training of health workers;^{A1,A3,A5,A8,A9,A19,A27,A30,A33} difficulties in constructing strategies to meet the complexity of care;^{A9,A27} and diagnostic and interdisciplinary approach.¹⁹

Concerning academic training in the area of palliative care, a qualitative study pointed out the insufficient preparation of Nursing workers to act in pediatric hospital units, indicating the emergence of professional training on the theme, which allows the promotion of qualified assistance,²⁰ as identified elsewhere.^{19,21}

Regarding the gaps identified in palliative care aimed at the children and youth public, it is worth noting Resolução nº 41, de 31 de outubro de 2018, which provides guidelines for the organization of palliative care in the Sistema Único de Saúde (SUS). Its Article 3 includes in its objectives²² the offering of disciplines and programmatic content in the undergraduate and specialization teaching of health professionals; permanent education for health

workers in the SUS; and humanized health care, based on evidence, with equitable and cost-effective access,^{A6,A19,A25} covering the entire line of care and all levels of care.

With regard to the experience of nurses in dealing with the death and terminality of children with advanced cancer, one of the biggest challenges in coping with the situation is the lack of professional training on the process of death, dying, and mourning,^{A22,A34} which describes Thanatology.²³ This lack can generate barriers to promoting Nursing care in the scopes of emotions, communication, knowledge, and management.

In the scope of emotions,^{A3,A4,A15,A20} some gaps in dealing with emotions when facing a child with conditions that threaten the continuity of life occur through feelings such as uneasiness, discomfort, helplessness, and the desire to preserve the child's life when facing suffering and the death process.²¹

In the scope of communication, difficulties related to communicating with family members and members of the multiprofessional team were revealed to establish an effective care plan.^{A16, A17, A19,A24} Furthermore, there was a lack of inclusion of Nursing technicians in discussions, orientations, and decisions about palliative care for pediatric patients.²¹ In this perspective, it is opportune to emphasize that the lack of sharing^{A23} about the decisions can harm the continuity of assistance and the quality of care provided. Furthermore, the communication of difficult news^{A4,A11} made in a deficient and excluding way, in addition to hindering the interpersonal relationship, constitutes a challenge for professionals, family members, and even the children.²²

In the scope of knowledge, a study with Nursing professionals reported a limited understanding of the philosophy of palliative care, restricting it to implementing standardized conducts of end-of-life care,^{A8,A19,A29} which include the decision not to perform cardiac resuscitation, therapeutic suspension of oxygen therapy and drugs, and analgesic assistance.²¹ Similarly, another study identified a mistaken understanding of palliative care, associating it with the curative model, which justifies the predominance of professional and family conducts guided by socially accepted paradigms.²⁴ These conceptions denote an imaginary vision of this care modality, associating it with a reductionist flow of previously established practices.

Regarding the challenges to implementing family-oriented actions, a scoping analysis highlighted implications related to the lack of support for parents caring for children with a life-limiting condition,^{A8,A19,A33,A34} and the lack of support targeted support for the child's siblings.

The lack of access to psychological, home, and educational support was highlighted.²⁵

The need for inserting palliative care for children in an integrated and interdisciplinary care network and capable of empowering Nursing workers for ethical and humanistic care is emphasized. This aims to ensure its principles, considering the complexity and uniqueness of the daily experiences of patients and caregivers as they confront the fragility of the human condition,²⁶ especially in this phase of life.

CONCLUSION

This scoping review allowed us to map Nursing care for children with cancer in palliative care. It is a theme that refers to caring for others with a more humanistic approach and that, in recent years, has been gaining greater visibility, therefore making it further explored by national and international literature.

The evidence of the studies presented employing strategies indicated the dimension of palliative care in promoting the quality of life of this group of patients as well as its practices in the scope of oncopediatrics, since it is configured as an effective element of care for promoting Nursing care. Such strategies refer to controlling signs and symptoms, family support — especially in terminality — teamwork, and offering training to professionals.

Following this direction, we observed that the primary challenges for implementing Nursing care concern the difficulty in dealing with terminality and death, the need for complex care, and the conflicts inherent to the lack of knowledge of therapeutic communication techniques in palliative care among family members and the multiprofessional team. In addition to these factors, the information presented reveals the need for nurses to have an even more human and sensitive look toward patients and their families.

Our findings unveiled important strategies that have already been inserted over the years in the health services where nurses work, providing better Nursing care; an understanding of the practice that permeates the integral care of children according to their needs and those of their families. Thus, the relevance and uniqueness of this study stand out, in which the strategies for clinical practice are highlighted. In addition, it is paramount to point out the necessary strengthening of university education in health regarding the theme of palliative care and implementing in-service training and specialization courses. This is the factor that will effectively contribute to better preparing

professionals and, consequently, allow for better quality care in the context of pediatrics.

The idea is that this study contributes to mapping the current context of Nursing care for children with cancer in palliative care so that new empirical data can be generated and serve as a subsidy for new research that expands the knowledge about the theme from undergraduate Nursing courses to graduate studies. In addition, developing training courses on palliative care in health services directed to pediatric oncology care is emphasized.

This study has limitations, which are mainly due to the gaps in the theme, as demonstrated by the insufficiency of guidelines, protocols, and instruments aimed at Nursing care for this population.

Time does not stop, and science never stops. Hence, we recommend the continuity of research in the sense that, from future research, new elements may arise and help contribute to and expand knowledge about the science of Nursing, supporting the human and humanizing principles of caring for others and, in particular, of palliative care for children with cancer.

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