



# Comprehensive Care for Pediatric Oncology Patients and Their Families from the Perspective of Primary Health Care Nurses: A Scoping Review

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## Abstract

**Purpose:** To analyze scientific evidence on the role of APS nurses in the comprehensive care of pediatric oncology patients and their families, and to understand their practices, challenges, and strategies for promoting quality of life. **Design:** A scoping review was performed following the Joanna Briggs Institute extension for scoping reviews (PRISMA-ScR) and Arksey and O'Malley's framework. **Methods:** Databases LILACS, CINAHL, SCOPUS, Web of Science, and PUBMED were searched for peer-reviewed articles published in English, Spanish, or Portuguese from January 2014 to March 2024. Identified studies were screened, extracted, and analyzed independently by two researchers. **Results:** Of the 197 studies identified, 16 met the inclusion criteria. The comprehensive care provided by APS nurses to pediatric oncology patients and their families was categorized into: (1) practices, such as health monitoring, home visits, and psychosocial support; (2) challenges, including interprofessional communication barriers, lack of specialized training, and complexities in early diagnosis and referral; and (3) strategies, like educational programs, promotion of self-care, advocacy, and resource access support. **Conclusions:** This review underscores the crucial role of APS nurses in pediatric oncology care. By analyzing practices, challenges, and strategies, it highlights their efforts in enhancing clinical outcomes and addressing psychosocial needs. Future research should explore innovative approaches to improve holistic care delivery in this critical area. **Clinical Evidence:** The review highlights the essential role of APS nurses in pediatric oncology. Key practices include health monitoring, home visits, and psychosocial support. Challenges include communication barriers, lack of training, and complexities in early diagnosis. Effective strategies involve educational programs, promoting self-care, and resource advocacy.

## Keywords

Comprehensive Care; Pediatric Oncology; Primary Health Care; Nurses' Perspective; Family Support; Health Promotion

## 1. Introduction

Pediatric oncology is a complex field that requires an integrated approach, going beyond clinical treatment [1]. The

concept of holistic and comprehensive care, essential for the treatment of children and adolescents with cancer, considers not only the biological aspects of the disease but also the psychosocial, emotional, and spiritual factors that influence the well-being and quality of life of patients and their families [2-5]. In this context, Primary Health Care (APS) nurses play a crucial role in coordinating care, integrating services, and implementing the necessary interventions for comprehensive care [6, 7].

APS, as the entry point to the Brazilian Unified Health System (SUS), is vital to ensure the continuity and comprehensiveness of health actions. APS nurses are at the forefront of the early detection of cancer signs and symptoms, initiating diagnostic investigations and guiding families on the next steps in treatment. This close relationship with the community allows for a deep understanding of family dynamics and the individual needs of patients, facilitating a personalized approach [8-14].

Comprehensive care in APS involves integrating various dimensions of health, including medical treatment and emotional and psychosocial support. Studies indicate that psychological stress and anxiety are common among children with cancer and their families, requiring interventions that promote emotional well-being and resilience. Psychological support, through individual or group counseling and therapeutic activities such as art therapy and music therapy, has been shown to reduce stress and improve the quality of life of patients [15-19].

However, APS nurses face several challenges in providing comprehensive care. Continuous and specialized training is essential to handle the complexity of oncology cases and implement evidence-based interventions. However, resource scarcity, workload, and lack of integration between care levels can compromise the quality of care. Management strategies and public policies that promote professional training and adequate resource allocation are fundamental to overcoming these barriers [15-19].

Active participation of nurses in health education and family empowerment is crucial. Clearly informing about the disease, treatment, and support options improves family understanding and promotes more active participation in the care process, strengthening autonomy and decision-making capacity [8-14].

Home support programs, regular nurse visits, and the use of information and communication technologies, such as telemedicine and remote monitoring platforms, have proven effective in improving clinical outcomes and coordinating care, especially in hard-to-reach areas [8-14]. Interdisciplinary collaboration and the building of support networks, including doctors, psychologists, and social workers, ensure coordinated and integrated care, while complementary practices such as acupuncture and herbal medicine can complement conventional treatment and improve patients' quality of life [15-19].

Thus, this scoping review aims to analyze scientific evidence on the role of APS nurses in the comprehensive care of pediatric oncology patients and their families, understanding their practices, challenges, and strategies in promoting quality of life.

## **2. Materials and Methods**

### **2.1 Ethical Aspects**

Since this is a scoping review, which used publicly available data and did not involve human subjects, there was no need for approval by the Research Ethics Committee (CEP). However, it is important to note that the studies selected for the final sample were properly referenced [20].

### **2.2 Study Design**

A scoping review, developed in accordance with the recommendations of the international guideline Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) [21] and the Joanna Briggs Institute (JBI) Reviewer's Manual, 2020 version [22, 23], with a research protocol registered on the Open Science Framework (OSF) platform on June 13, 2024. It is important to highlight that the scoping review represents an innovative approach to systematic literature review, with growth in both national and international publications in the last decade. The method allows examining evidence, existing gaps, and key concepts related to a specific study object [22, 23]. During the development of this study, the following step structure was chosen, as conceptualized by Arksey and O'Malley [24]: (1) establishment of the research question; (2) identification of relevant studies in national and international literature; (3) analysis and extraction of studies; (4) data organization; (5) compilation, synthesis, interpretation, and reporting of results [24].

## 2.3 Methodological Procedure

Initially, a search of the scientific literature was conducted to identify reviews with a similar research scope. Platforms such as the International Prospective Register of Systematic Reviews (PROSPERO), Open Science Framework (OSF), The Cochrane Library, JBI Clinical Online Network of Evidence for Care and Therapeutics (COOnNECT+), and Database of Abstracts of Reviews of Effects (DARE) were examined. The search results revealed a gap in scientific publications related to objectives similar to those of this scoping review.

To formulate the research question, the "PCC" mnemonic was used, where "P" represents Population, "C" represents Concept, and "C" represents Context, which will serve as a guiding element for the searches in the databases [22, 23]. The Population consisted of studies involving children and adolescents (ages 0 to 19 years) diagnosed with pediatric neoplasms and/or suspected childhood cancer. The key Concept of this scoping review included studies detailing the strategies used by primary care nurses to promote comprehensive and holistic care for children and adolescents with cancer or suspected neoplastic diagnosis, as well as for their families and/or caregivers. The defined Context was Primary Health Care. Based on this, the following research question was formulated: *"What is the scientific evidence on the role of Primary Health Care (APS) nurses in the comprehensive care of pediatric oncology patients and their families, aiming to understand their practices, challenges, strategies, and contributions to promoting quality of life (QoL), considering not only clinical aspects but also psychosocial and emotional factors?"*

## 2.4 Data Collection and Organization

Data collection took place between January and March 2024 from the following databases: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, Web of Science, and Latin American and Caribbean Health Sciences Literature (LILACS).

The search strategy was conducted in two stages to identify relevant studies. Initially, descriptors from Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) were used in combination with Boolean operators "AND" and "OR" to refine the search across Portuguese and English sources.

In preparation for the peer-reviewed literature search and gray literature, a specialized librarian was consulted for guidance on identifying relevant databases and search terms [25]. Thus, complementing the first stage, the second stage was conducted through a new search using the keywords and descriptors identified in the databases. A controlled vocabulary was modified for each database. The search strategy was adapted according to the specificities of each source used; however, the combinations between descriptors were preserved, along with time restriction filters (2014 to 2024).

Additionally, it is noteworthy that Table 1 demonstrates the strategies developed with the descriptors used, aided by the Boolean operators "AND" and "OR" to compose the search, as well as the quantification of the articles located and selected in each database.

## 2.5 Inclusion and Exclusion Criteria

The scoping review included qualitative and quantitative studies focusing on strategies that legitimize the role of primary care nurses in promoting comprehensive and holistic care for children and adolescents (ages 0 to 19 years) diagnosed with pediatric neoplasms or suspected cancer, as well as for their families and/or caregivers in the context of primary health care. Qualitative studies of any theoretical and methodological approach were considered, as well as studies published in English, Spanish, or Portuguese, from 2014 to 2024. It is important to note that, as the year 2024 has not yet ended and new studies may be published, the search for articles was conducted until January 31, 2024. This period is justified by the intensification of publications and discussions on characterizing strategies related to the role of primary care nurses in promoting comprehensive and holistic care for children and adolescents diagnosed with pediatric neoplasms or suspected cancer.

Studies that addressed other types of cancer without focusing on the role of nurses in primary care, based on literature or theory, were excluded. In addition, opinion articles, theses, and studies that did not address the characterization of strategies related to the role of primary care nurses in promoting comprehensive and holistic care for children and adolescents diagnosed with pediatric neoplasms or suspected cancer were excluded.

**Table 1. Search strategies for articles in databases**

Database	Search Strategy
PubMed (n = 55)	("Health Care" OR "Nursing Care" OR "Comprehensive Health Care" OR "Health Education" OR "Health Strategies" OR "Health Promotion" OR "Quality of Life" OR "Early Diagnosis" OR "Early Detection of Cancer") AND ("Childhood Cancer Survivors" OR "Children Cancer Survivors" OR "Pediatric Patient" OR Child OR Children OR Childhood OR adolescent* OR teen*) AND (Family) AND (Oncology OR Cancer OR Neoplasm) AND (Nursing OR Nurses OR "Family Nurse Practitioners" OR "Nurses, Community Health" OR "Nurse's Role" OR "Oncology Nursing") AND ("Primary Health Care" OR "Healthcare Models")
CINAHL (n = 40)	("Health Care" OR "Nursing Care" OR "Comprehensive Health Care" OR "Health Education" OR "Health Strategies" OR "Health Promotion" OR "Quality of Life" OR "Early Diagnosis" OR "Early Detection of Cancer") AND ("Childhood Cancer Survivors" OR "Children Cancer Survivors" OR "Pediatric Patient" OR Child OR Children OR Childhood OR adolescent* OR teen*) AND (Family) AND (Oncology OR Cancer OR Neoplasm) AND (Nursing OR Nurses OR "Family Nurse Practitioners" OR "Nurses, Community Health" OR "Nurse's Role" OR "Oncology Nursing") AND ("Primary Health Care" OR "Healthcare Models")
SCOPUS (n = 22)	("Health Care" OR "Nursing Care" OR "Comprehensive Health Care" OR "Health Education" OR "Health Strategies" OR "Health Promotion" OR "Quality of Life" OR "Early Diagnosis" OR "Early Detection of Cancer") AND ("Childhood Cancer Survivors" OR "Children Cancer Survivors" OR "Pediatric Patient" OR Child OR Children OR Childhood OR adolescent* OR teen*) AND (Family) AND (Oncology OR Cancer OR Neoplasm) AND (Nursing OR Nurses OR "Family Nurse Practitioners" OR "Nurses, Community Health" OR "Nurse's Role" OR "Oncology Nursing") AND ("Primary Health Care" OR "Healthcare Models")
Web of Science (n = 28)	("Health Care" OR "Nursing Care" OR "Comprehensive Health Care" OR "Health Education" OR "Health Strategies" OR "Health Promotion" OR "Quality of Life" OR "Early Diagnosis" OR "Early Detection of Cancer") AND ("Childhood Cancer Survivors" OR "Children Cancer Survivors" OR "Pediatric Patient" OR Child OR Children OR Childhood OR adolescent* OR teen*) AND (Family) AND (Oncology OR Cancer OR Neoplasm) AND (Nursing OR Nurses OR "Family Nurse Practitioners" OR "Nurses, Community Health" OR "Nurse's Role" OR "Oncology Nursing") AND ("Primary Health Care" OR "Healthcare Models")
LILACS (n = 52)	("Cuidado de Saúde" OR "Cuidados de Enfermagem" OR "Assistência de Saúde" OR "Assistência Integral à Saúde" OR "Educação em Saúde" OR "Atenção Integral à Saúde da Criança e do Adolescente" OR "Estratégias de Saúde" OR "Promoção da Saúde" OR "Qualidade de Vida" OR "Diagnóstico Precoce" OR "Detecção Precoce de Câncer") AND ("Sobreviventes de Câncer Infantil" OR "Sobreviventes de Câncer Infantil" OR "Paciente Pediátrico" OR Criança OR Crianças OR Infância OR adolescente* OR adolescente*) AND (Família OR Familiares OR Cuidadores) AND (Oncologia OR Câncer OR Neoplasia) AND (Enfermagem OR Enfermeiros OR Enfermeiras OR "Enfermeiras de Saúde da Família" OR "Enfermeiros de Saúde Comunitária" OR "Profissional de Enfermagem" OR "Enfermagem Onco-

**Explanatory Note:** The asterisk (\*) was used as a truncation operator in the search strategy to include all possible variations of the keywords. This operator allows for the retrieval of terms with different suffixes or morphological variations, thus broadening the search scope. For example, the term "neoplasms" includes both "neoplasms" and "neoplasm"; "adolescent\*" retrieves both "adolescent" and "adolescents". The use of the asterisk ensures that the search is comprehensive and includes all possible forms of the relevant words for the study.

## 2.6 Analysis of Results

For this study, the Content Analysis methodology was used to classify and critically analyze the messages of the articles into different categories, grouping elements with common characteristics [26]. Discrepancies were resolved through discussion between reviewers, with the intervention of a third reviewer when necessary.

The articles were read and cataloged in a Microsoft Excel 2010 spreadsheet. Data were analyzed using Bardin's thematic analysis technique [27], which facilitated the identification of thematic cores and the categorization of results. Excerpts with common themes were extracted to define and categorize the data, which were described and analyzed for their meanings.

For evidence analysis, data such as authors, year, journal, country, study setting, language, objectives, protocol, main results, and conclusions were extracted. Articles that met the inclusion criteria were translated and

independently evaluated by two team members, with discrepancies resolved by a third researcher.

Thematic analysis, as per Braun & Clarke [28], was used to interpret the information from the articles, allowing the identification of prominent themes. Qualitative and quantitative data were organized into a matrix to integrate narrative and statistical evidence [29]. Preliminary themes were discussed and agreed upon before being finalized by one author (JS), and later reviewed [28].

The selection and screening of articles were performed using Mendeley® for duplicate removal and Rayyan for blind screening of titles and abstracts. Discrepancies were resolved in meetings with a third reviewer. The full reading of the selected articles was conducted, and a retrospective search of the references identified additional relevant studies.

The classification of the level of evidence followed the grading system recommended by JBI [22, 23], which comprises five levels of evidence: level 5 (expert opinion), level 4 (descriptive observational studies, such as cross-sectional studies, for example), level 3 (analytical observational studies, such as cohort and case-control studies, for example), level 2 (quasi-experimental studies), and level 1 (experimental studies, including systematic reviews and randomized clinical trials). After this stage, the articles were characterized, and the results related to the research question were synthesized and described, grouped into guiding axes [30].

Furthermore, the data analysis included numerical counting and descriptive statistics to characterize the publications. Qualitative Content Analysis [31] elucidated the role of nurses in promoting holistic care in pediatric oncology. The Integrated Convergent Analysis methodology was employed to transform quantitative data into textual descriptions or narrative interpretations [32].

### 3. Results

#### 3.1 Search Results

The identification of studies (Figure 1) through databases and records resulted in 197 works. Of these, 181 studies were fully examined by reading the articles. In the end, 16 studies were included in the final sample.

Table 2 summarizes the 16 studies with relevant information for the research question, illustrating the synthesis of data, as well as the role of Primary Health Care (APS) nurses in the comprehensive care of pediatric oncology patients and their families.

**Table 2. A summary of research studies included in the review**

Code / Authorship / Year of Publication / Country of Study Publication / Journal	Methodological Design / Sample Size / Level of Evidence	Studies Objectives	Conclusions of the Studies
(E1) / Monteiro et al. / 2014 / Brazil / Uerj Journal Nursing	Qualitative study using semi-structured interviews, with Bardin's content analysis / (n = 14) nurses / Level of Evidence (IV)	To understand the nursing care actions for children with cancer in palliative care.	Nurses care or children in palliative care in Primary Health Care in a unique way, guided by understanding, compassion, and respect for their and their family's needs throughout the treatment process.
(E2) / Lima / 2015 / Brazil / APS Magazine Primary Health Care	Cross-sectional, descriptive study with both quantitative and qualitative approaches, using Bardin's content analysis / (n = 14) nurses / Level of Evidence (IV)	Evaluate the theoretical knowledge of Primary Health Care nurses regarding early identification of childhood cancer in the municipality of Recife, Pernambuco.	It becomes crucial to provide qualified care with trained professionals and comprehensive assistance to minimize delays in the diagnosis of childhood cancer in Primary Health Care.
(E3) / Thoresen et al. / 2016 / Norway / Scandinavian Journal of Primary Health Care	A retrospective cross-sectional registry study using a billing registry data source / (n = 5752) patient with a cancer-related contact in the material / Level of Evidence (IV)	To investigate how cancer patients in Norway use primary care out-of-hours (OOH) services and describe different contact types and procedures.	There was no indication of overuse of OOH services by cancer patients in Norway, which could indicate good quality of cancer care in general.

**Table 2 Continued**

(E4) / Wakiuchi et al. / 2016 / Brazil / Gaúcha Nursing Magazine	Qualitative research grounded in Heideggerian phenomenology / (n = 10) patients / Level of Evidence (IV)	Understanding cancer patients' experiences regarding the care received and their relationship with professionals in the Family Health Strategy.	Understanding these experiences prompts reflection on the care provided in this care setting and the importance of professionals overcoming impersonal and inauthentic attitudes to transcend to a new level of relational and care provision.
(E5) / Carduff et al. / 2016 / United Kingdom / BMC Primary Care	Pilot study modeled according to the complex intervention framework of the Medical Research Council / (n = 04) health reference centers recruited / Level of Evidence (II)	The aim of this project was to model and pilot a systematic approach to identify, assess and support carers of people with supportive and palliative care needs in primary care.	This approach to identifying and supporting carers was acceptable, but success was dependent on engagement within the whole practice. Carers did not tend to self-identify, nor ask for help. Practices need to proactively identify carers using existing opportunities, resources and computer systems, and also adopt a public health approach to raise carer awareness and perceived support within their communities.
(E6) / da Rosa et al. / 2017 / Brazil / Cogitare Nursing	Observational, descriptive study / (n = 84) nurses / Level of Evidence (IV)	Identifying the demands for care and training in Oncology among nurses working in Primary Health Care.	The main demands for care and qualification deficits involve the most incident malignant neoplasms, the impact of cancer, oncological therapies, and their side effects. The data show that despite experience in primary care, many professionals feel the need for training to enable them to provide specialized and qualified care.
(E7) / de Santana et al. / 2017 / Brazil / Academic Highlights	Retrospective study, with a quantitative approach, conducted using patient medical record data / (n = 292) patients / Level of Evidence (IV)	Describing nursing diagnoses and care provided to children and adolescents with cancer in Primary Health Care.	The care systematization was present in all hospital record entries, whether through diagnostic titles or through the provision of nursing care.
(E8) / de Souza et al. / 2017 / Brazil / Anna Nery School Magazine Nursing Magazine	Cross-sectional study with a quantitative approach / (n = 77) nurses / Level of Evidence (IV)	Identifying the qualifications and understanding the role of nurses in the Family Health Strategy in oncological care.	It was evidenced that nurses are unprepared to care for cancer patients and there is an explicit need for continuing education.
(E9) / Friestino et al. / 2017 / Brazil / Brazilian Journal of Cancerology	Qualitative study with an exploratory approach / (n = 27) healthcare professionals / Level of Evidence (IV)	Understanding the perceptions of healthcare professionals working in Primary Health Care regarding early diagnosis of childhood cancer.	The perceptions found indicate the need to enhance the training of healthcare professionals working in the care of children and adolescents in Primary Health Care, focusing on the early diagnosis of childhood cancer.
(E10) / Nadeau et al. / 2017 / United States of America / Journal of Pediatric Oncology Nursing	Descriptive cross-sectional design with surveys applied to patients/families and nurses / (n = 59) patients/families and (n = 57) nurses / Level of Evidence (IV)	To evaluate patient/family and nurse perceptions of the primary nursing model through assessing gaps in its operationalization and satisfaction within an inpatient setting.	Overall, patients, families, and nurses value continuity of care and meaningful nurse-patient relationships, which are fundamental to primary nursing care.

Table 2 Continued

(E11) / Østergaard et al. / 2017 / Denmark / Journal of Clinical Nursing	A cross-sectional study / ( <i>n</i> = 1720) nurses were available for analysis / Level of Evidence (IV)	To investigate attitudes towards family involvement in care among a broad sample of Danish nurses from all sectors and healthcare settings.	Families are considered important in nursing care. Younger nurses with a basic education, short-term engagement at a hospital and no experiences with illness within their own families were predictors of less supportive attitudes towards including the family in nursing care.
(E12) / Miranda et al. / 2018 / Brazil / Health Magazine	Descriptive and qualitative study / ( <i>n</i> = 03) studies / Level of Evidence (IV)	Characterize the contributions of nurses to early diagnosis of childhood cancer in Primary Health Care.	Nurses can collaborate in screening for signs and symptoms among children and adolescents in Primary Health Care to increase the likelihood of cure and support continuity of care, focusing on their families and communities. They can also participate in ongoing training for nursing and healthcare teams.
(E13) / Paixão et al. / 2018 / Brazil / Journal Nursing UFPE online	Descriptive study / ( <i>n</i> = 11) nurses / Level of Evidence (IV)	To identify the scientific productions that address the participation of nurses, who work in primary care, early detection and management of cases of childhood cancer.	The nurse has an important participation in the diagnoses of pediatric oncologist, through the detection of physiological changes, establishing a relationship of help with patient and family, through effective communication, measures to alleviate suffering and support to family members. These practices, however, have not been the focus of scientific studies making it necessary to increase knowledge production in the area that will allow a more solid, concrete and safe practice.
(E14) / Dias et al. / 2020 / Brazil / Reference Nursing Journal	Exploratory study conducted in 03 health units / ( <i>n</i> = 11) nurses / Level of Evidence (IV)	Investigate the possibilities and limitations regarding early detection of childhood cancer, based on reports from professionals working in Primary Health Care.	Therefore, it was found that this study will enable these professionals to better address early diagnosis of cancer in children and adolescents treated in Primary Health Care.
(E15) / Souza et al. / 2021 / Brazil / Brazilian Journal of Development	Exploratory study / ( <i>n</i> = 10) nurses / Level of Evidence (IV)	Identifying how nursing care for children or adolescents with cancer has been conducted in Primary Health Care.	In the context of Primary Health Care, it is concluded that nurses are not adequately prepared to provide holistic care for children and adolescents with cancer, as well as their families, addressing all their physical, psychological, and social needs.
(E16) / Amorim et al. / 2023 / Brazil / Research Journal Care is Fundamental	Descriptive study, qualitative / ( <i>n</i> = 14) nurses / Level of Evidence (IV)	To identify the knowledge of families of children cared for in Primary Health Care about the signs and symptoms of childhood cancer and the role of nurses in this process.	The involvement of families in well-child visits and the sharing of information by healthcare professionals are resources that can facilitate the recognition of warning signs and symptoms of childhood cancer, especially in Primary Health Care.

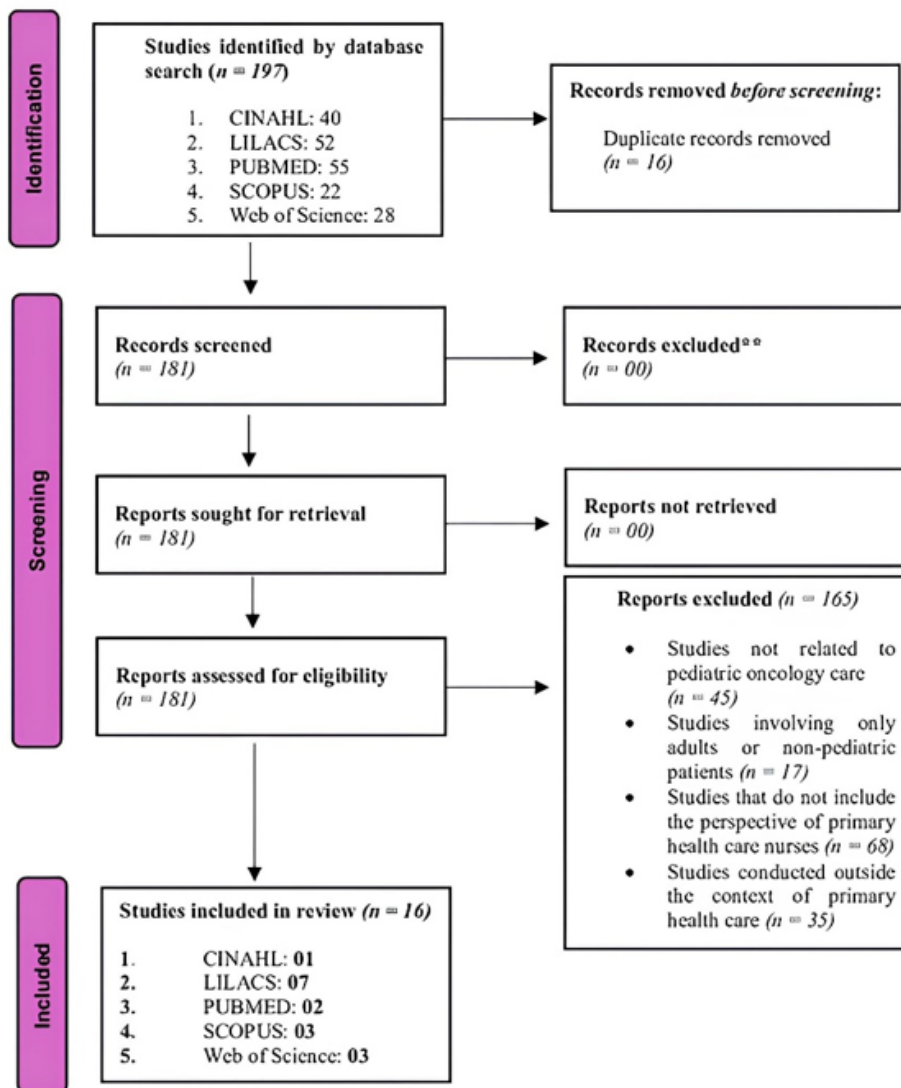


Figure 1. PRISMA diagram showing the article selection process [21].

### 3.2 Characteristics of Eligible Studies

Analyzing the final sample of studies in this scoping review, limited geographic diversity was observed, with studies originating from only five countries, concentrated in the American and European continents. The American continent led with 13 studies (81.25%), followed by Europe with 3 studies (18.75%). Among the countries, Brazil had the highest number of studies (12, 75%), while the United States, Denmark, Norway, and the United Kingdom had one study each (6.25%).

Regarding methodology, most studies were classified as evidence level IV (93.75%), covering various qualitative approaches such as cross-sectional and phenomenological. Only one study was classified as evidence level II (6.25%), being a pilot study.

The objectives of the studies varied, including investigation and analysis of the practices and challenges faced by Primary Health Care nurses in the care of pediatric oncology patients. The analysis revealed the complexity of care and the importance of continuous training for professionals. The early detection of childhood cancer is hindered by a lack of knowledge of the signs and symptoms, highlighting the need for education and effective communication between professionals and families (Table 3).



**Table 3. Description of results from selected studies: analysis of key findings**

Code / Authorship / Year of Publication	Description of Main Results	Key Findings and Analysis
(E1) / Monteiro et al. / 2014	As a result, six analytical categories emerged: Providing comfort to the child; Caring for the family; Meeting the child's needs; Ensuring the child's quality of life; Offering spiritual, emotional, and religious support; Being close to the child and showing availability.	As evidenced, the study identified six distinct analytical categories pivotal in pediatric oncology care: Providing essential comfort to pediatric patients, ensuring comprehensive support for their families, meeting the specific needs of each child, enhancing their overall quality of life, offering crucial spiritual, emotional, and religious guidance, and maintaining close proximity and availability to the child throughout their care journey.
(E2) / Lima / 2015	Based on the results, it was established that nurses' lack of knowledge about the topic contributes to delays in the early diagnosis of this neoplasm.	Based on these findings, it is clear that addressing the knowledge gaps among nurses is crucial to mitigating delays in early neoplasm diagnosis. Enhanced education and training programs can significantly improve early detection rates, thereby optimizing patient outcomes and reducing the burden on healthcare systems.
(E3) / Thoresen et al. / 2016	Children with cancer received more home visits and had more contact with municipal nursing services compared to other patients.	Children diagnosed with cancer demonstrated higher rates of home visits and greater engagement with municipal nursing services in comparison to their peers without cancer. This underscores the specialized and intensive support required for pediatric oncology patients, highlighting the importance of tailored healthcare services to meet their unique needs effectively.
(E4) / Wakiuchi et al. / 2016	Some patients encountered impersonal nursing professionals and a lack of empathy, interaction, and individualized care, while others had their expectations met, experiencing comprehensive care filled with solicitude, shared feelings, and respect.	The study revealed varying patient experiences within healthcare settings: some encountered impersonal nursing professionals lacking empathy, interaction, and personalized care, while others reported receiving comprehensive care characterized by compassion, shared emotions, and respectful treatment. These findings underscore the critical role of empathetic and patient-centered care in enhancing overall patient satisfaction and well-being.
(E5) / Carduff et al. / 2016	As a result of the qualitative interviews, the study indicated that caregivers of children and adolescents with childhood cancer value horizontal communication with the nursing team and the establishment of empathetic bonds.	The qualitative interviews highlighted that caregiver of children and adolescents with childhood cancer highly value horizontal communication with the nursing team and the establishment of empathetic bonds. These findings underscore the importance of collaborative and compassionate care approaches in supporting families throughout the cancer treatment journey.
(E6) / da Rosa et al. / 2017	The study included 84 nurses; 41 (48.81%) graduated more than ten years ago (12.04±6.99 years); 46 (54.76%) consider their oncology education during undergraduate training insufficient and report a lack of further training in this area after graduation.	The main demands for care and qualification deficits involve the most incident malignant neoplasms, the impact of cancer, oncological therapies, and their side effects.

Table 3 Continued

(E7) / de Santana et al. / 2017 / Brazil / Academic Highlights	The study identified 292 cancer patients between 2011 and 2012. The pediatric oncology population was predominantly male (59.59%), with Acute Lymphoblastic Leukemia being the most common neoplasm. The research identified 584 nursing diagnoses, with an average of 2.01 nursing diagnoses per patient.	The main nursing diagnoses were: Risk for infection (30.14%); Impaired comfort (15.07%); Imbalanced nutrition less than body requirements (11.82%); and Impaired physical mobility (6.51%). It was possible to observe the significant workload dedicated to pediatric oncology-hematology patients, and the effective execution of the nursing process within the institution.
(E8) / de Souza et al. / 2017	Training in oncology care is infrequent, reflecting a high level of unawareness regarding the National Oncology Care Policy.	It was found that 95% of professionals provided care to oncology patients, with home visits and nursing consultations being the most prevalent. Regarding the National Policy for Oncology Care, 96% of nurses declared they were not familiar with it.
(E9) / Friestino et al. / 2017	The study included workers from different professional categories. It was identified that there is little contact with the topic of early diagnosis of childhood cancer in daily practice, as well as feelings of insecurity and a lack of knowledge regarding the subject.	Relationship and bond with the family were present in all groups. Good technical knowledge, teamwork with diverse competencies, and a structured healthcare network contribute to improving early diagnosis in children and adolescents with cancer.
(E10) / Nadeau et al. / 2017	Of the 59 patient/family respondents, 93.2% prefer to have a primary nurse care for them and 85% are satisfied with how often they are assigned a primary care team member. Similarly, 63% of the 57 nurse respondents are satisfied with the current implementation of our primary nursing model and 61% state the model reflects good continuity of care.	The majority of patients and families (93.2%) prefer having a primary nurse, and 85% are satisfied with their frequency of assignment. Among nurses, 63% are satisfied with the current primary nursing model, with 61% noting good continuity of care. These findings highlight strong support for the primary nursing approach among both patients and nurses.
(E11) / Østergaard et al. / 2017	In general, the nurses considered the family as important in patient care.	Nurses who held master's and doctorate degrees scored significantly higher than nurses with a basic nursing education. Nurses who had had experience with illness within their own families tended to score higher on the family as a conversational partner subscale than those without this experience.
(E12) / Miranda et al. / 2018	Two empirical categories emerged: "support for early detection of childhood cancer" and "training of the nursing and healthcare team in primary care."	Two empirical categories emerged: one focused on supporting early detection of childhood cancer, while the other emphasized training for the nursing and healthcare team in primary care.
(E13) / Paixão et al. / 2018	Limiting factors in addressing cancer include failure in communication between generalist and specialist professionals, care fragmentation, lack of preparedness and training among generalist professionals, and the absence of seeking guidelines, treatment summaries, and care plans by professionals.	Recent findings underscore critical barriers in cancer care, including ineffective communication between generalist and specialist professionals, fragmented care pathways, inadequate training and preparedness among generalist professionals, and a noticeable absence of proactive utilization of guidelines, treatment summaries, and care plans. Addressing these issues is crucial for optimizing cancer management and improving patient outcomes.

Table 3 Continued

(E14) / Dias et al. / 2020	Presented possibilities include: contextualization and interpretation of clinical results, as well as systematic and interdisciplinary care.	As limitations, there were: lack of specificity of signs and symptoms of childhood cancer, non-compliance with the principle of accessibility, and the need for training/capacitation.
(E15) / Souza et al. / 2021	Peculiarities of daily care in Primary Health Care were observed, emphasizing the importance of the nursing professional who monitors health conditions of the population, whether individually or collectively. This includes daily activities such as providing home care to oncology patients and their families.	Observations of daily care in Primary Health Care highlighted the pivotal role of nursing professionals in monitoring the health conditions of the population, both individually and collectively. This encompasses essential tasks such as delivering home care to oncology patients and their families, underscoring the critical and multifaceted responsibilities of nurses in community health settings.
(E16) / Amorim et al. / 2023	Two analytical categories were listed: "knowledge and perceptions of families about childhood cancer" and "information needs regarding childhood cancer."	Two analytical categories have been identified: "families' understanding and perspectives on childhood cancer" and "informational requirements regarding childhood cancer."

Furthermore, based on the findings of each study, it is emphasized that comprehensive care for pediatric oncology patients and their families in Primary Health Care by nurses was categorized into the following subcategories: (1) practices for comprehensive care (monitoring and health care), (2) challenges to implementing comprehensive care (structural and educational barriers; communication and training; diagnosis and referral), and (3) strategies to improve quality of life (education and self-care; advocacy and external resources).

## 4. Categories and Subcategories of Studies

### 4.1 Practices Adopted in Comprehensive Care for Pediatric Oncology Patients and Their Families by Primary Health Care Nurses

#### 4.1.1 General Care Practices

Nurses play a crucial role in primary health care by providing comprehensive care to pediatric oncology patients and their families. Practices include emotional, educational, and social support, in addition to clinical treatment. Interventions such as home visits, health education, and psychological support are essential to mitigate the impact of childhood cancer. Coordination with other healthcare professionals and the creation of individualized care plans are recommended practices to meet the specific needs of patients [2, 5, 7].

#### 4.1.2 Monitoring and Care

Continuous health monitoring is fundamental for effective care management, allowing the early detection of complications and efficient communication among the multidisciplinary team. Home visits and outpatient care enable contextualized assessments and promote treatment adherence, while emotional and psychosocial support helps mitigate the stress associated with cancer diagnosis and treatment [4, 6, 8, 10, 15-17].

### 4.2 Challenges in Implementing Comprehensive Care

#### 4.2.1 Structural and Educational Barriers

The implementation of comprehensive care faces challenges such as a lack of human and material resources, gaps in specific training in pediatric oncology, and fragmentation of health services. Sociocultural barriers, such as stigma and resistance to treatment, also hinder care. These difficulties require health policies that promote professional training and service integration [3, 8-10, 19].

#### 4.2.2 Communication and Training

Barriers in interprofessional communication and a lack of specific training in pediatric oncology are significant challenges. Ineffective communication can lead to fragmented care, and the lack of training limits professionals'

ability to provide quality care. Educational programs and effective communication strategies are recommended to overcome these challenges [7, 15, 19].

#### **4.2.3 Diagnosis and Referral**

The complexity of early diagnosis and appropriate referral is a critical challenge. Nonspecific symptoms and a lack of clear guidelines can delay diagnosis and treatment. Training professionals to recognize signs and establish prompt referrals is crucial to improving outcomes [19].

### **4.3 Strategies and Interventions to Improve Quality of Life**

#### **4.3.1 Education and Self-care**

Nurses develop strategies to improve the quality of life for patients and their families, including health education and promoting self-care. Educational programs empower families on disease management and treatment adherence, while emotional support and the promotion of self-care practices help improve quality of life [6, 7, 16, 33-38].

#### **4.3.2 Advocacy and External Resources**

Advocacy and support for accessing external resources are essential practices that help reduce the financial and social stress of families. Nurses play a crucial role in navigating and connecting patients with community resources and assistance programs, promoting comprehensive and sustainable care [6, 8-10].

## **5. Discussion**

The scoping review provided a comprehensive overview of nursing practices in Primary Health Care for the comprehensive care of pediatric oncology patients and their families. The implementation of educational programs stands out as a crucial strategy to empower patients and families about the nature of the disease, treatment options, and management of side effects (E1, E2, E12) [8, 16, 17]. These programs not only increase knowledge but also strengthen families' ability to face the challenges of childhood cancer in an informed and proactive manner, promoting better treatment adherence and positive long-term clinical outcomes [39, 40].

Furthermore, the emphasis on continuity of care through home visits and outpatient follow-up has been widely recognized in the literature as an effective practice for closely monitoring the health status of patients and providing ongoing support to families (E4, E7, E14) [10, 12, 19]. Additional studies highlight that these interventions not only improve access to care, especially in remote or resource-limited areas, but also strengthen the bond between nurses, patients, and their families, contributing to a more integrated and patient-centered care experience [41, 42].

However, the implementation of these practices faces significant challenges. Major barriers in interprofessional communication have been identified as an obstacle to effective care coordination between different levels of health (E3, E6, E10) [33, 35, 36]. The lack of specialized training in pediatric oncology among Primary Health Care professionals has also been frequently cited as a significant limitation, negatively impacting the quality and effectiveness of the care provided [43, 44].

In addition to clinical challenges, the socioeconomic and psychosocial issues faced by families of children with cancer in Primary Health Care settings are equally pressing. Advocacy and support for accessing external resources emerge as essential elements in mitigating the financial and emotional impacts of childhood cancer, promoting family resilience and care sustainability throughout the disease cycle (E5, E16) [34, 38]. Additional studies emphasize that effective advocacy strategies and interprofessional collaboration are crucial to overcoming these challenges and ensuring that all children have equitable access to high-quality care [44].

The review covered studies that highlight the importance of effective communication and interprofessional collaboration in Primary Health Care for the integrated management of pediatric cancer. Research indicates that the lack of clear and integrated communication among professionals from different specialties can lead to gaps in care coordination and management of potential treatment complications (E3, E6, E10) [33, 35, 36]. Interventions aimed at improving interprofessional communication, such as standardized information transfer protocols and regular interdisciplinary meetings, are essential to optimize clinical outcomes and enhance the patient and family experience [45, 46].

Moreover, the review underscored the importance of ongoing and specialized education in pediatric oncology for nurses and health professionals in Primary Health Care. Studies demonstrate that inadequate training in these areas can lead to delays in diagnosis, inappropriate treatment, and difficulties in managing complex symptoms associated

with childhood cancer (E8, E9, E13) [5, 11, 18]. Investments in ongoing education programs, realistic simulations, and partnerships with specialized centers are essential to effectively equip health professionals to provide quality and compassionate care to children and their families [47, 48].

Beyond clinical and educational aspects, the review highlighted the need for robust public policies and adequate resources to support pediatric oncology care in Primary Health Care. Critical challenges faced by many health units include inadequate funding, limited access to essential medications, and insufficient infrastructure to provide comprehensive and quality care (E5, E16) [34, 38]. It is imperative that governments and health institutions invest in more resilient and sustainable health systems that ensure equity in care access and promote positive outcomes for all children affected by cancer [49-51].

This scoping review faces some limitations. First, the inclusion of some relevant studies may have been hindered due to language restrictions or specific limitations of the databases used. Additionally, the diversity of contexts studied and methodological heterogeneity may restrict the generalization of the identified practices. Language restrictions and selection bias during the screening of studies are also important considerations. The absence of longitudinal studies and the possible outdated nature of the analyzed practices represent other relevant limitations to be considered.

## 6. Conclusion

This scoping review provides a comprehensive overview of the practices adopted by nurses in Primary Health Care (APS) for the care of children with cancer and their families. The evidence highlights the importance of practices such as continuous health monitoring, home visits, emotional and psychosocial support, as well as educational strategies and promotion of self-care.

The reviewed studies revealed significant challenges in implementing comprehensive care, including barriers in interprofessional communication, lack of specific training in pediatric oncology, and complexity in early diagnosis and referral. These obstacles underscore the need for investments in continuous education and training for health professionals in APS to improve early detection and comprehensive support for families.

The strategies and interventions identified in this review demonstrate the potential to significantly improve the quality of life of pediatric cancer patients and their families. The implementation of educational programs, support for self-care, and advocacy for access to external resources are crucial to promoting better health outcomes and well-being.

The implications for practice, education, and research are substantial. Health professionals need to be equipped with up-to-date knowledge and specific skills to provide holistic and high-quality care. Continuous education, interprofessional collaboration, and effective health policies are essential to strengthen support in APS for pediatric oncology care.

## 7. Recommendations for Future Research and Policy Changes

To address the challenges identified, future research should explore innovative and evidence-based interventions to improve holistic care delivery in APS. Studies evaluating the impact of specific training programs in pediatric oncology and initiatives that promote effective communication between different levels of care are particularly needed. Additionally, public policies should be developed to ensure adequate resources and institutional support for the continuous training of health professionals, as well as for the implementation of integrated healthcare practices involving multidisciplinary teams.

Thus, this scoping review provides a comprehensive overview of the current practices and challenges faced by nurses in APS in pediatric oncology care. Significant advances can be achieved with the ongoing commitment of all involved to improve support and quality of life for children with cancer and their families in the community.

## Author Contributions

**Pedro Emílio Gomes Prates:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Project administration. **Antonio Jorge Silva Correa-Júnior:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing, Resources. **Natália Cristina Betoni Vieira:** Methodology, Validation, Formal analysis, Investigation, Resources, Writing - review & editing. **Pedro Jacinto Ferreira:** Conceptualization, Methodology,

Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing. **Tatiana Mara da Silva Russo:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration. **Camila Maria Silva Paraizo-Horvath:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration. **André Aparecido da Silva Teles:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration. **Helena Megumi Sonobe:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration.

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## Public Involvement Statement

Not applicable.

## Guidelines and Standards Statement

This manuscript was drafted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement.

## Data Availability Statement

No new data were created or analyzed in this study. Data sharing is not applicable to this article.

## Use of Artificial Intelligence

Not applicable.

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## Declaration of Conflicting Interests

The authors declare no conflicts of interest.

## Disclosure Statement

The authors report there are no competing interests to declare.

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