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# PEDIATRIC ONCOLOGY NURSING PRACTICE IN LATIN AMERICA AND THE CARIBBEAN



cure **all** Americas

# PEDIATRIC ONCOLOGY NURSING PRACTICE IN LATIN AMERICA AND THE CARIBBEAN

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Pediatric oncology nursing practice in Latin America and the Caribbean

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# ACRONYMS

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<b>NCDs</b>	noncommunicable diseases
<b>PAHO</b>	Pan American Health Organization
<b>PFCC</b>	patient- and family-centered care
<b>PHC</b>	primary health care
<b>SDGs</b>	Sustainable Development Goals
<b>WHO</b>	World Health Organization



# ABSTRACT

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## *Introduction*

Cancer is one of the leading causes of death from disease in children and adolescents worldwide. In Latin America and the Caribbean, in particular, childhood and adolescent cancer care is highly heterogeneous, as health systems, resources, care processes, and health outcomes vary considerably among the different countries in the region.

This technical report has been developed within the framework of the WHO Global Initiative for Childhood Cancer. Its goal is to improve the situation of children and adolescents with cancer worldwide, giving them the best chances of survival, living a full life and, above all, enjoying quality of life and dying without suffering.

One of the main pillars of the Initiative and the CureAll Americas framework is strengthening centers of excellence and promoting training and good practices within the health workforce, especially among pediatric oncology nurses, who specialize in nursing care for children and adolescents with cancer and their families. Pediatric oncology nurse practitioners provide compassionate, non-traumatic, complex, continuous, ethical, conscious care centered on children and adolescents and their families in order to meet the physical, emotional, psychosocial, and cultural needs of the people involved.

## *Objective*

This report is aimed at health administrators, hospital managers, and professional pediatric oncology nursing groups. Its objective is to identify, systematize, and consolidate available evidence on the scope of pediatric oncology nursing practice in Latin America and the Caribbean based on essential core competencies, in order to incorporate them into clinical practice, teaching, and research.

## *Methodology*

The report preparation process included a systematic scoping review aimed at finding the best evidence for pediatric oncology nursing practice. Patient- and family-centered care and the conceptual model of competencies for teenagers and young adults with cancer, developed by the Teenage Cancer Trust with the support of the Royal College of Nursing, were used as the theoretical foundations for the systematization of the recommendations found here.

## *Results*

This publication outlines the process of creating competencies for nurses caring for adolescents and young people with cancer, based on six domains: 1) clinical and supportive care; 2) education and research; 3) engagement, advocacy, and promotion; 4) the interprofessional team and the journey of the child or adolescent with cancer and their family; 5) leadership and professional development and 6) development of health services and policies. Although designed for adolescents and young adults, the domains—areas that include a series of skills necessary for professional practice—can be extended to the skills required to care for children with cancer.

## **Conclusions**

This report compiles and systematizes recommendations to support professional pediatric oncology nursing practice in Latin America and the Caribbean, centered on caring for children and adolescents with cancer, as well as their families. It can also be used by training institutions, professional associations, professional regulatory bodies, managers, and public policymakers to help establish essential competencies for pediatric oncology nursing practice in Latin America and the Caribbean.





# INTRODUCTION

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In recent decades, the epidemiological profile of children and adolescents<sup>1</sup> across the world has been changing. In the past, this population was mainly affected by infectious and parasitic diseases. However, in recent decades, a growing number of chronic diseases (including diabetes mellitus, hypertension, respiratory diseases, and cancer) have emerged, resulting in a global disease burden that affects all countries. Causes of death have also changed. External causes are now the leading cause of death, followed by cancer, which is the leading cause of death from disease in this age group.

Noncommunicable diseases (NCDs) are the leading causes of death globally, accounting for four million deaths a year—equivalent to 71% of all deaths worldwide. Cardiovascular diseases account for most NCD deaths (17.9 million people annually), followed by cancer (9.3 million), respiratory diseases (4.1 million), and diabetes (1.5 million). These four disease groups account for over 80% of all premature NCD deaths. This mainly affects low- and middle-income countries, where 77% of NCD deaths are concentrated. Simultaneous demographic and epidemiological transitions in these countries have largely contributed to the change in the chronic disease risk profile. Most low- and middle-income countries continue to experience high NCD rates, creating a triple disease burden: (a) addressing infectious and deficiency diseases; (b) the significant burden of deaths from external causes; and (c) the predominant presence of chronic diseases (1-2).

The demographic, epidemiological, and nutrition transition process worldwide suggests that cancer burden will have a growing impact in the coming decades, with low-income countries bearing the largest part of the global burden (2). According to the World Health Organization (WHO), cancer accounted for 10 million deaths in 2020. Cancer also has a high psychosocial and economic burden, both for those suffering from it and for families and health systems. It therefore represents a major global public health issue.

Including childhood cancer as a public health priority is feasible, effective, and sustainable. It offers an important opportunity to catalyze progress in cancer management, save lives, and reduce suffering, as well as to demonstrate the success of the NCD surveillance agenda. Investing in children and adolescents and childhood cancer programs is a strategic priority for governments, as it helps to save hundreds of thousands of lives each year at a low per capita cost. In addition to the economic rationale, tackling childhood cancer should be seen as a matter of equality, human rights, and social justice.

In 2017, the World Health Assembly (1) adopted Resolution WHA70.12 on Cancer prevention and control in the context of an integrated approach. With a view to its implementation, WHO and the International Agency for Research on Cancer (IARC) worked with other UN organizations and partners to launch the WHO Global Initiative for Childhood Cancer in 2018. Its goal was to improve the situation of children and adolescents with cancer worldwide, giving them the best chances of survival, living a full life and, above all, enjoying quality of life and dying without suffering. The Global Initiative is part of the response to the World Health Assembly resolution on cancer prevention and control in the context of an integrated approach, which urges governments and WHO to accelerate measures aimed at achieving the goals specified in the Global action plan for the prevention and control of NCDs and the United Nations 2030 Agenda for Sustainable Development. This includes the agreement on 17 Sustainable Development Goals (SDGs)—including SDG 3 (good health and well-being), one of the aims of which is to reduce premature mortality from NCDs; and SDG 10 (reduce inequality within and among countries)—all in

line with achieving universal health coverage.

In this context, this report on pediatric oncology nursing practice in Latin America and the Caribbean is aimed at health administrators, hospital managers, and professional pediatric oncology nursing groups. Its objective is to identify and systematize available evidence on the scope of pediatric oncology nursing practice in Latin America and the Caribbean based on core competencies, in order to incorporate these into clinical practice, teaching, and research in hospitals in the region.

The preparation of this report included a systematic scoping review aimed at finding the best evidence for this type of clinical practice. Patient- and family-centered care and the conceptual model of competencies for teenagers and young adults with cancer, developed by the Teenage Cancer Trust with the support of the Royal College of Nursing, were used as the theoretical foundations for the systematization of the recommendations found here.

The following chapters will describe the background and objectives of the conceptual model of pediatric oncology practice in the region and, in particular, how it applies to the comprehensive care of children and adolescents with cancer. Recommendations and conclusions will also be formulated to support public childhood cancer health policies.



# 1. BACKGROUND

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## 1.1. The context of childhood cancer worldwide and in Latin America and the Caribbean

The latest report on the global cancer burden, prepared by the International Agency for Research on Cancer (IARC)—based on the GLOBOCAN 2020 estimates of cancer incidence and mortality and focusing on geographical variability in 185 countries around the world—estimated around 19.3 million new cancer cases and 10 million deaths in 2020. Notably, there is considerable variation between and within countries with respect to the most commonly diagnosed cancer and the leading cause of cancer death, depending on the level of economic development, social factors, and lifestyle (2).

Accurate data on the childhood cancer burden is crucial to planning and prioritizing health policies. Model-based estimates are needed, as many countries lack or have insufficient cancer surveillance data. Although global incidence and mortality estimates are available, little prior analysis of the global childhood cancer burden is represented in disability-adjusted life years (DALYs) (3).

Childhood and adolescent cancer belong to a group of diseases that share an uncontrolled proliferation of abnormal cells and the ability to affect any part of the body (3). Unlike adult cancer, childhood cancer tends to be embryonic in nature and mainly affects cells in the hematopoietic system and supporting tissues. In addition, childhood cancer usually has short latency periods, and is more aggressive, with accelerated growth. However, it has a good prognosis in this age group when diagnosed early and treated in specialized centers (4). Pediatric tumors account for 1–4% of all malignant tumors in most populations (3). In low- and middle-income countries, where the child population is around 50%, pediatric tumors represent 3–10% of all neoplasms (5).

Over the past four decades, significant advances have been made in the treatment of childhood cancer. Currently, around 80% of children and adolescents with cancer in high-income countries can be cured, as diagnosis is usually early and treatment is carried out at specialized centers. In low- and middle-income countries, however, children and adolescents are four times more likely to die from the disease (6). Some of the reasons for this include: difficulty accessing diagnosis and treatment; advanced stage of disease at the time of diagnosis; lack of access to affordable treatment, supportive care at referral centers, and health professionals with specialized knowledge and training; and treatment dropout due to families' inability to afford direct health care costs (4, 7). The underlying reasons for this disparity have been linked to health systems indicators, such as national annual health expenditure per capita, number of medical and nursing professionals per 1 000 people, and institutional capacity, i.e., whether there is an adequate number of qualified health professionals and supportive care resources, such as medicines and blood products (8).

Many cancer patients will continue to be diagnosed annually in the coming decades: from around 14 million patients globally per year in 2012 (9) to 21.6 million patients per year by 2030 (10-11), an expected increase of 50%. All of these patients will need timely diagnosis and optimal treatment to improve their survival. It is therefore becoming increasingly essential to ensure that national and

regional health systems effectively treat and care for these patients (12).

In Latin America, in particular, childhood and adolescent cancer care is highly heterogeneous, as health systems, resources, care processes, and health outcomes vary considerably among the different countries in the region (13). The quality of epidemiological data also varies and comparability is often limited, as most countries have little regional information on incidence, survival, and mortality. Furthermore, children and adolescents in many Latin American countries suffer from issues such as malnutrition, barriers to accessing health services, and difficulties in the care process, all of which have a negative impact on childhood cancer outcomes (14).

A particular issue in many Latin American subregions is the lack of medical professionals specializing in pediatric hematology and oncology, resulting in late diagnoses, long journeys—sometimes to other countries (15)—, and the use of non-standardized treatment protocols that negatively affect survival.

Guzman et al. (13) discuss the length of the “initial period” —which includes the periods from diagnosis to treatment— documented in the literature for Latin America, by country and type of cancer, as well as distribution according to disease stage at the time of diagnosis. The common barriers identified are closely linked to income and geographical area. These inequalities lead to difficulties accessing facilities that enable timely diagnosis and treatment, thereby prolonging this initial period (16-20). Financial and geographic distances across Latin America inhibit timely and continuous access. In remote regions of Colombia, for example, more than 80% of patients had to travel long distances to reach a specialized diagnostic center, and the time between symptom onset and diagnosis exceeded 90 days for a significant percentage of children (21). In Argentina, distance also affected access to diagnosis and treatment, as did the socioeconomic status of patients’ home province. As a result, children from less developed areas had more delayed diagnoses (16-19). In Mexico, 11% of patients diagnosed with childhood cancer had to leave their hometown, and 69% of patients treated in Mexico City came from elsewhere (24). By contrast, socioeconomic status did not affect the diagnosis and treatment of children with cancer in the city of São Paulo, Brazil (25).

The level of specialization at treatment centers has also been repeatedly documented. Children diagnosed and treated in highly specialized centers have a much higher survival rate (16, 17, 19, 22, 23).

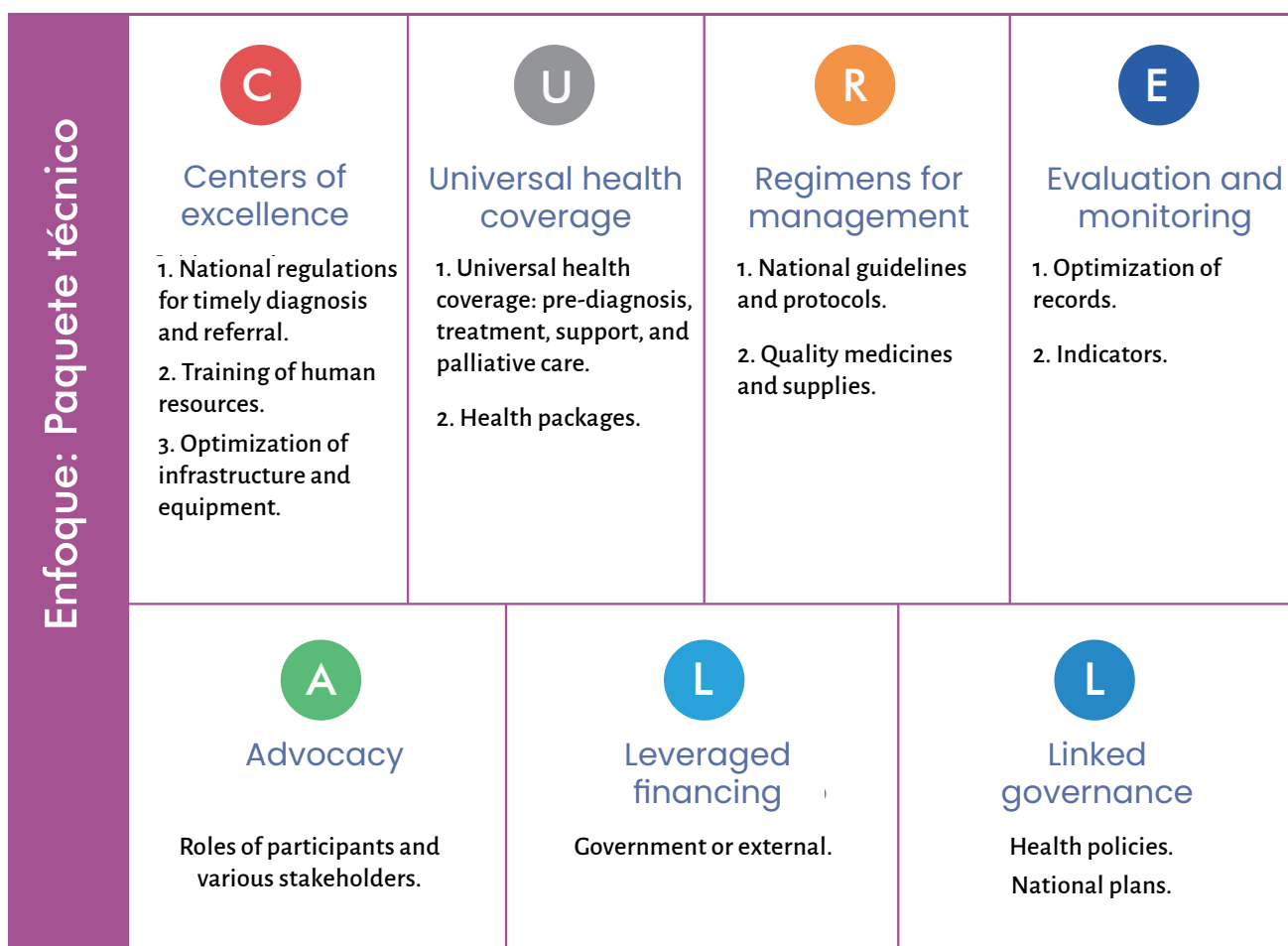
The length of time from diagnosis to treatment also depends on disease severity. In Latin America, it is not always possible to offer continuous treatment (21). Living in large cities (26, 27) reduces the odds of treatment dropout and improves survival and lifespan compared to rural areas. Having parents who are not in formal employment increases the risk of treatment dropout (26). Prior to 2010, it was reported that around 18% or more of patients had discontinued or dropped out of treatment in some Latin American countries (Colombia, Mexico, Paraguay, and Peru) (24). This situation has improved substantially in many countries, with dropout rates close to zero in parts of Brazil, El Salvador, and Paraguay, and at private centers in Colombia (15, 28-30).

The study conducted by Orozco et al. (31), on children with cancer treated at a hospital in Managua (Nicaragua), found that many patients came from remote areas and their families had few economic resources or means of transportation. As a result, by the time they arrived at the hospital, many children had advanced-stage disease, accompanied by comorbidities such as malnutrition, parasitic disease, and other infections. When the disease went into remission, some parents were also reluctant to participate in the maintenance protocols needed to complete survival therapy, blaming

these treatments for “causing disease”. Families used the adverse effects of chemotherapy to justify treatment dropout, despite explanations from the health team.

In an attempt to tackle this issue, the WHO Global Initiative for Childhood Cancer establishes a series of goals aimed at improving the situation of children and adolescents with cancer worldwide, and increasing survival rates to at least 60% by 2030. The Initiative has two objectives: increasing countries’ capacity to provide quality services, and increasing prioritization of childhood cancer at global, regional, and national levels (6). CureAll is an acronym used to identify the four main pillars and three enablers of the Global Initiative (see Figure 1).

**Figure 1.** Framework of the WHO Global Initiative for Childhood Cancer, CureAll Americas.



**Source:** World Health Organization. WHO Global Initiative for Childhood Cancer: an overview. Geneva: WHO; 2020. Available from: <https://www.who.int/docs/default-source/documents/health-topics/cancer/who-childhood-cancer-overview-booklet.pdf>

This publication presents a framework for guiding and assessing the current situation in a country or region, developing an action plan, implementing strategies, and monitoring action. The WHO Global Initiative for Childhood Cancer involves more than 100 participating organizations and hundreds of experts worldwide. The CureAll framework is based on four pillars and three enablers, as described below:

## PILLARS:

**C** Centers of excellence and service networks with specialized personnel.

.....

**U** Comprehensive universal health coverage and quality essential services.

.....

**R** Diagnostic and treatment regimens and protocols, with proposed personalized plans to help provide quality services through technologies, drugs, and evidence-based target molecular therapies.

.....

**E** Evaluation and monitoring, with robust information systems that guarantee an effective, quality implementation with constant process improvement.

## ENABLERS:

**A** Advocacy.

.....

**L** Leveraged financing.

.....

**L** Linked governance.



### 1.2. Challenges for early detection and timely diagnosis

Unlike in adult cancer, initiatives such as prevention and screening have not proven effective in childhood cancer to date, as this population has not yet been exposed to the risk factors that lead to the disease in later life. Therefore, early cancer diagnosis is a strategic factor for comprehensive child and adolescent health care, as it reduces mortality and sequelae resulting from aggressive treatment and speeds up research and diagnosis (32). However, professionals' limited capacity to detect cancer early and existing barriers in health systems mean that specialized services are often accessed only once the disease severity has become apparent (33).

WHO is supporting governments in assessing current cancer diagnosis and treatment capacities, including: the availability of medicines and technologies; defining and funding priority cancer diagnosis and treatment programs; and including childhood cancer in national strategies, health benefit packages, and social security schemes (6).

A major obstacle to the early diagnosis of childhood cancer is the non-specific nature of its signs and

symptoms, which are confused with those of other common childhood pathologies. Added to this is a lack of complete data recorded in health information systems, and insufficient logistics to organize the primary health care (PHC) work process required to absorb this high demand, leading to a longer therapeutic itinerary (34- 35).

The Brazilian Ministry of Health has proposed protocols (34) to assist health professionals in managing both suspected and confirmed cases within a line of care establishing flows and actions from PHC to highly complex care, identifying the procedures to be adopted in the event of suspected disease, as well as for diagnostic confirmation and treatment (36). All professionals on multidisciplinary and interdisciplinary PHC teams perform crucial roles in childhood and adolescent cancer care, ranging from first contact with patients showing signs and symptoms to referral and follow-up during and after treatment. PHC nurses are responsible, among other things, for identifying cancer signs and symptoms in children and adolescents, from the systematization of nursing care through the nursing process. During and after cancer diagnosis and treatment, they perform the necessary interventions and guidance in the care plan. They also act as leading professionals in carrying out person-centered plans to care for complex PHC cases (36).

PHC has some fundamental characteristics that make it a unique environment for both the early diagnosis of childhood and adolescent cancer and follow-up during treatment in specialized centers. The service should be close and easily accessible to the community, so that health issues, such as cancer symptoms, can be resolved or addressed as soon as possible. It must also provide longitudinal industry-standard care, following up the individuals and families under its responsibility before, during, and after cancer. PHC is also where the care process can be coordinated. Communication can be established with other services performing the complex tests required for diagnosis and follow-up, as well as with various specialists who may become part of the care environment (36).

### **1.3. Essential competencies of nurses caring for children and adolescents with cancer**

Despite differences between countries, there has been a marked improvement in the survival rate of children and adolescents with cancer since the 1970s. The best indicators reflect advances in therapy, diagnostics, improved supportive care (7, 37), and nursing (38). Nurses are responsible for prevention, disease control, and quality-of-life measures; therefore, they need the skills to provide care in all phases of the diagnostic-therapeutic process (diagnostic assessment, treatment, rehabilitation, and family care). Nurses caring for cancer patients need to quickly learn how to incorporate new knowledge and technologies into their daily work, which often takes place in a context where this population has multiple comorbidities (39).

Pediatric oncology is a highly specialized field requiring critical thinking and technical skills to safely deliver targeted cancer treatment regimens, supportive care, and follow-up of patient decline in the context of family-centered care (40). Pediatric oncology nursing practice also requires extensive knowledge (art and science of nursing); sound problem-solving, decision-making, and critical thinking skills; and a high degree of compassion and sensitivity towards children, adolescents, young adults, their families, and their community (41).

Due to the specific nature of the care process, there is a growing need for nursing professionals with specialized knowledge, skills, and experience to occupy positions where they can develop and supervise clinical nursing practice; guide the education and training of the health team, patients, and their families; and lead research in the nursing field (42). Nurses should seek professional development through specialization courses, improvement courses, postgraduate courses, residencies, training programs, refresher courses, and congresses to ensure familiarity with the latest scientific and technical advances. In this vein, a successful education program between Canada and Nicaragua was developed with the aim

of strengthening pediatric oncology nursing. The results showed that international collaboration was fundamental to the success of this type of program in low-income countries (31).

Krishnasamy et al. (43) argue that specialized oncology nursing practice has not been sufficiently explored to date. They based this conclusion on two studies. The first, published more than 20 years ago, described the characteristics needed for specialized oncology nursing practice (44). A phenomenological study of 38 oncology nurses in the United States of America identified the importance of supportive interpersonal relationships, communication, and commitment to care, fundamental for the development of specialist cancer nurses. The second study, which also took a qualitative approach, was conducted with a sample of 68 pediatric oncology nurse practitioners (45). It identified the ability to establish supportive interpersonal relationships and mentorships and actively integrate evidence into daily care as characteristics of specialized practice.

Krishnasamy et al. (43) determined that the inability to describe and define the characteristics of specialized nursing practice restricts the ability to aid training and development in this field, and to design robust studies that demonstrate how specialist cancer nurses impact the outcomes of patient care and health systems. On this basis, the authors conducted an exploratory and descriptive study, applying a focus group methodology and an approach based on inductive thematic data analysis. The study, involving 24 nursing professionals from an oncology center in Australia, identified seven main themes: knowledge, leadership, adaptability, communication, motivation, patient-centered care, and organization and culture. The authors concluded that many of the characteristics of the specialists identified in the study reflected traits shared with other specialty nursing groups. “Adaptability” was of particular relevance to oncology nurses, reflecting the complexity of modern cancer treatment and reaffirming Benner’s (46) definition of a nurse practitioner as one who is able to seamlessly connect knowledge and experience, applying them to the contexts of clinical practice. They emphasized that understanding the characteristics of cancer specialists can help inform and support professional practice advancement and guide future research. Identifying, systematizing, and consolidating available evidence on the skills of nurses caring for children and adolescents with cancer can therefore help to achieve the goals of the WHO Global Initiative for Childhood Cancer.

#### **1.4. Definitions**

Nurse practitioners have a higher level of training than generalists and are authorized to practice as specialists with advanced experience in a branch of the nursing field. Specialized practice includes clinical, teaching, administrative, research, and advisory roles (47-48). Specialties are certified by specialization courses taught by accredited institutions or by criteria determined by recognized scientific associations in the professional practice field.

Pediatric hematology and oncology nursing is a dynamic and evolving field, based on knowledge derived from theory, research, and practice. Pediatric nurses not only need to acquire this knowledge, but be able to apply it creatively and scientifically when caring for children, adolescents, young adults, and their families (41). From playfully encouraging a child to take their medication to saving their life using critical thinking, pediatric hematology and oncology nurses make a difference in their patients’ lives.

These professionals may work in hospital settings (inpatient and outpatient care units); in doctors’ offices; in home care services; in radiation centers; in palliative care or psychosocial support services; in chemotherapy, biotherapy, immunosuppressant, or blood product administration units; in the education sector; providing support to patients during treatment; and performing effective interventions (41).



Based on the above, and within the scope of practice, pediatric oncology nurses can be defined as professionals specializing in the nursing care of children and adolescents with cancer and their families. Pediatric oncology nurse practitioners provide compassionate, non-traumatic, complex, continuous, ethical, conscious care centered on children and adolescents and their families in order to meet the physical, emotional, psychosocial, and cultural needs of the people involved. They use evidence-based best practices in their work and are guided by their patients' best interests.

The work of pediatric oncology nurses is organized around and infiltrated by core constructs—such as evidence-based practice, nursing theories, health care science, autonomy, empowerment, work process management, and health education or literacy. The scope of their practice must be aligned with the real health needs of the patients and family members involved in this process.

The Association of Pediatric Hematology/Oncology Nursing (APHON) acknowledges the complexity of caring for children and adolescents with cancer and their families. Current challenges include: monitoring advances in science and technology; providing transitional care to survivors; establishing partnerships with cooperative groups to propose clinical trials; applying scientific evidence to advance clinical practice; implementing protocols to reduce medication errors and improve patient safety; changes in family dynamics, considering cultural diversity; changes in health systems; proposed nursing qualification projects through continuous training; regulating professional practice; and establishing standards of excellence for training institutions (41).

The concept of competencies encompasses the knowledge, skills, and attitudes supporting the delivery of appropriate, evidence-based care. It also includes safe practice in any setting across the health care continuum, and the principles of respect and preservation of dignity (49). The International Council of Nurses (ICN) regards competency as the effective combination of knowledge, skill, and judgment demonstrated by an individual in daily practice or work performance. In definitions of nursing, there is a broad consensus that, when performing these duties according to the professional standards required, competency reflects knowledge, understanding, and judgment; a set of cognitive, technical, or psychomotor and interpersonal skills; and a range of personal attributes and attitudes (47, 50). According to the ICN, nurse practitioners have a higher level of training than generalist nurses and are authorized to practice as specialists with advanced experience in a branch of the nursing field.

In a document on the essential competencies of neonatal and pediatric nurses (51), the Brazilian Society of Pediatric Nurses (SOBEP) defines professional competency as a quality or individual capacity to perform a function based on essential prerequisites (core competencies) that must be applied to neonatal and pediatric nursing, although some can be extended to other specialist nursing areas. The same document defines pediatric nurses as professionals with a degree in nursing—who have been certified after completing a *lato sensu* specialization course or a residency course in pediatric nursing, or who have obtained a specialist title from SOBEP—who provide care aimed at preventing diseases and injuries, and the promotion, protection, and recovery of the health of children and adolescents and their families.

Competencies are acquired through education and training, and are supported and monitored by the rules governing professional practice. They allow health professionals to make clinical decisions and propose appropriate measures (49). From this perspective, scope of practice is defined as a set of roles, functions, responsibilities, and activities for which a registered or licensed professional has the necessary education, competencies, and authorization. It defines the responsibility and limits of professional practice (50). Depending on the country concerned, competencies in nursing, pediatric nursing, and pediatric oncology nursing fall under different occupational categories (49).

Nursing students in both high-income and low- and middle-income countries often receive little or no pediatric oncology training. As a result, nurses hired to work in this specialty often enter practice with

little knowledge about how to care for children and adolescents with cancer, whose care needs are unique and complex. High-quality nursing care is essential to achieve the best possible outcomes for patients worldwide; in order to improve these outcomes, it is essential to measure and evaluate factors influencing the quality of pediatric oncology nursing care (40).

## **1.5. Objective**

The objective of this publication is to identify, systematize, and consolidate available evidence on the scope of pediatric oncology nursing practice in Latin America and the Caribbean from the perspective of essential core competencies, in order to incorporate them into clinical practice, teaching, and research. To achieve this objective, we will use the scoping review methodology described in Annex 2.



## 2. RECOMMENDATIONS FOR CLINICAL PRACTICE AND EDUCATIONAL INSTITUTIONS

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The essential competencies for pediatric oncology nursing practice in Latin America and the Caribbean were established based on a scoping review. The theoretical structure guiding the development process is presented below.

### 2.1. Theoretical foundations

The patient- and family-centered care (PFCC) model—a widely used and globally recognized framework (52–54), enabling interaction between the different facets of pediatric oncology nursing practice—was used as the theoretical foundation for the scope of this practice in Latin America.

Patient- and family-centered care is a model for health care planning, delivery, and evaluation whose core principles include mutually beneficial partnerships between health professionals, patients, and families. The model ensures that pediatric care is planned to consider and involve the whole family, not just the patient. In it, all family members are recognized as care recipients (52). Cancer patients and their families have the right to family-centered care, incorporating the developmental needs of each member and respecting family resources and different coping mechanisms.

The model redefines health care relationships, prioritizing collaboration between people from different age groups, at different levels of care, in different health contexts. In PFCC, patients and their families define the family members and determine how each member participates in the care and decision-making process. This approach recognizes that patients and their families are key partners in improving the quality of health care. In addition, patient and family safety initiatives, health professional training, research, facility design and architecture, and health policy-making are all elements that lead to better outcomes, an improved patient and family care experience, greater satisfaction among the health workforce, and smarter resource allocation (53).

In 1992, the US Institute for Patient- and Family-Centered Care was created, with the aim of organizing, managing, planning, and implementing measures to promote PFCC in different health care areas for children and adolescents and their families (52). Nine elements were defined and have come to characterize the distinctive features of PFCC: 1) recognizing the family as a constant in the lives of children and adolescents; 2) facilitating collaboration between parents and professionals at all levels of health care; 3) respecting the racial, ethnic, cultural, and socioeconomic diversity of families; 4) recognizing the strengths and uniqueness of each family and respecting different coping methods; 5) sharing complete and unbiased information with the family on a regular basis; 6) encouraging and facilitating support and networking among families; 7) responding to the developmental needs of children and adolescents and their families as part of health care practices; 8) adopting policies and practices that promote emotional and financial support for families; and 9) developing a care plan that is flexible, culturally compatible, and meets family demands (52).

Based on these principles, the Institute for Patient- and Family-Centered Care systematized the fundamental bases of the model into four constructs:

1. Dignity and respect: the health care team must listen to and honor patient and family decisions and incorporate their beliefs, values, and cultural context into the planning and delivery of care.
2. Information sharing: share complete and unbiased information on the disease with patients and their families in ways that are affirmative and useful.
3. Participation: patients and their families must be encouraged and supported to participate in care and decision-making processes at the level they choose.
4. Collaboration: patients, families, and health professionals must collaborate in developing, implementing, and evaluating policies and programs; designing health care facilities; professional education; and delivering care (53, 55).

Evidence shows that the patient- and family-centered care model benefits everyone involved (patients, families, and health professionals), as it aims to improve health outcomes—such as decreasing health care and health system costs; more efficient resource allocation; reducing errors and processes; greater patient, family, and professional satisfaction; greater patient and family self-efficacy; and better health education (56-57). However, despite the potential advantages of the model, researchers continue to question why PFCC has not been successfully implemented in different countries and health services (54, 58).

The principles of patient-centered care described are comparable to the World Health Organization Framework on integrated people-centered health services. This model defines people-centered care as an approach to care that consciously adopts the perspectives of individuals, caregivers, families, and communities as participants and beneficiaries of health systems. These, in turn, are organized around the integral needs of individuals rather than around individual diseases. People-centered care requires patients to have the education, information, and support they need to make the best decisions and participate in their own care and caregivers to be able to perform their role to the best of their ability within a supportive home environment (59).

The publication “Competencies: Caring for teenagers and young adults with cancer: a competence and career framework for nursing”, produced by the Teenage Cancer Trust with the support of the Royal College of Nursing (60), was also used as a theoretical foundation. This paper outlines the process of developing competencies for nurses caring for adolescents and young people with cancer, based on six domains: 1) clinical and supportive care; 2) education and research; 3) engagement, advocacy, and promotion; 4) the interprofessional team and the journey of the child or adolescent with cancer and their family; 5) leadership and professional development; and 6) development of health policies and services. Although designed for adolescents and young adults, the domains —areas that include a series of skills necessary for professional practice (51)— can be extended to the skills required for caring for children with cancer.

The paper (60) emphasizes that the model should be used as a tool to help nurses develop their practice. It can also help management assess the competency of its workforce and provide a road map

for succession planning and role development. The model covers a wide range of specific skills needed by nurses working with adolescents and young adults in all health care settings. Due to this scope and flexibility, it presents characteristics relevant to pediatric oncology nursing practice, including in Latin America and the Caribbean.

Joining the two theoretical frameworks brings together children, adolescents, and their families and the delivery of comprehensive, holistic, and humanized health care. Broad similarities between the two models were evident, such as the premise of personalized care, based on the needs and perspectives of children and adolescents and their families. Families are considered unique; therefore, they require an individualized care plan adapted to their characteristics. Professionals must accompany them, adopt their points of view, and try to understand how the disease and its treatment affects their lives.

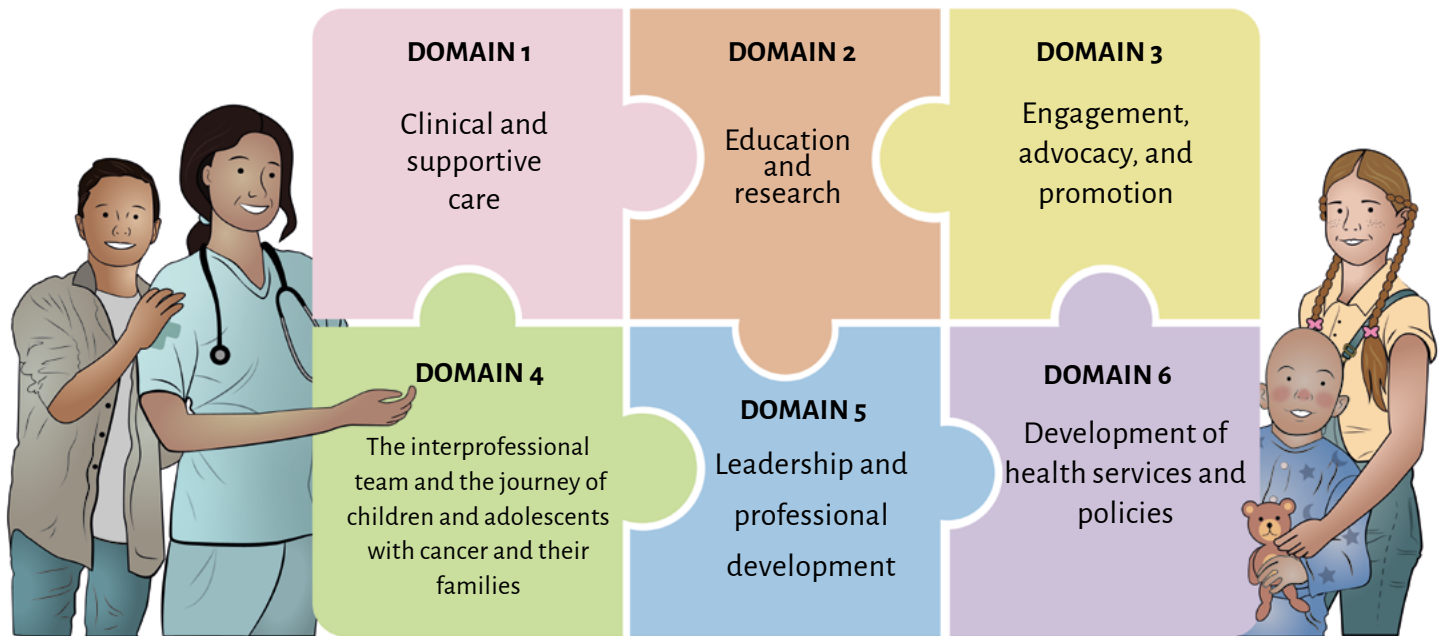
By placing people at the center of care, both models highlight the need to find out people's perspectives, how they think, and how they evolve. They highlight communication as an important pillar of professional practice, emphasizing interpersonal, assertive, and truthful relationships as essential to establishing bonds and trust. The ethical issues of care and research development are crucial.

It is also important to invite the family to participate and get involved in the child's care, and to respect the family's decisions, in particular the self-assessment of their preparedness to accept this challenge, join the team, and share responsibility in the care process. Both the exchange of information within the interprofessional team and shared management are essential to clarify processes and ensure that the family is comfortable with the decisions made. This is aligned with the principle of advocacy and health promotion—both in terms of the family's participation and involvement on behalf of their children, and the role of nurses in advocating for patients on their journey—in order to improve patients' clinical condition and promote a dignified quality of life. Another area of common ground is the need to consider beliefs, values, and culture at different moments in the care process.

Finally, it is worth noting that the theoretical foundations are also in line with the guidance of the WHO Global Initiative for Childhood Cancer (6) regarding the need for centers of excellence and service networks with a specialized workforce. Equipping staff with the necessary skills and complying with the objectives of the International Society of Paediatric Oncology Strategy 2021-2025 (61) is considered essential. These objectives are: 1) advocating for children and adolescents with cancer worldwide; 2) promoting research to improve outcomes for cancer patients; 3) providing education and training; 4) increasing membership and engagement; and (5) strengthening and expanding strategic partnerships. These objectives are in line with the theoretical frameworks adopted here to formulate recommendations on the scope of pediatric oncology nursing practice.

## 2.2. Essential competencies and skills of pediatric oncology nurses in Latin America and the Caribbean

The following is a summary of the essential competencies and skills of pediatric oncology nurses based on the results of the scoping review (Tables 1 to 6).



● **Table 1.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: clinical and supportive care

Objective	Competency
To apply knowledge and understand the guiding principles of care centered on children and adolescents with cancer and undergoing cancer treatment, as well as their families.	- Recognizes children, adolescents, and their families as a single comprehensive care unit.
To apply knowledge related to the growth and development stages of children and adolescents.	- Recognizes the specific aspects of patient growth and development over the disease course.
To consider communication as one of the core elements of the relationship with children, adolescents, and their families, incorporating the best communication strategies, in order to promote health literacy and the participation of all those involved.	- Establishes interpersonal relationships and communicates with the patient, family, and interprofessional team in order to promote compliance with the therapeutic plan and foster the bond between family, patient, and team.  - Promotes clear and effective communication in educational processes, helping to build health knowledge.

Objective	Competency
To act responsibly in accordance with legislation and professional codes of conduct when advocating for patients' rights.	<ul style="list-style-type: none"> <li>- Develops clinical practice based on professional ethics and the recognition of individual rights.</li> </ul>
To identify cancer symptoms in children and adolescents with cancer, and intervene effectively in their treatment.	<ul style="list-style-type: none"> <li>- Knows how to define, evaluate, and treat cancer symptoms.</li> <li>- Acts to identify and measure cancer symptoms.</li> <li>- Develops personalized interventions to manage cancer symptoms.</li> </ul>
To manage and deliver safe, quality care to children and adolescents with cancer, and their families, during treatment.	<ul style="list-style-type: none"> <li>- Demonstrates technical competency and mastery of the specific aspects of caring for children and adolescents with cancer.</li> <li>- Demonstrates technical competency and mastery of the specific aspects of caring for children and adolescents with cancer undergoing radiotherapy.</li> </ul>
To promote access to complementary therapies in the interests of comprehensive and humanized care.	<ul style="list-style-type: none"> <li>- Knows about and promotes complementary therapies.</li> </ul>
To recognize and act in pediatric oncology emergencies.	<ul style="list-style-type: none"> <li>- Demonstrates technical/scientific competency and mastery of the specific aspects of pediatric oncology emergencies.</li> </ul>
To act and deliver personalized nursing care in the era of precision medicine.	<ul style="list-style-type: none"> <li>- Provides personalized pediatric oncology nursing care in the era of precision medicine.</li> </ul>
To apply knowledge related to treatment sequelae or late effects and childhood cancer survival.	<ul style="list-style-type: none"> <li>- Ensures survivors' quality of life.</li> </ul>
To understand the principles governing the processes of death and mourning, and apply related knowledge.	<ul style="list-style-type: none"> <li>- Promotes palliative care.</li> </ul>
To promote the systematization of nursing care for children and adolescents and their families.	<ul style="list-style-type: none"> <li>- Uses the stages of the nursing process to implement and promote specialized care.</li> </ul>

● **Table 2.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: education and research

Objective	Competency
To carry out continuous health education activities, using different approaches, strategies, and technologies to ensure a more effective exchange of information within the team.	<ul style="list-style-type: none"> <li>- Promotes continuous health education activities within the nursing team.</li> </ul>
To help develop health services for children and adolescents with cancer and their families, in collaboration with other services in the health care network.	<ul style="list-style-type: none"> <li>- Gets involved in network education projects, focusing on caring for children and adolescents and their families.</li> </ul>
To understand the importance of adopting an evidence-based approach to nursing practice when caring for children and adolescents with cancer and their families.	<ul style="list-style-type: none"> <li>- Applies evidence-based practice.</li> </ul>
To help develop good clinical research practice in pediatric oncology.	<ul style="list-style-type: none"> <li>- Coordinates clinical trials.</li> <li>- Conducts clinical research activities, considering ethical and legal aspects.</li> </ul>

● **Table 3.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: engagement, advocacy, and promotion

Objective	Competency
To ensure the participation of children, adolescents, and their families, by asking their opinion on the delivery of services and improvements in care.	<ul style="list-style-type: none"> <li>- Considers the opinion and knowledge of each person, identifying, discussing, and searching for the best solutions.</li> </ul>
To provide support for self-care.	<ul style="list-style-type: none"> <li>- Provides support for self-care in order to achieve the best patient outcomes.</li> </ul>



- **Table 4.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: the interprofessional team and the journey of children and adolescents with cancer and their families

Objective	Competency
To act as a member of the interdisciplinary team participating in case report meetings.	- Forms part of the interdisciplinary team, whose purpose is to provide the services needed to comprehensively care for children, adolescents, and their families.
To guarantee access to the health services network during the journey of children and adolescents with cancer and their families.	- Works on designing and implementing the patient's and family's journey in the pediatric oncology service network.

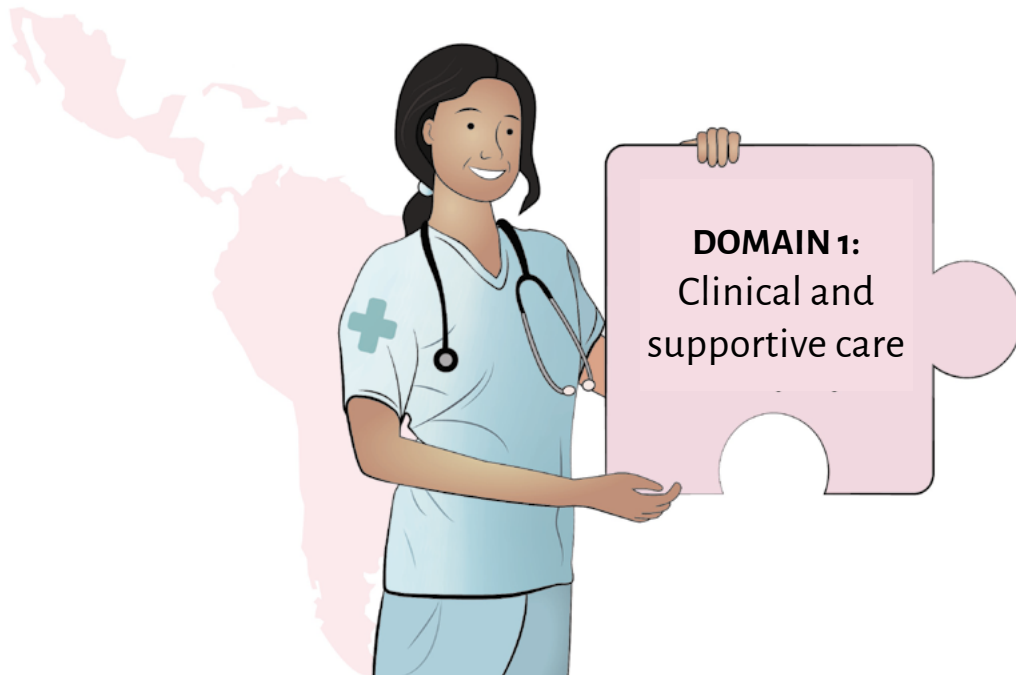
- **Table 5.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: leadership and personal development

Objective	Competency
To demonstrate personal and professional leadership qualities, positively influencing the care process and demonstrating commitment to the personal and professional development of other team members.	- Performs the role of team leader to achieve common goals, encouraging others to take initiative. - Values the team's professional development within pediatric oncology health services.
To demonstrate resilience and emotional intelligence when faced with the demands of the pediatric oncology nursing work process.	- Demonstrates resilience and emotional intelligence when caring for children and adolescents with cancer and their families.

- **Table 6.** Essential competencies of pediatric oncology nursing in Latin America and the Caribbean: development of health services and policies

Objective	Competency
To participate in developing pediatric oncology health policies, considering the social determinants of health in the health-disease-care process, with the aim of reducing childhood cancer morbidity and mortality and improving quality of life.	- Participates in discussions aimed at developing policies to improve services and work processes, and in the implementation thereof.

Below, we present more information on the essential domains, competencies, and skills of pediatric oncology nurses.



- Demonstrates and applies specific nursing skills and knowledge in order to meet the complex needs of children and adolescents with cancer using an individualized care plan centered on physical, psychosocial, spiritual, and cultural aspects throughout the disease course.
- Advocates for the individual rights of children and adolescents and their families.
- Recognizes that pediatric oncology nursing requires specialized knowledge to address the complexities of childhood, adolescence, and family life; the impact of cancer and its treatments on the lives of this population; and survival and the processes of loss and grief.

### **1A) Understand and apply the guiding principles of care centered on children, adolescents, and families experiencing cancer and receiving cancer treatment.**

#### **Competency**

Recognizes children and adolescents and their families as a comprehensive care unit.

#### **Skills**

- Demonstrates knowledge about the disease course, including the psychosocial aspects of cancer, and cultural and spiritual influences on patient responses to the disease, as well as those of caregivers, family, and social supports (62–65).
- Demonstrates an ability to conduct patient- and family-centered care assessments during all stages of cancer patient care, from prevention to end of life (65–67).
- Recognizes that each cancer patient's experience is unique and there is a need for an individualized, comprehensive, and holistic approach when developing the care plan (64- 65).
- Provides psychosocial support to children and adolescents and their families (68- 69).
- Establishes relationships of trust with parents of children and adolescents with cancer (70).

- Guides decisions according to the patient's objectives and concerns, considering each family's context, cultural values, and dynamics (71).
- Encourages healthy siblings to visit ill siblings in hospital (71).
- Encourages parents to consider requesting sick leave or family leave from work, if possible (70).
- Encourages parents to maintain discipline in ill and healthy children (69).
- Encourages parents to live each day with their healthy children (70).
- Encourages parents to have time alone as a couple on a routine basis (70).
- Encourages families to spend time together and to value it (70).
- Reassures families in their decisions (e.g., explaining that whatever decision they make is the best one for them) (70, 72).
- Supports families in continuing relationships and maintaining safe daily life (73).
- Helps families to advise healthy siblings about the situation of ill siblings and changes in care goals (70).
- Offers suggestions for involving healthy siblings in caring for ill siblings (e.g., reading them a story, helping with food, helping them choose clothes) (70).
- Assesses the ability of patients and their families to cope with the disease and adopt new health behaviors (74).
- Participates in and supports the family at the time of diagnosis (73).
- Develops accessible, compassionate, and honest relational care (67, 73, 75).
- Develops an intuitive and reflective practice, and uses empathy to understand what an experience means to children, adolescents, and their families (75).

## **1B) Apply knowledge related to the growth and development stages of children and adolescents.**

### **Competency**

Recognizes the specific aspects of patient growth and development over the disease course.

### **Skills**

- Knows the theories guiding the growth and development process, and evaluates the physical, cognitive, emotional, and social aspects (62).
- Monitors growth and development using quantitative parameters and measurement scales (51).
- Refers cases requiring interventions under the competency of other health professionals (51).
- Demonstrates knowledge about language development and cognition at different stages of the life course (62, 76).
- Encourages children and adolescents with cancer to attend school (hospital classes or regular school) as much as possible and as soon as possible. Participating for short periods or attending school sporadically can facilitate their inclusion in social networks

and increase the feeling of continuing with the “work of childhood and adolescence” (70).

- Converses openly and offers a private space to talk about individual developmental needs (e.g., education on adolescent sexuality, tobacco, alcohol, and drug use) (71).
- Promotes and encourages free play in any care setting, enabling environments that facilitate age-appropriate play (51).
- Recognizes and seeks to alleviate difficult emotions through creative care that includes art and play (63).

**1C) Consider communication as one of the core elements of the relationship with children, adolescents, and their families, incorporating the best communication strategies, in order to promote health literacy and the participation of all those involved.**

**Competency**

Establishes interpersonal relationships and communicates with the patient, family, and multidisciplinary health team in order to promote compliance with the therapeutic plan and foster bonds between family, patient, and team.

**Skills**

- Demonstrates knowledge and communicates effectively, considering the different stages of child and adolescent development, adapting interventions to the age group’s level of understanding (62, 70, 76).
- Explores what the child, adolescent, and family already know (70).
- Uses resources to communicate with the patient, such as creative interventions using art, music, and therapeutic play (62, 63).
- Conveys clear information about health care to ethnically diverse groups through a variety of media (68, 70, 72, 77-78).
- Demonstrates an ability to incorporate communication strategies when discussing cancer-specific information with patients and their families to improve health literacy and improve access, understanding, and use of health information (65, 78).
- Makes use of information and communication technologies to provide remote services, communicating through telehealth platforms or another virtual environment (79).
- Establishes an open dialogue with families, considering them as team members, respecting their traditional beliefs, and creating an environment where they feel comfortable communicating (68, 70, 78).
- Knows and makes use of cultural care in a conscious and sensitive way, understanding that health professionals will not always know how to communicate difficult news to individuals or the family. For example, some important family members (such as grandparents) may be allowed to give more sensitive information (68).

## Competency

Promotes clear and effective communication in educational processes, helping to build health knowledge.

## Skills

- Develops active listening and nonverbal communication (67, 71, 74).
- Considers the opinions of children or adolescents in the care process (71).
- Reviews the information provided, setting aside sufficient time to consider decisions. Encourages questions around lingering doubts, concerns, or needs that have not yet been addressed (71).
- Uses colloquial language, incorporating humor and play in a developmentally appropriate manner (70).
- Provides appropriate and timely education to patients, families, and caregivers to facilitate understanding and support informed decision-making (63, 72).
- Considers providing information to the child or adolescent first, when appropriate (71).
- Demonstrates an ability to incorporate communication strategies during the grieving process in order to construct meaning for patients and their families (65).
- Uses simple language, avoids jargon or acronyms, and reinforces information using various methods of communication (e.g., pamphlets, brochures, videos, etc.) (71).
- Provides information about procedures as soon as possible, so that the child or adolescent has as much time as possible to process the information, ask questions, and prepare mentally (71).
- Discusses fears or uncertainties, in particular, about managing pain and other symptoms, and provides assurances regarding available supportive therapies to maximize comfort (71, 80).
- Assesses the educational needs of each patient and records them in their medical record (80).
- Offers health education to patients and their families, including topics on the safe use of medications and nutritional guidance (80).
- Plans and uses methods with appropriate language for patient and family education, considering their values and preferences, and for sufficient interaction with the team, so that meaningful learning can take place (80).
- Communicates so that the family understands the course of treatment in response to physical, emotional, and social needs (62, 73, 78).
- Demonstrates interpersonal communication skills enabling the effective exchange of ideas and information with patients, families, and health professionals at all levels. This includes writing, speaking, and listening skills (72).
- Assesses the educational needs of patients, families, and caregivers, considering barriers to care (e.g., literacy, language, cultural influences, comorbidities) (72).

- Provides and reinforces education to patients, families, and caregivers about diagnosis, treatment options, managing side effects and aftercare, care, and survival (e.g., survival care plan, treatment summary) (72,78).
- Guides and educates patients, families, and caregivers about the cancer health care system, the roles of interprofessional team members, and available resources (72).
- Educates and reinforces the importance of patient, family member, and caregiver compliance with treatment schedules, protocols, and follow-up (72).
- Obtains or develops cancer-related educational materials for patients, staff, and community members (72).
- Provides education and resources to facilitate decision-making and timely access to quality medical and psychosocial care at all stages of cancer treatment (72, 78).

### **1D) Act responsibly in accordance with legislation and professional codes of conduct when advocating for patients' rights.**

#### **Competency**

Develops clinical practice based on professional ethics and the recognition of individual rights.

#### **Skills**

- Knows the rules of conduct and legal and ethical foundations of pediatric oncology nursing (51).
- Recognizes, protects, and helps to realize the rights of children, adolescents, and families (51, 72).
- Respects and promotes the autonomy of children and adolescents and their families (51).
- Uses ethical knowledge to guide behavior in support of children and adolescents and their families (51, 64).
- Reconciles technological care with the values associated with ethical-relational care, i.e., sensitivity and affection (being close; comforting; protecting; and respecting dignity, integrity, and autonomy) (51).
- Addresses legal issues related to cancer treatment, such as the administration of chemotherapy and hemotherapy (76).
- Considers interprofessional ethics when promoting an understanding of complex issues and building effective evaluation processes to improve cancer treatment (65).
- Helps to ensure that, following diagnosis, treatment is initiated in a timely manner, in accordance with government policies in the respective country (36).
- Applies knowledge and understanding of professional boundaries and ethical dilemmas that arise in the care of children and adolescents and their families (71).
- Provides honest answers to questions asked by children and adolescents with cancer, as well as by their healthy siblings (70, 71).
- Considers confidentiality requests from parents, and respectfully explores the concerns and values of children and adolescents and their families (71).

- Adapts clinical care to the needs of patients in each care setting, complying with the principles of competencies defined by professional regulatory bodies (81).
- Promotes a patient- and family-centered care environment for ethical decision-making in support of cancer patients (72).
- Complies with established regulations regarding patient information and privacy (72).
- Properly identifies, reports, and records cases of unsafe practices and professional misconduct (51).
- Considers the opinion of children and adolescents, based on their perspectives and respecting their preferences (72).

**1E) Identify symptom clusters presented by children and adolescents with cancer throughout the disease course, and intervene effectively in their treatment.**

**Competency**

Knows how to define and evaluate cancer symptom clusters.

**Skills**

- Establishes a common conceptual framework and approach for assessing the measurement of symptom clusters (82-83).
- Carries out personalized assessments, interventions, and outcome measures for symptom clusters that evolve over the disease course (82-84).
- Assesses the mechanisms underlying symptom clusters, including, but not limited to: a) immune system inflammation, b) sympathetic nervous system activation, c) hypothalamic-pituitary-adrenal axis activation, and d) central nervous system changes (82-86).
- Determines the best methods for assessing biobehavioral mechanisms for concomitant symptom clusters (82-83, 85-86).

**Competency**

Helps to identify and measure cancer symptom clusters.

**Skills**

- Uses qualitative and quantitative methods to identify and measure cancer symptom clusters using validated scales (69).
- Develops a common dataset to collect elements and assess data comparability through cancer symptom cluster findings (82-83).
- Uses validated and reliable quantitative tools to measure outcomes related to symptom clusters in pediatric oncology (82-83).
- Analyzes data on cancer symptom clusters from mid-range nursing theories (82-83, 85, 87).

## Competency

Develops interventions to manage cancer symptom clusters.

## Skills

- Proposes the most effective interventions for various symptom clusters and determines the most appropriate outcome with which to study the intervention against symptom clusters, basing the type of intervention on tumor type, frequency, dose, and follow-up (82-83, 87).

## **1F) Manage and deliver safe, quality care to children and adolescents and their families, considering them as an integral part of the specific clinical context of the cancer and its treatment.**

## Competency

Demonstrates technical competency and mastery of the specific aspects of caring for children and adolescents with cancer who are undergoing chemotherapy.

## Skills

- Is familiar with cancer terminology, common cancers, and their routine treatments, disease variations associated with specific prevention strategies, diagnosis and treatment options, and cancer-related genes in hereditary cancers, as well as best practices combined with scope of practice (65, 88-89).
- Recognizes the interaction of genetic, environmental, and behavioral factors in cancer predisposition, cancer onset, response to treatment, and health maintenance, and demonstrates sensitivity to mitigate stigma and understand supporting theories (65, 88- 89).
- Understands the components of the immune system, the process of hematopoiesis, and agents' interaction with other elements of the immune system (76).
- Demonstrates knowledge about the symptoms and effects of chemotherapy, including specific information about medications, side effects, toxicity, and safe handling (62, 88- 89).
- Participates in clinical evaluation and immediately identifies adverse effects of chemotherapy and biotherapy (62, 72, 88-89).
- Acts to control toxicity, symptoms, and late effects (62, 88-89).
- Helps to treat nausea and vomiting (62, 88- 89).
- Acts safely when administering chemotherapy, considering the use of personal protective equipment, the risks of occupational exposure, and safe handling and disposal practice (62, 76, 88-90).
- Administers antineoplastic chemotherapy according to drug pharmacokinetics and therapeutic protocol (88- 89).
- Promotes and disseminates risk and health prevention measures through patient and family education, with the aim of improving the patient's quality of life (88-89).



- Knows the drugs and their characteristics: dilution, conservation, stability, incompatibilities, and photosensitivity, as well as infusion speed and time (88-89).
- Checks the laboratory tests of the child or adolescent before starting the chemotherapy administration procedure (88-89).
- Knows about care in chemotherapy extravasation and when administering vesicant and irritant drugs (88-90).
- Is familiar with and performs primary nursing care with tunneled and non-tunneled central catheters: dressing, heparinization (closed system), and cap change (88-89).
- Handles, uses, and administers blood and blood products in accordance with institutional policy and procedures (80, 88-89).
- Acts to combat pain relief through patient evaluation and effective treatment (67, 80).
- Proposes and develops chemotherapy training programs for the team (88-89).
- Develops and applies nursing protocols for the prevention, treatment, or mitigation of side effects in children and adolescents undergoing cancer treatment, considering the specific characteristics of the child or adolescent and their family (8- 89).
- Develops and introduces technical operating manuals on chemotherapy procedures for nursing staff (88-89).

### **Competency**

Demonstrates technical competency and mastery of the specific aspects of caring for children and adolescents with cancer who are undergoing radiotherapy.

### **Skills**

- Knows the patient's medical record and radiation site (88-89).
- Identifies, recognizes, and provides nursing care, guiding treatment, preventing complications, and mitigating side effects, such as cancer-related fatigue, loss of appetite, skin reactions, mucositis, nausea and vomiting, diarrhea, and alopecia, depending on the irradiated site (88-89).
- Identifies and recognizes skin damage, and advises patients and families during the nursing visit (88-89).

## **1G) Promote access to complementary therapies in the interests of comprehensive and humanized care.**

### **Competency**

Is familiar with and promotes complementary therapies.

### **Skills**

- Understands the concept and context of the use of complementary therapies, including risk indicators, options, and self-management (65).
- Establishes culturally appropriate and evidence-based care models based on the specific

needs of patients and their families, context, history, and health system (91).

- Participates in the family counseling process with a non-judgmental approach, establishing spaces for dialogue on belief systems, concerns, and risks or benefits, involving all actors in the decision-making process (86, 91).
- Designs comprehensive care plans—which can be established a priori with all actors actively involved in their design and execution—in order to ensure the timely delivery of care so that clinical outcomes are not diminished (91).
- Proposes educational approaches, such as two-way initiatives targeting traditional or complementary health care providers, conventional medical professionals, and families, in order to inform decision-making (91-92).
- Conducts and participates in clinical and translational research, with the aim of successfully integrating complementary and traditional therapies into childhood cancer treatment (87, 91).

## **1H) Recognize pediatric oncology emergencies, and act when they arise.**

### **Competency**

Demonstrates technical-scientific competency and mastery of the specific aspects of pediatric oncology emergencies.

### **Skills**

- Identifies and recognizes the most common complications of chemotherapy treatment related to infectious pathologies (febrile neutropenia, fungal infection) (88-89).
- Identifies signs and symptoms and provides nursing care for emergencies requiring immediate intervention (superior vena cava syndrome; acute spinal cord compression, intracranial hypertension, hyperleukocytosis; ATRA (all-trans retinoic acid) syndrome; tumor lysis syndrome, hypercalcemia) (88-89).
- Provides resuscitation care, in accordance with institutional standard operating procedures (80, 88-89).

## **1I) Act and deliver personalized nursing care in the era of precision medicine.**

### **Competency**

Provides personalized pediatric oncology nursing care in the era of precision medicine.

### **Skills**

- Integrates new evidence-based genetic and genomic information into pediatric oncology nursing practice (87, 93-95).
- Understands the basic concepts of genetics and genomics, patterns of inheritance and variation, gene-environment interactions, and how these factors influence disease development (93-95).

- Understands the relationship of genetics and genomics with health, prevention, detection, diagnosis, prognosis, treatment selection, and monitoring of treatment efficacy (93-95).
- Demonstrates an ability to identify family history in at least three generations and constructs a family history pedigree using appropriate terminology and symbols, considering genetic, environmental, and genomic risks (65, 93-95).
- Knows about genetic technologies and advances, as well as their effects on medical care, treatments, and outcomes (93-95).
- Analyzes the influence of genetic and genomic factors on health promotion, disease prevention, and treatment options (93-95).
- Recognizes patients who could benefit from genetic services and the possibility of referring them to these services based on their family history and genetic, environmental, behavioral, cultural, and ethnic risk factors (93-95).
- Identifies ethical, legal, and social implications related to genetic information, testing, and technologies (93-95).
- Understands the psychosocial effects of genetic information on individuals and families (93-95).
- Designs a care plan that incorporates genetic and genomic information to improve patient outcomes (93-95).
- Evaluates the impact and effectiveness of information, technology, interventions, and genetic or genomic treatment on the patient (93-95).
- Advocates on patients' behalf for access to genetic or genomic services, including support for autonomous and informed decision-making (93-95).
- Advocates for patients to receive genetic education prior to genetic testing, counseling, and informed consent, as well as decisive communication following the test and the development of an individualized plan based on the result and according to a risk assessment (93-95).
- Promotes an interprofessional health approach to provide comprehensive and individualized genomic care (93-95).
- Promotes the use and collection of family history, psychosocial factors, and patient care data, as well as record keeping (93-95).
- Creates content with accurate and understandable information, and patient education tools on the era of precision medicine, in order to empower patients and inform the general population (87, 94, 96).
- Integrates knowledge of precision medicine interventions into patient care workflows in a useful and safe way so that patients can make informed decisions about their care (87, 94).
- Supports participation in international professional nursing alliances with robust genomic clinical practice frameworks to apply omics medicine and precision medicine (87, 94, 96).

## **1J) Apply knowledge related to treatment sequelae or after-effects and childhood cancer survival.**

### **Competency**

Provides care that enhances survivors' quality of life.

### **Skills**

- Understands the most common after-effects of survival-related treatments, including physical side effects, comorbidities, need for screening and surveillance, uncertainty about cancer recurrence, impact on fertility and sexuality, self-care, relationships with family and friends, spirituality, and family economic hardship due to cancer treatment (65).
- Is able to support cancer survivors and their families and caregivers—effectively, mindfully, and compassionately—as they cope with daily life, including lifestyle, school, sexual relationships, and adolescent fertility and intimacy issues (65).
- Establishes a follow-up plan, in collaboration with the patient and family, according to guidelines and protocols for late effects and survival-related care (97).
- Helps to deliver education programs for health professionals focusing on after-effects and survival-related care (97).
- Uses validated tools to assess and identify the effects and consequences of disease and treatment on quality of life (74).
- Considers the consequences of the disease on the lives of children and adolescents and their families, in addition to broadly and comprehensively addressing psychosocial issues (74-75).
- Looks for strategies to educate survivors to make healthy decisions, adopt health-promoting behaviors, and remain in follow-up over time (66).
- Explores and uses technologies available on social media to provide necessary health information and support for childhood cancer survivors (66).
- Promotes transitional care that prepares for the shift from illness to wellness as patients progress toward long-term follow-up (66, 72).

## **1K) Apply knowledge and understand the principles governing the dying process for children, adolescents, families, and others.**

### **Competency**

Promotes palliative care.

### **Skills**

- Promotes care aimed at relieving pain and other symptoms (63, 67).
- Promotes a palliative care-centered approach to symptom management, nutrition, mobility, and quality of life (65).

- Recognizes the impact of culture and diversity on the issue of cancer and its threatening nature (65).
- Appropriates knowledge about the dying process and proposes interventions for patients, families, communities, friends, and teams (65).
- Helps children and adolescents and their families with issues related to palliative and end-of-life care, based on bioethics principles (72).

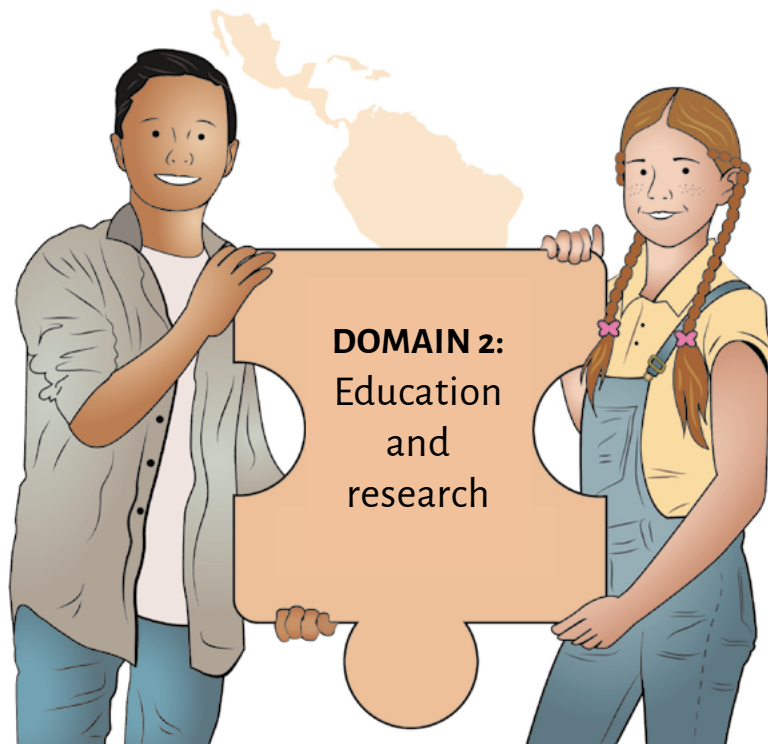
## **1L) Promote the systematization of nursing care for children and adolescents and their families.**

### **Competency**

Uses the stages of the nursing process to implement and promote skilled care.

### **Skills**

- Systematizes nursing care considering: a) nursing history (data collection and physical examination); b) nursing diagnosis; c) care planning; d) care delivery; and e) assessment of nursing care (74, 80).
- Incorporates the cultural preferences, values, beliefs, and health behaviors of children and adolescents with cancer and their families into the care management plan (80, 88-89, 98).
- Records the systematization of nursing care in the patient's medical record (80, 88-89, 98).
- Reassesses the patient and the proposed care measures at appropriate intervals to continue or update the care plan, in collaboration with the interdisciplinary team (80, 88-89, 98).
- Uses specific and validated tools to assess the needs of children and their families (80, 88-89, 98).



Provides evidence-based care to children and adolescents with cancer and their families. This practice supports the advancement of nursing research and childhood and adolescent cancer care services, promoting local, regional, and national development through collaborative work. This approach determines how evidence shapes nursing practice, as well as the development of services for children, adolescents, and families living through cancer. It also includes participation in continuous health education activities.

**2A) Carry out continuous health education activities, using different approaches, strategies, and technologies to ensure a more effective exchange of information within the team.**

### **Competency**

Promotes continuous health education activities within the nursing team.

### **Skills**

- Demonstrates an ability to use educator skills to deliver education and training to nurses, other health professionals, and students (42, 65).
- Seeks to understand adult teaching and learning strategies (62).
- Assesses the team's teaching and learning process (62).
- Implements comprehensive training programs for nursing professionals based on the systematic assessment of face-to-face or online learning needs (66, 80, 88-89).
- Seeks to ensure that team members have adequate skills to work in the different care settings for cancer patients and their families (66, 80, 88-89).
- Develops and implements standard operating procedures and technical manuals for nursing staff in different areas of activity (88-89).

**2B) Contribute to the development of health services for children and adolescents with cancer and their families, in collaboration with other services in the health care network.**

**Competency**

Contributes to network education projects, focusing on caring for children and adolescents and their families.

**Skills**

- Implements collaborative education projects (42, 99).
- Promotes multicenter education aimed at improving quality of care (99).
- Participates in creating communication platforms and disseminating collaborative network education projects (99).
- Implements education projects in various settings to strengthen local, regional, and national capacity (99).

**2C) Understand the importance of an evidence-based approach to nursing practice when caring for children and adolescents with cancer and their families.**

**Competency**

Applies evidence to practice.

**Skills**

- Applies research outcomes to improve quality of care and promote scientific evidence-based care (62, 74, 81, 100).
- Develops research protocols (62).
- Systematically investigates practice-based issues (62).
- Develops research based on research priorities in pediatric oncology (101).
- Evaluates new products for safe clinical care (62).
- Develops qualitative research based on cultural values such as fate, suffering, resignation, and coping to develop culturally competent interventions (77, 102).

**2D) Contribute to the development of good clinical research practices in pediatric oncology.**

**Competency**

Coordinates clinical trials.

## Skills

- Participates in clinical research in collaborative groups (103).
- Helps to manage the care of patients enrolled in clinical trials, ensuring that all trial requirements are met in accordance with the protocol (104).
- Provides complete information to patients participating in clinical trials (100).
- Acts as a specialist in toxicity protocols or situations that may require treatment delays, dose reduction, or possible withdrawal from a clinical trial (104).
- Participates in team meetings to discuss the possible use of investigational therapies to help answer questions, provide information, and provide emotional support to patients and families (104).
- Acts as a mediator between the patient enrolled in the research and the head oncologist (104).
- Helps to determine local feasibility, identifies patients eligible for a clinical trial, provides education to family and staff, and facilitates data collection. Helps to evaluate the research agreement (103).
- Helps to manage and audit the ethical conditions of research with children and adolescents and their families (105).
- Prepares the clinical research standard operating procedures manual (98, 105).
- Develops a continuous education program for clinical research site staff to ensure that all members are trained to perform their duties (105).
- Maintains up-to-date study records that are always available for inspection by competent regulatory authorities (98, 105).
- Anticipates the direct and indirect costs of carrying out the study, and schedules the total project implementation time (98, 105).

## Competency

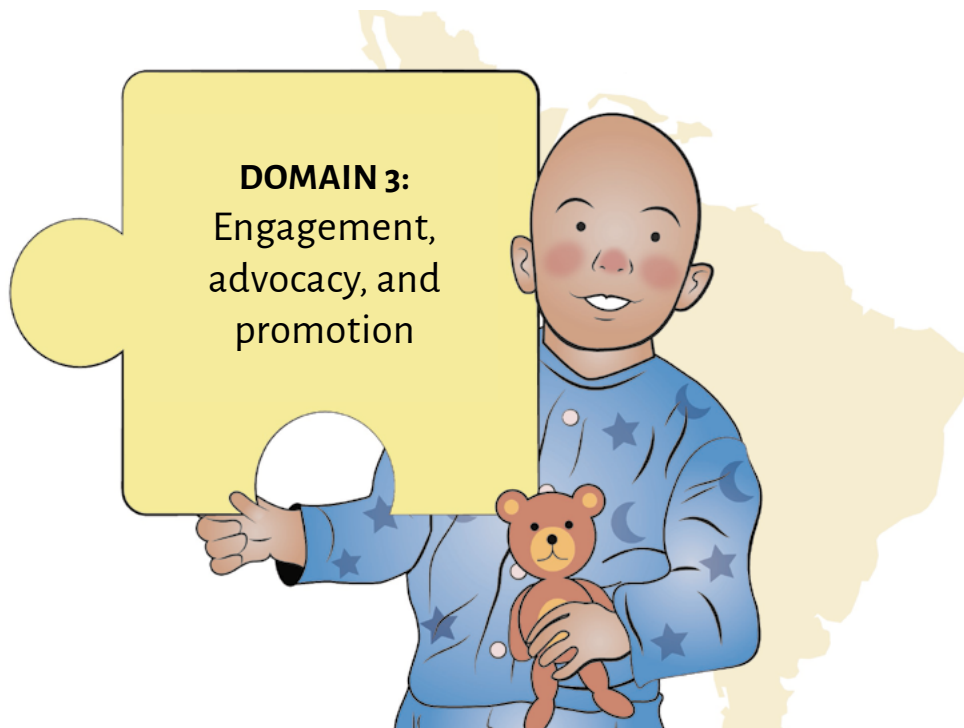
Conducts clinical research activities, considering ethical and legal aspects.

## Skills

- Knows the ethical principles associated with clinical trials (76).
- Informs the family and child or adolescent about the clinical trial, in understandable language, and leads the informed consent and assent process (71, 76, 100, 103).
- Acts as a source of patient recruitment for clinical research protocol enrollment (98, 105).
- Performs a critical analysis of the discomfort, risks, and benefits associated with clinical research. Describes measures to prevent or mitigate foreseeable risks and discomfort. Describes the procedures to be adopted in the event of foreseeable risks and discomfort (105).



- Oversees protocol procedures and routines, scheduling the flowchart to prevent non-compliance (98, 105).
- Promotes conditions conducive to special patient visits (with medical research staff, nursing and psychology professionals, or nutritionists, etc.) and specific examinations (e.g., positron emission tomography scans), in addition to scheduled visits, in order to improve safety (105).
- Follows up on visits, identifying problems and expediting specialized care (98, 105).
- Follows up regularly on the patient's clinical situation due to the need to assess response to treatment and side effects (105).
- Advocates for children and adolescents and their families, encouraging questions and assessing whether participants understand what the research involves (78, 103).



Advocates for patients and their families, working with and alongside them, promoting their empowerment and ensuring that their opinions, choices, and decision-making processes are respected and seen as essential in all aspects of care. This practice recognizes the importance of the nurse's role in supporting and advocating for patient decisions in all aspects of cancer treatment.

**3A) Ensure the participation of children and adolescents and their families to find out their views on the delivery of services and improvements in care.**

**Competency**

Considers the point of view and knowledge of each person, involving them in identifying the best solutions, and in related conversations.

**Skills**

- Respects the perspective of children and adolescents and their families, and recognizes their ability to choose their own care and take part in it, adapting the level of participation to the level of development (63).
- Seeks to understand what the patient and family know about the disease and treatment, as well as what they want to know, before initiating dialogue (64, 70).
- Includes healthy siblings in care, providing them with opportunities to express their thoughts and concerns (70).
- Addresses children or adolescents directly during visits, and involves them, recognizing them as collaborating members of the health team (71).
- Explores their preferences to include them in the decision-making process (71).

- Supports younger children and those who may not be able to express their own needs, in order to study their readiness and ability to receive information and make decisions (71).
- Reassesses preferences, as circumstances may change as the child or adolescent matures and progresses through treatment (71).
- Considers parental participation, respecting the preferences of the child or adolescent (e.g., excluding parents for privacy or including them for emotional support) (71).
- Demonstrates companionship and provides comfort, hope, and reassurance through conversations about feelings, interests, and life “beyond cancer” (71).
- Encourages the active participation of children and adolescents in their own care (71).
- Defends the right of children and adolescents to know their diagnosis, respecting their stage of development (78).
- Enables patients and their families to advocate for themselves and communicate their needs (72).

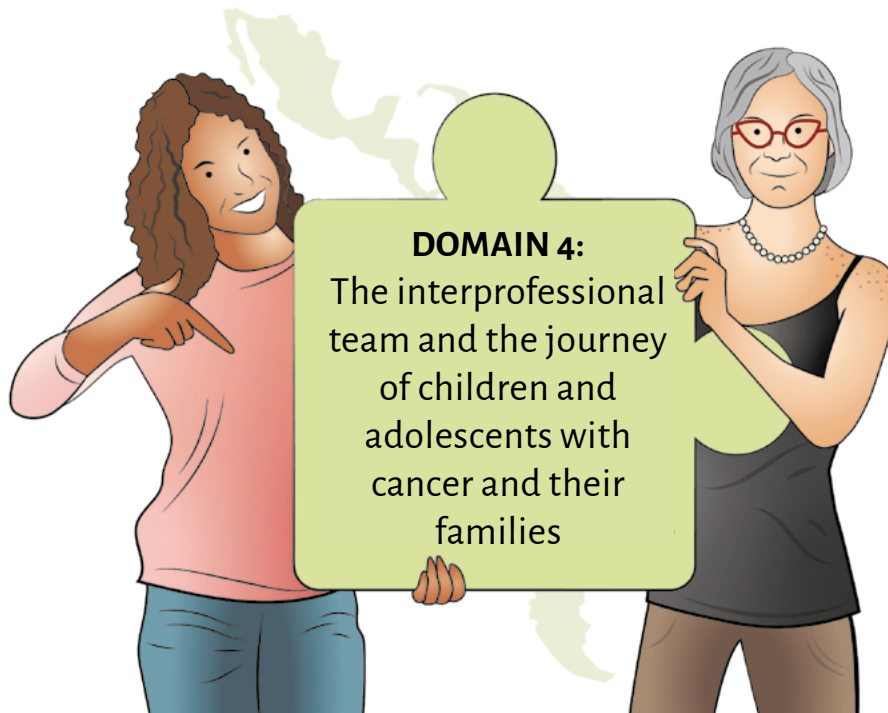
## **B) Provide support for self-care.**

### **Competency**

Provides support for self-care and improved patient outcomes throughout the cancer course.

### **Skills**

- Actively involves children and adolescents and their families in self-care and in the promotion of health literacy (106).
- Assesses health risk factors and the self-care capacity of children and adolescents and their families (106).
- Develops a shared agenda for the health team, children and adolescents, and their families throughout the diagnosis, treatment, survival, or palliative care process (106).
- Motivates behavioral changes by applying behavioral theories, with the aim of strengthening self-care (106).
- Addresses and presents self-care coping and improvement strategies (106).
- Monitors the self-care process of children and adolescents and their families, including through remote monitoring and telephone screening (106, 107).
- Encourages children and adolescents to take responsibility for their care (e.g., by allowing them to be responsible for taking their medications or measuring their blood glucose) (71).
- Provides information to facilitate self-care, including ensuring support for transition services, vocational help, and survival information (71).



Forms part of an interdisciplinary team with specific pediatric oncology nursing knowledge and skills. This action recognizes the diversity of professionals and services treating childhood cancer and collaborative work, ensuring that people receive person- and family-centered care, based on the resources available in the health system.

#### **4A) Act as a member of the interdisciplinary team participating in systematic meetings to treat case reports.**

##### **Competency**

Forms part of the interdisciplinary team, whose purpose is to provide the services needed for comprehensive care of children, adolescents, and their families.

##### **Skills**

- Demonstrates an ability to collaborate, provide care, coordinate, and work with interprofessional teams in order to maximize care and partnerships with patients and families for mutual learning and assessment of practices (65-66, 72).
- Participates in discussions with the team and with children and adolescents and their families about diagnosis and treatment plans (61).
- Promotes interdisciplinary collaboration and participates in round tables on case reports (68, 80, 108).
- Participates in team conversations about patient prognosis in order to support families and help them process the information received (78).
- Involves the interdisciplinary team to meet the physical and psychosocial needs of adolescents (e.g., puberty, sexuality, and body image) (71, 74).
- Facilitates communication between members of the interprofessional team to prevent fragmented or delayed care that could have a negative impact (72).

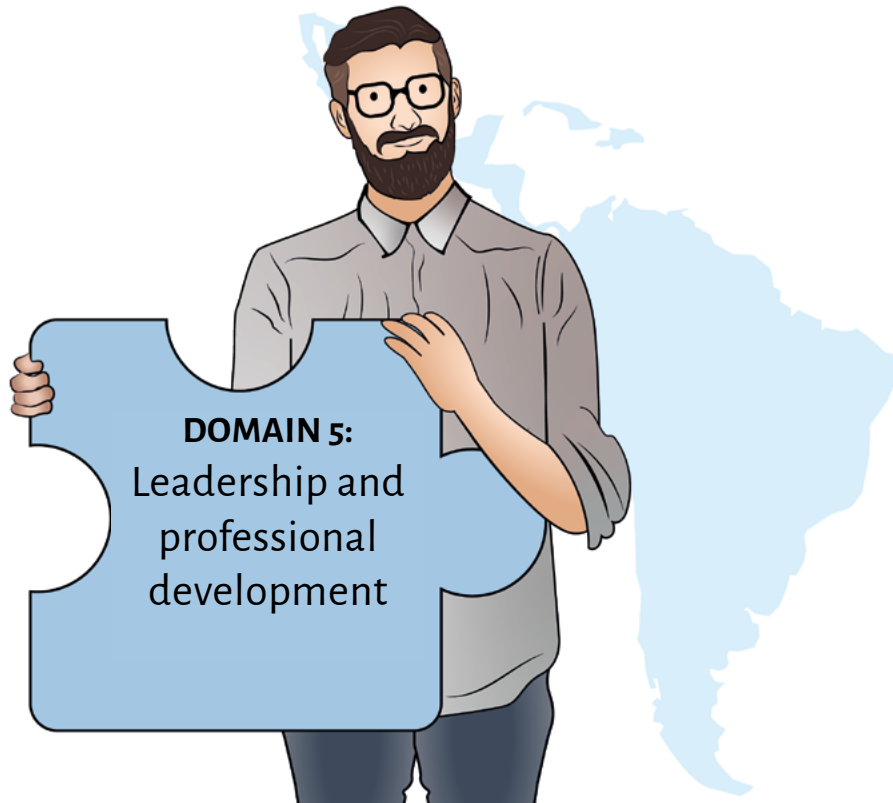
## **4B) Guarantee access to the health services network during the journey of children and adolescents with cancer and their families.**

### **Competency**

Helps to define and implement the patient's and family's journey in the pediatric oncology service network.

### **Skills**

- Understands the cancer journey, including psychosocial, physiological, and cultural factors affecting prevention, early detection, treatment, rehabilitation, survival, palliative care, and end-of-life care (65, 73).
- Coordinates care for cancer survivors, cancer patients, or those at risk of developing the disease (72, 74).
- Recognizes factors affecting access to health services, such as ethnicity, culture, health beliefs, social status, economic status, geographic and language barriers, communication skills, disabilities, and health literacy (65, 81, 109).
- Demonstrates knowledge of the resources available to assist patients seeking information or services during the cancer journey, as well as skills to leverage these resources (65).
- Works on prevention and screening, and facilitates the transition of care according to the phase of the diagnostic and therapeutic process (73, 81).
- Includes home and school visits in the care plan, in order to promote the activities of daily living of children and adolescents and their families (73).
- Facilitates care coordination and dialogue between hospital and community teams (73).



Facilitates nursing leadership when caring for children, adolescents, and families suffering from cancer and its consequences. This domain recognizes the importance of nurses' professional development and leadership, their ability to communicate within organizational structures, and their contributions to delivering skilled care to children and adolescents with cancer and their families.

**5A) Demonstrate personal and professional leadership qualities, positively influencing the care process, and committing to personal and professional development—both for self and for other team members—in order to care for children and adolescents and their families in different clinical practice settings.**

### **Competency**

Performs the role of team leader to achieve common goals, encouraging responsibility and initiative.

### **Skills**

- Demonstrates leadership in structuring an effective, collaborative, and productive nursing team (65).
- Assesses and selects candidates for the nursing team (62).
- Supervises, trains, guides, and assesses the performance of nursing staff (62).
- Recommends the termination of team members' employment contracts, where appropriate (62).
- Implements and assesses cultural competency programs, and selects professionals from different cultures (109).

- Promotes culturally sensitive care, and helps patients from different cultures access quality care (109).
- Seeks to establish a culture of trust and peace, sharing ideas, and ensuring that the team can identify common expectations and mutual goals (65).
- Expands existing processes for investigating patient and caregiver satisfaction with pediatric oncology services, or develops new ones (90).
- Organizes and manages concurrent or conflicting objectives or processes shaping the flow of communication within interprofessional teams, including the interaction between autonomous professional practice and interprofessional team collaboration, in order to support effective communication and team cohesion (65).
- Recognizes unhealthy work environments or situations in which personal health and safety are at risk or that may endanger the health and safety of others—such as team members or patients—and develops strategies to address them in collaboration with colleagues and within systems (65, 80).
- Establishes strong leadership in the field of nursing, capable of establishing alliances with leaders from other specialties and areas of care (68).
- Recognizes own leadership development needs and seeks appropriate personal and professional development opportunities (60).
- Proposes networks with nursing professionals in similar positions at local and national levels to learn from one other about the practice (60).
- Seeks to identify and develop nursing leaders of the future (60).
- Promotes lifelong learning and evidence-based practice to improve the care of children and adolescents with a past, current, or potential cancer diagnosis (72).

### **Competency**

Values professional development within and from pediatric oncology health services.

### **Skills**

- Demonstrates commitment to continuous learning and constantly seeks to improve own knowledge to support own practice (51, 62).
- Keeps technical and scientific knowledge on individual, collective, and environmental biosafety up-to-date, with the aim of preventing or avoiding accidents or situations that may cause physical or environmental damage (88-89).
- Recognizes the need to maintain and incorporate up-to-date knowledge on good practice guidelines based on evidence from the most recent literature on pediatric cancer care (69).
- Demonstrates adaptive capacity and flexibility to take on various roles in interprofessional groups and support team members through collaborative practice (69).
- Establishes and maintains effective partnerships and interprofessional working relationships with patients, families, and other team members or organizations, in order to achieve common goals (69).

**5B) Demonstrate resilience and emotional intelligence when faced with the demands of the pediatric oncology nursing process.**

**Competency**

Demonstrates resilience and emotional intelligence when caring for children and adolescents with cancer and their families.

**Skills**

- Recognizes the need for self-care, reflective practice, and mutual care by the team, in order to build resilience as a health professional providing care in the pediatric oncology field and to be able to participate in strategies recognizing the burden of stress and suffering resulting from the dying process (65).
- Recognizes the impact of grief on himself and the strategies and resources available to facilitate self-care, in order to use these resources in own practice, in counseling, and in teams (65).





Demonstrates commitment to developing health services and policies for children and adolescents with cancer and their families, as well as for the professionals involved. Recognizes the variety of scenarios in which nurses can act, and the different roles they can play.

**6A) Help develop equitable pediatric oncology health policies, considering the social determinants of health in the health-disease-care process, with the aim of reducing childhood cancer morbidity and mortality and improving quality of life.**

**Competency**

Participates in developing and implementing policies to improve work processes and services.

**Skills**

- Actively participates in planning and implementing childhood cancer prevention, early detection, and care measures (35, 98).
- Participates in the shared managerial decision-making process aimed at developing fair pediatric oncology health policies, in order to reduce cancer morbidity and mortality in children and adolescents, and to improve quality of life (35, 98).
- Helps cancer patients and their families and caregivers overcome health system barriers (72).
- Evaluates, supervises, and promotes continuous education spaces with a view to improving the quality of information in hospital cancer registries and population-based cancer registries, to ensure more complete data on cancer surveillance in children and young people (35, 98).

- Understands the cancer care network, decentralized action, and an intersectoral approach as pillars to achieving comprehensive health care (35, 98).
- Understands the economic effects of childhood cancer, negatively affecting the main drivers of economic growth, including work, productivity, and public investment (35, 98).
- Promotes investment in childhood cancer prevention and early detection policies to address health inequalities (98).
- Promotes intra and inter-sectoral integration measures, promoting the strategy of continuous care lines in pediatric oncology (98).
- Creates synergies between existing programs—for example, in the maternal and child area—to promote integrated actions in childhood cancer management (35, 98).
- Coordinates with civil society organizations and participates in national and international campaigns to raise awareness and combat childhood cancer (35, 98).
- Demonstrates leadership in policy decision-making, at the international, national, and local levels, with a view to managing childhood cancer at different levels of government and in each Latin American country (35).
- Promotes more available health system resources as a whole and, in particular, for pediatric oncology (98).

### 2.3. Research priorities in pediatric oncology nursing

Based on the scoping review, a list of research priorities was prepared and ordered by specific topics.

#### *Personalized pediatric oncology care in the era of precision medicine*

- Studies related to ethical, legal, and social implications, such as privacy, personal data protection vis-à-vis employers and health insurance, and obtaining patient informed consent to store and use omics or other health-related information (87, 94, 96, 110).
- Studies on personalized nursing care in health systems and institutions (e.g., institutional review boards, ethics boards, or professional nursing practice committees) (94, 96, 110).
- Studies related to health information systems centered on omics information with a view to improving the care of children and adolescents with cancer (94, 96, 110).
- Research generating knowledge on patient, family, and caregiver education formats and modalities, related to personalized nursing care in the era of precision medicine, centered on the prevention and management of symptoms throughout life (94, 96, 110).
- Research in the nursing field identifying which interventions would promote the best health outcomes, given the scientific, digital, lifestyle, and environmental characteristics of patients (94, 96, 110).
- Research on reliable and valid measures to assess the delivery of personalized nursing care by health providers, and in clinical, hospital, and primary health care settings (94, 96, 110).

### *Treatment of cancer symptom clusters*

- Studies on the trajectory, development, and severity of cancer symptom clusters over time (during and after treatment), as well as on identifying clusters from multiple perspectives (children, parents, professionals) (69, 82-83, 85).
- Studies evaluating the biological mechanisms involved in the genesis of symptom clusters over time, as well as the interrelationships between these symptoms by age group, diagnosis, and treatment phase (69, 82-83, 85).
- Research contributing to a better understanding of the etiology and psychosocial and biological mechanisms of cancer-related symptoms (82-83, 85).
- Research using biomarkers in response to nursing interventions targeting cancer symptom clusters, making it possible to accurately determine the efficacy of these interventions (82-83, 85).
- Research contributing to a greater understanding of the complex biological networks related to the symptoms presented by pediatric cancer patients and their caregivers (82-83, 85).
- Studies applying mixed methods to identify generic and disease-specific symptom clusters in order to compare and contrast changes in the number and types of symptom clusters over time (82-83, 85).
- Studies using new clinical trial designs to determine whether they can be used to tailor interventions to treat single or multiple symptoms within a symptom cluster (82-83, 85).

### *Palliative and end-of-life care*

- Studies aimed at understanding the emotional and physical needs of patients and families, as well as the relationships between patients, families, and health professionals during palliative care (69).
- Studies aimed at understanding how social media can alleviate the suffering of children, adolescents, and their families, as well as caregivers and clinical service providers at the end of life (69, 111).
- Research on how health professionals should inform families, especially at difficult moments, such as disease recurrence, or when families are part of a population whose native language is not the one used in health services or whose values may not coincide with the values expected by the local culture (69).
- Research on the characteristics of cancer-related deaths in pediatric oncology and the impact on bereaved survivors (family members and caregivers) (112).
- Research on end-of-life decision-making (112).
- Research on pain relief strategies in children and adolescents receiving end-of-life care (112).
- Studies on interventions promoting adaptation in childhood cancer survivors, as well as the impact of late treatment effects on the educational process (86, 111, 112).

## *Clinical care*

- Studies on the incidence of infections associated with access techniques in intravenous devices (113).
- Studies on treatment approaches to prevent or treat chemotherapy-induced mucositis and nursing interventions that may decrease prolonged neutropenia (113).
- Research on approaches to treat depression in children and adolescents with cancer (113).
- Research evaluating the efficacy of anesthesia, sedatives, or educational support techniques in reducing patient anxiety during medical procedures (112).
- Global and unique research, from cells (micro) to communities (macro), from a single child to an entire family system, from diagnosis to long-term survival, and from life with cancer to death from this disease (114).
- Research identifying strategies to mitigate the adverse effects of chemotherapy and radiotherapy (112).
- Research on interdisciplinary collaborative practice around cancer prognosis, including the impact of communication quality, prognostic understanding, decision-making, quality of life, therapeutic alliance, and satisfaction of children, adolescents, and their families (78).
- Research on complementary therapies in pediatric oncology symptom management (91, 92, 115, 116).
- Studies to evaluate telephone interventions used by nursing professionals in response to calls from patients and family members (111).

## *Work process and management*

- Research on the work of nurses and nurse navigators (72).
- Studies on professional burnout in nursing professionals working in pediatric oncology (113).
- Research on staff sizing and strategies for recruiting nursing professionals for the specialty (113).
- Studies to assess the physical effects of working hours (shifts, weekends, etc.) on nurses' daily lives (113).
- Comparative studies on work environment-related stressors for newly graduated pediatric oncology nursing professionals compared with experienced nurses (113).

## *Qualitative research*

- Qualitative studies to better understand phenomena that have not yet been thoroughly investigated using other approaches (67, 73, 78, 117).
- Multicenter studies to expand knowledge of phenomena by including multiple participants, different locations, and the experience of researchers from different sites (102).

- Studies on family and community support focusing on psychosocial and cultural resilience (69).

### *Outpatient treatment versus inpatient treatment*

- Comparative studies on cost, quality-of-life, and disease response variables, as well as on caregiver burden in outpatient care versus inpatient care (111).
- Studies comparing the quality of life of children and adolescents receiving outpatient care versus those receiving inpatient care (111).

### *Family surveys*

- Comprehensive studies on the lives of families of children and adolescents with cancer, as well as their response to new living conditions (118).
- Studies that evaluate family vulnerabilities and skills during diagnosis and treatment initiation (118).
- Studies identifying families at higher psychosocial risk at the time of their children's cancer diagnosis, with a view to developing interventions to strengthen their skills (118).
- Studies to understand the most common treatment-related problems experienced by children and adolescents with cancer and their families at home (111).



## 3. CONCLUSIONS AND FINAL CONSIDERATIONS

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The aim of this technical report is to present the essential competencies for pediatric oncology nursing practice in Latin America and the Caribbean. A scoping review was initially prepared to search for the best evidence for this practice. Patient- and family-centered care and the conceptual model of competencies for caring for teenagers and young adults with cancer, developed by the Teenage Cancer Trust with the support of the Royal College of Nursing, were used as the theoretical foundations to systematize the recommendations presented here.

Joining these two models made it possible to lay the foundations for the care of children, adolescents, and their families based on the principle of comprehensive care and a holistic and humanized approach to the process. By placing people at the center of care, the two models demonstrate the need to learn about people's perspectives, their way of thinking, and how they develop. This makes communication an important tool for professional practice, with an emphasis on assertive and truthful interpersonal relationships to establish bonds and build trust. The exchange of information by the interprofessional team and shared management are also crucial in both models, as they empower the family to make informed decisions. The ethical issues around care also play a fundamental role.

Another founding principle of both models is advocacy or promotion. This pertains to both the family's participation and involvement, as a spokesperson for their children, and the nurse's role in advocating for patients during their journey—with a view to improving their clinical condition and promoting a decent quality of life, considering their beliefs, values, and culture at different moments of health care. Research in the nursing field is another pillar on which both models are based.

The theoretical foundations are also in line with the guidelines of the WHO Global Initiative for Childhood Cancer, namely, considering the need for centers of excellence and care networks with specialized interprofessional teams based on collaborative practice. Continuous education and training are therefore key to increasing the skills, clinical knowledge, leadership, and policy capacity of pediatric oncology nurses.

This report compiles and systematizes recommendations to support professional pediatric oncology nursing practice in Latin America and the Caribbean, centered on caring for children and adolescents with cancer, as well as their families. It can also be used to support training institutions, professional associations, professional regulatory bodies, managers, and public policymakers in proposing essential competencies for pediatric oncology nursing practice in Latin America and the Caribbean.

This publication is a pioneering effort to systematize competencies based on a comprehensive scoping review. As a result, its results may support dialogues aimed at establishing competencies in different Latin American and Caribbean regions, considering the unique training, health system, and professional pediatric oncology nursing practices in each country.



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# ANNEXES

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## Annex A. Case studies in Latin American and Caribbean countries

### *Case 1. Difficulties in nursing practice involving children and adolescents with cancer (Costa Rica)*

Costa Rica has been in a position to treat children with malignant diseases since 1969. Since then, nursing professionals have been an important pillar in the fight against childhood cancer. However, they face various day-to-day difficulties related to infrastructure, supplies, and staffing.

- Current diagnoses and treatments are complex, making infrastructure a challenge. Adequate patient care requires protective isolation techniques due to patients' immunosuppressive status, and proper management of excreta and waste with cytotoxic content.
- Most nursing professionals in low- and middle-income countries face difficulties administering chemotherapy, including lack of supplies, such as personal protective equipment and suitable devices. This leads to exposure risks for both staff and families of children with cancer.
- A lack of trained personnel increases the risk of childhood cancer care, as unexperienced staff with no knowledge on how to care for these patients are sometimes rostered to cover the shifts of specialized staff. Existing nursing staff are also overloaded, leading to the risk of professional burnout in the long term.

Despite these difficulties, nurses will always provide 100% commitment to ensuring that children and adolescents with cancer have a better quality of life.

**Figure A1. Pediatric oncology nursing clinical practice in Costa Rica**

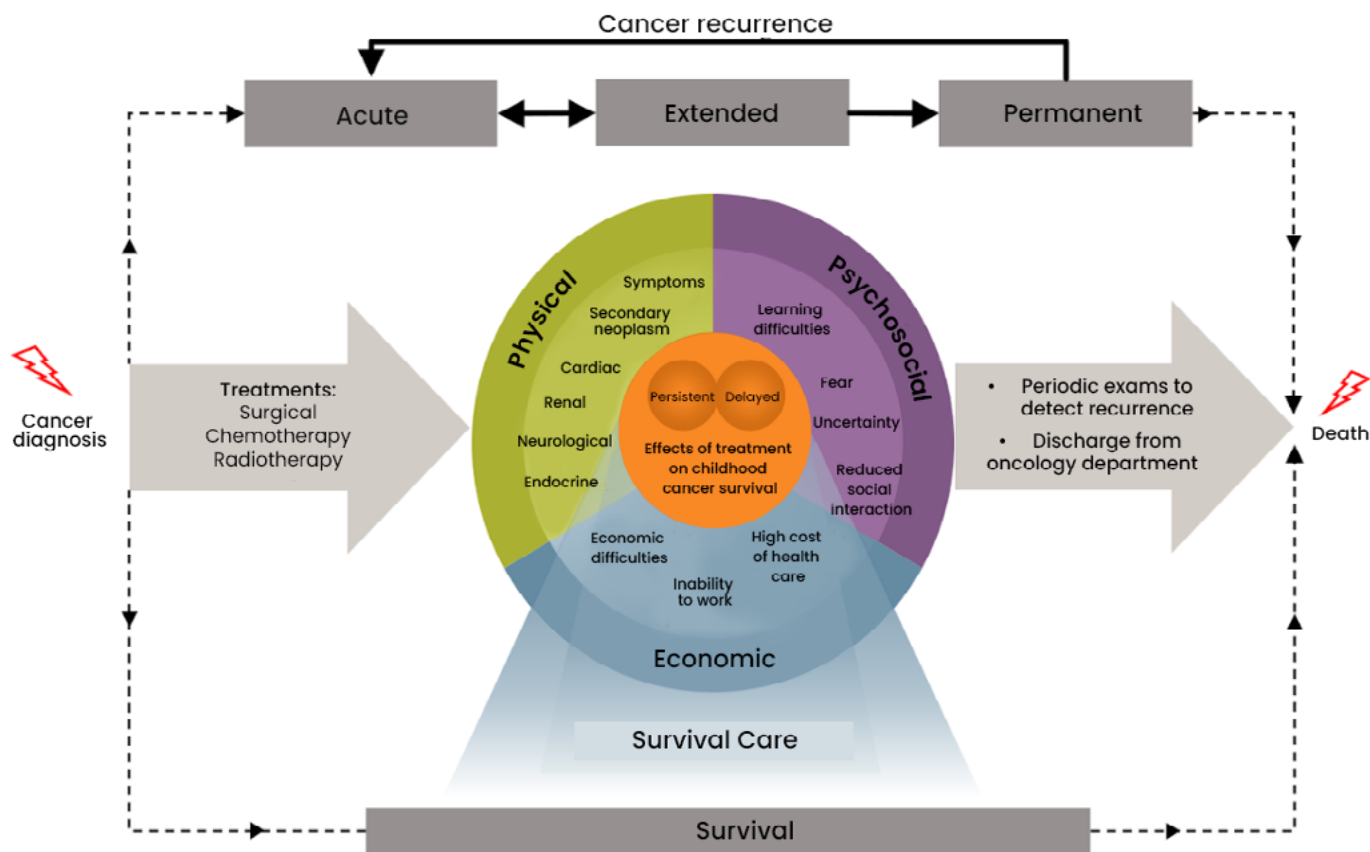


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**Case 2. Follow-up for childhood cancer survivors: reflections on pediatric oncology nursing (Brazil)**

In recent years, advances in cancer therapies have increased the survival of children and adolescents with this disease. As a result, there has been an exponential increase in the number of children surviving cancer. As the childhood cancer survival rate improves, it is important to consider long-term after-effects. Childhood cancer survivors are at high risk of developing physical, psychosocial, and economic effects throughout their lives. To mitigate these effects, survival care must be provided. Survivor follow-up should include the following components: a) prevention, screening, and interventions for recurrence, and long-term and late effects, and early detection of new cancers; b) assessment, support, management, and provision of information related to physical, psychological, social, and spiritual needs; c) follow-up, information, and promotion of healthy lifestyle habits and disease prevention. In addition, children and adolescents should receive a summary of their treatment history, including the type of treatment received, doses of chemotherapy and radiotherapy, dates, procedure, and fields. Although nursing professionals play a key role in all phases of survival care (design, process, follow-up, and coordination), survival care is still not provided in most cancer centers in Brazil; other centers in Latin America and the Caribbean may also lack this care. It is thus essential to promote the necessary changes so that nurses take on this important role and include survival care in their clinical practice.

**Figure A2. Pediatric oncology nursing care model**



**Case 3. National nursing priorities to manage childhood cancer in Central America and the Caribbean**

In October 2020, an online focus group was organized with head nurses from pediatric cancer referral centers in Central America and the Caribbean. The focus group’s aim was to determine nursing priorities for national childhood cancer management plans. Focus group participants included 17 nurses in leadership positions representing eight hospitals in Costa Rica, two in the Dominican Republic, and one in El Salvador, Guatemala, Haiti, Honduras, and Panama, respectively. One of the nurse practitioners specialized in the WHO Global Initiative for Childhood Cancer was in charge of facilitating the meeting. She informed participants about the global nursing priorities recently published by the Initiative. Participants were then asked to comment on whether the global priorities coincided with their local priorities. They were also asked to explain their specific local and national priorities. Overall, the head nurses said that the Initiative’s global priorities were applicable to their regions and aligned with their overall priorities. They also identified region-specific priorities.

Specific nursing priorities for national childhood cancer management plans in Central America and the Caribbean included: 1) subspecialty education; 2) specialized human resources; 3) recognition and incentives; and 4) safe work environments and occupational safety. Table A1 provides descriptions of each priority. In late October 2020, the head nurses’ priorities were presented to the Pan American Health Organization (PAHO) technical advisors, Ministry of Health officials, foundation leaders, pediatric oncology medical professionals, and nursing professionals from Central American and Caribbean countries.



● **Table 1.** Nursing priorities identified for national childhood cancer management plans in Latin America and the Caribbean

Prioridad	Descripción
Subspecialty education	<ul style="list-style-type: none"> <li>- Strengthening and standardizing nursing education programs by establishing the high-school qualifications required to enter into practice</li> <li>- Integrating pediatric oncology education into all phases of nursing education and professional practice</li> <li>- Primary health care</li> <li>- Bachelor's degree programs</li> <li>- Hospital guidance and continuous education (taught by nurse practitioners)</li> <li>- Continuing professional development (conferences)</li> <li>- Specialty certification and advanced degrees</li> </ul>
Specialized staff	<ul style="list-style-type: none"> <li>- Adequate staffing of duly trained nursing professionals</li> <li>- Consider current nurse-to-patient ratios: from 1:5 to 1:18 (average ~ 10 patients per nurse); the recommended ratio is 1:5 (basic SIOOP nursing standards)</li> <li>- Combining skills and opportunity cost</li> <li>- Are we making the best use of nurses' knowledge and experience? Could certain duties be delegated to lower-paid professionals? (e.g., nursing professional/technician/assistant carries out the same responsibilities for the same salary. → Reduces nurses' motivation to further education)</li> </ul>

Prioridad	Descripción
Recognition and incentives	<ul style="list-style-type: none"> <li>- Recognition and incentive programs or career advancement</li> <li>- Competitive salaries to improve retention or reduce turnover</li> <li>- Reward or recognition for experienced and knowledgeable nursing professionals</li> <li>- Opportunities for advancement or professional leadership</li> <li>- Support for professional development (i.e. providing time, funding, materials, and space)</li> <li>- Support to prevent and manage compassion fatigue and burnout</li> </ul>
Safe work environments and occupational safety	<ul style="list-style-type: none"> <li>- Standardized guidelines for safe handling of hazardous drugs and monitoring compliance with safety protocols</li> <li>- Preparation and dispensing</li> <li>- Storage and handling</li> <li>- Administration</li> <li>- Readiness</li> <li>- Appropriate safety equipment and safe work environment</li> <li>- Biosafety cabinet and chemotherapy preparation room</li> <li>- Personal protective equipment (PPE)</li> <li>- Occupational exposure tests</li> </ul>

**Source:** The authors, based on data extracted from: Pergert P, Sullivan CE, Adde M, Afungchwi GM, Downing J, Hollis R et al. An ethical imperative: safety and specialization as nursing priorities of WHO Global Initiative for Childhood Cancer. *Pediatr Blood Cancer*. 2020;67(4):e28143. Available from: <https://doi.org/10.1002/pbc.28143>; Sullivan C, Challinor J, Pergert P, Afungchwi G, Downing J, Morrissey L et al. Strengthening the global nursing workforce for childhood cancer. *The Lancet Oncology*. 2020;21(12):1550-1552. Available from: [https://doi.org/10.1016/S1470-2045\(20\)30425-3](https://doi.org/10.1016/S1470-2045(20)30425-3); Day S, Hollis R, Challinor J, Bevilacqua G, Bosomprah E. Baseline standards for paediatric oncology nursing care in low to middle income countries: position statement of the SIOP PODC Nursing Working Group. *Lancet Oncology*. 2014;15(7):681. Available from: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(14\)70213-X/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(14)70213-X/fulltext).

#### **Case 4. Pediatric oncology nursing navigation services (Colombia)**

High-complexity institutions in Colombia provide navigation services for patients diagnosed with childhood cancer. These have been developed under the leadership of nursing professionals. The city of Cali has two cross-cutting navigation programs that span the patient care process. Navigation aims to reduce cancer morbidity and mortality by removing barriers affecting timely pediatric care.

The navigation program establishes internal authorization routes between the institutions providing childhood cancer care services and insurers—the entities paying for them. These partnerships directly impact the chances of receiving care and communication between those responsible for ensuring comprehensive patient care. Other aspects of the program include care coordination, provision of support services, and ensuring multidisciplinary care.

Given the specific characteristics of the Colombian health system, adopting strategies such as nursing navigation is useful to improve the care of patients diagnosed with childhood cancer, as it helps to integrate clinical and administrative management. This, in turn, removes obstacles such as service fragmentation, reduces the administrative burden on patients and their families, provides education, follow-up, and encourages treatment adherence.

**Figure A3. Pediatric oncology nursing service in Colombia**



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#### **Case 5. Experiences as nurse practitioners for children and adolescents with cancer (Chile)**

The Pontifical Catholic University of Chile Pediatric Oncology Nursing Program was started in 1992 by Rina González. Its aim was to create a training facility for pediatric nursing professionals that would further understanding of childhood and adolescent cancer. Its approach centered on the biopsychosocial and spiritual problems arising from the disease process itself and treatment. This two-semester theoretical clinical program covers the knowledge and skills for comprehensive and humanized care in the early detection and diagnosis process, in the active treatment phase, in hematopoietic stem cell transplantation, and in follow-up or palliative care, along with the ethical aspects of care, care management, and education, all based on theoretical models in the field.

To date, 53 nurses have graduated; more than 80% of these belong to the Chilean public health system. Of these nurses, more than 70% still perform clinical duties in cancer units. The rest carry out administrative coordination tasks in the same hospitals or teach at universities.

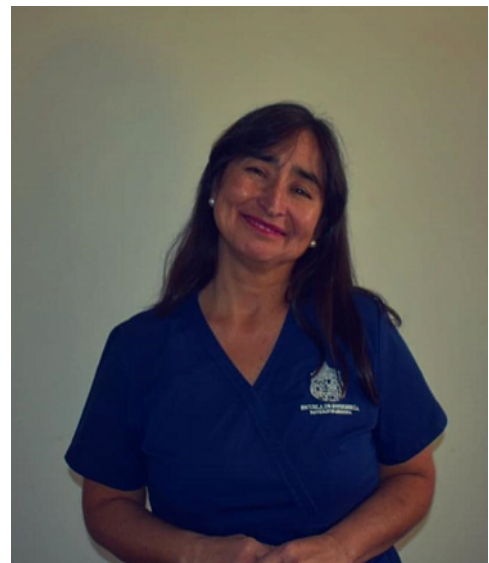
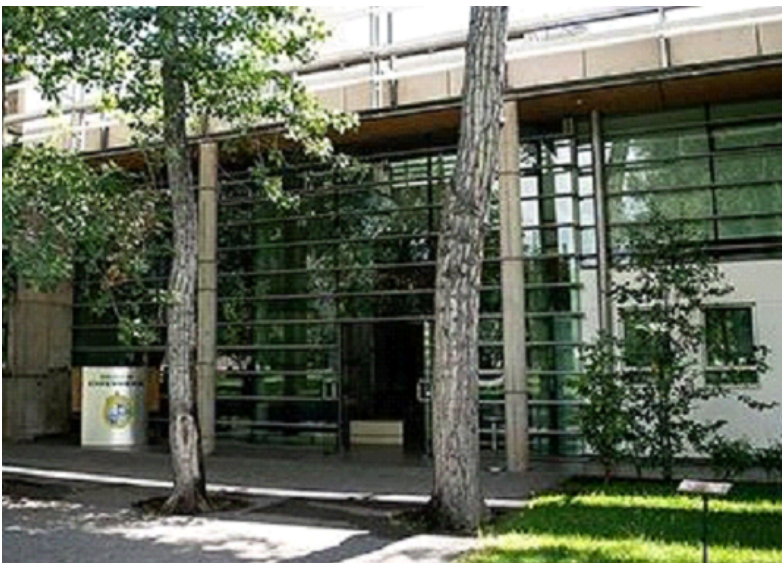
Some experiences:

“Personally, I found it very enriching, because when you grow as a professional you grow as a person. It enriches you because, when you improve your nursing care, you go home happy. I go through life happily knowing that I can contribute new ideas to advance pediatric oncology nursing. Professionally, it meant taking a fresh look at what I do. As you learn new things, you think of lots of ideas and projects that you want to implement in your daily work.”

“This specialty enabled me to learn more about pediatric oncology nursing, developing an evidence-based practice based on humanized care of both children and adolescents and their families. This allowed me, after 10 years, to take on the important task of training other colleagues and join the program as a teacher. I now coordinate it.”

“The specialty has been a driving force in my professional development. As an academic, I have dedicated a large part of my work to developing research on grief among parents of children with cancer and health professionals themselves. I’m convinced that we as caregivers have to be well to provide quality, timely, and humane care.”

**Figure A4. Pediatric oncology nursing education in Chile**



© Paula Vega, Rina González, Rosario Luengo and Carolina Robledo.

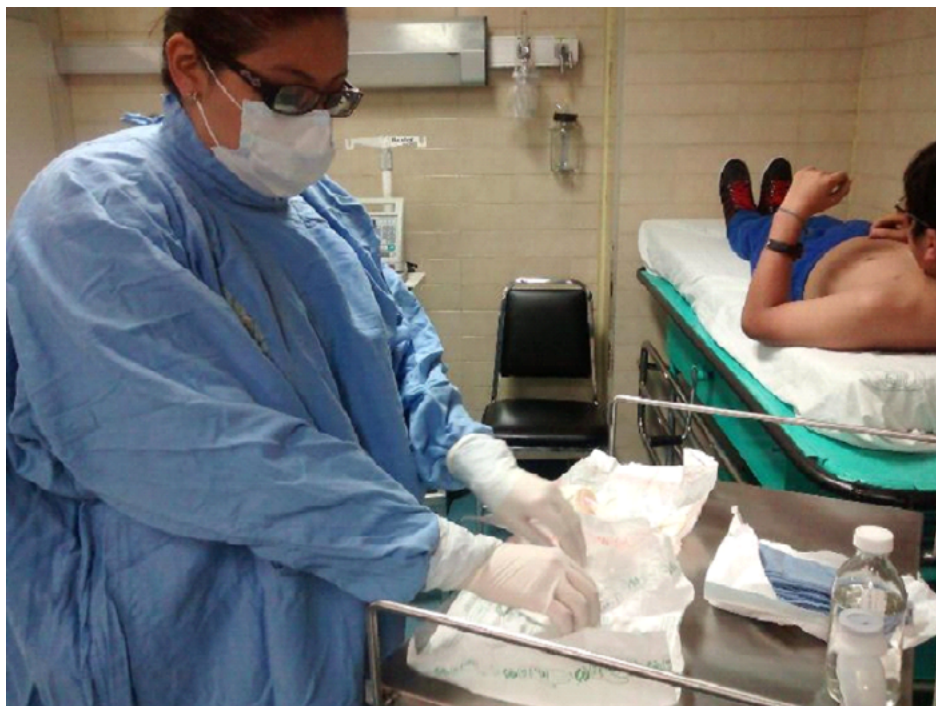
### **Case 6. Challenges delivering pediatric oncology nursing education (Mexico)**

In Mexico, nursing professionals do not currently receive subspecialty training in pediatric oncology nursing. Training is limited to post-graduate or specialty oncology nursing studies, where only a fraction of the program (less than 50%) is dedicated to pediatric cancer patients. Furthermore, the pediatric nursing specialization only covers a unit of knowledge. This is not enough to reach the level of training required to care for children with cancer.

A major reason for this problem is the lack of an official health system registry dedicated to childhood cancer. Each institution records cases independently; there is no centralized database showing the increase in childhood cancer cases or how the disease is progressing. As a result, it may seem as though professional training is not required. Population dynamics and mortality rates, however, irrefutably show us that the number of children with cancer is increasing day by day; furthermore, a lack of screening, professionals with specific training, and poor hospital infrastructure can result in deaths.

Providing pediatric oncology nursing education in Mexico would help to deliver highly specialized care to the child population. This could facilitate the timely detection of diseases and treatment-emergent adverse effects, which are a significant cause of childhood cancer deaths. A vocational training program could reduce the national death rate and provide effective, quality care to a population requiring meticulous and timely care.

**Figure A6. Pediatric oncology nursing clinical practice in Mexico**



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### Case 7. OncoPed en Ação education project: nursing training for pediatric oncology care (Brazil)

OncoPed en Ação [OncoPed in Action] is an education project created by experienced pediatric oncology nurses. Its aim is to develop educational activities for nursing professionals involved in caring for children and adolescents with cancer and their families.

Characters that reflect different age groups, ethnicities, and pathologies are included in educational activities posted on social media alongside complementary professional training courses. Classes cover (but are not limited to) the following areas: suspected childhood cancer, palliative care, chemotherapy in children and adolescents, family-centered care for children with cancer, diagnostics, bone marrow transplant, and central and peripheral venous access.

Over a 12-month period, six courses with 82 participants, five webinars, and 16 live events were held. Classes on signs and symptoms were also held at eight academic oncology and pediatric societies, and active discussions on films, scientific articles, and books were organized. Participants representing 19 Brazilian states have taken part in the activities to date.

In conclusion, this activity is seen as a relevant initiative offering quality content aimed at improving care. It is a space to share experiences, dialogue, and collaborate within the network of professionals committed to caring for children and adolescents and their families.

Figure A6. OncoPed en Ação Project



### Case 8. International collaboration in pediatric oncology nursing (International Society of Paediatric Oncology [SIOP])

Nurses who are members of the International Society of Paediatric Oncology (SIOP), a non-State actor in official relations with WHO, have been actively involved in the WHO Global Initiative for Childhood Cancer. In September 2018, Julia Challinor, a nurse and SIOP advocacy officer at the time, attended the meeting held in Geneva to announce the roll-out of the Initiative. Seven SIOP nurses formed part of the first six WHO Global Initiative working groups (policies; access to medicines and technologies; quality centers; records; costs and research; and advocacy and promotion) to ensure that nursing issues were addressed. The seven SIOP nurses trained the WHO initiative nurse practitioners along with two additional nurses from the working groups. In 2020, the nurse practitioners published the article entitled "An ethical imperative: safety and specialization as nursing priorities of WHO Global Initiative

for Childhood Cancer”,<sup>1</sup> which was translated into Spanish and shared with nursing professionals in Latin America. The nurse practitioners also organized two webinars in February 2021. In the webinar aimed at pediatric oncology nursing professionals in the Americas, nurse Zulma Carpio presented the priorities and activities of the WHO Global Initiative for Childhood Cancer Nursing Committee in Peru, namely: improving nursing specialization; integration into multidisciplinary care; leadership; decentralized care; staffing; and evidence-based practice. Collaboration is ongoing between the WHO Global Initiative in Latin America and the SIOP nursing committee, as well as WHO Global Initiative nurse practitioners.

**Figure A7. CureAll educational poster aimed at pediatric oncology nursing professionals**



**WHO GLOBAL INITIATIVE  
FOR CHILDHOOD CANCER (GICC)**

**Nursing Update  
from the GICC  
Nurse Practitioners**

**With Spanish translation**



<sup>1</sup>Pergert P, Sullivan CE, Adde M, Afungchwi GM, Downing J, Hollis R et al. An ethical imperative: safety and specialization as nursing priorities of WHO Global Initiative for Childhood Cancer. *Pediatr Blood Cancer*. 2020;67(4):e28143. Available from: <https://doi.org/10.1002/pbc.28143>. <https://doi.org/10.1002/pbc.28143>.

### **Case 9. Chemotherapy and biotherapy education in Latin America (Association of Pediatric Hematology/Oncology Nursing [APHON])**

Chemotherapy and biotherapy are the backbone of pediatric cancer treatment. Nurses are often responsible for administering and sometimes preparing chemotherapy or biotherapy. Although, in the United States, the Association of Pediatric Hematology/Oncology Nursing (APHON) offers standardized and certified education for professionals in English, no standard comprehensive course was available in Spanish for nurses in Latin America and the Caribbean. In 2015, APHON surveyed nursing and medical professionals from 14 countries in the region and confirmed the need for a comprehensive chemotherapy and biotherapy course, as well as the interest it aroused. To address this need, APHON partnered with St. Jude Global to culturally adapt, translate into Spanish, and conduct a series of pilot courses for providers and instructors with nursing professionals from Latin America and the Caribbean.

Between 2016 and 2017, 206 nurses in the region participated in four pilot courses for providers, and 17 nurses participated in two courses for instructors. An evaluation of the pilot series determined that the course was appropriate for the practice and education levels of nurses in Latin America and the Caribbean.<sup>2</sup> Once the pilot phase was completed, two courses were held for providers in Mexico and Chile in 2019, and a third course was held for instructors throughout the region. Since the 2020-2021 academic year, a course for providers from Latin America and the Caribbean—online due to COVID-19—has been held with nursing professionals in Peru; this year a second course is scheduled, as well as another for Colombia. APHON will continue to provide these online courses. Its ultimate goal is to support the creation of a sustainable instructor network in Latin America and the Caribbean, enabling courses to be taught locally. A total of 309 providers from 70 hospitals and 29 instructors in the region have participated in the APHON program. In 2021, a Portuguese course was started and a course for providers aimed at nursing professionals in Brazil was completed.

**Figure A8. Association of Pediatric Hematology/Oncology Nursing logo**



<sup>2</sup> Sullivan CE, Morrissey L, Day SW, Chen Y, Shirey M, Landier W. Predictors of hospitals' nonachievement of baseline nursing standards for pediatric oncology. *Cancer Nurs.* 2020;43(4):E197-206.



### **Case 10. Regional research, education, and quality improvement project initiatives in Latin America (St. Jude Global)**

Nursing care is essential to closing the survival gap between children with cancer in high-income and low- and middle-income countries. Low- and middle-income countries often lack specialized pediatric oncology nursing education. To bridge this gap, St. Jude Children’s Research Hospital, through the Global Nursing program, has implemented several initiatives aimed at strengthening nursing competencies in Latin America.

In 1991, St. Jude nurses traveled to different hospitals to give on-site lectures. In 2000, a training institution was created for nursing professionals working in pediatric oncology units in El Salvador. A three-month program was designed and implemented over five years. The model was neither profitable nor sustainable, however; so, in 2007 an approach based on the creation of a nurse educator network was adopted, in collaboration with the Dr. Luis Calvo Mackenna Hospital in Santiago, Chile. Its aim was to establish the role of the pediatric oncology nurse educator. Through an intensive four-week training program, senior nursing professionals gained pediatric oncology nursing knowledge and skills, and teaching skills based on adult learning principles. All graduate nurse educators in the region belong to the St. Jude Latin American Nurse Educator Network (LANEN). This community promotes professional development, education, and support for the implementation of quality improvement projects. In addition, the annual Central American Pediatric Hematology and Oncology Association (AHOPCA) conference provides an opportunity for nurse educators to engage, network, and strengthen collaboration.

In order to strengthen nurses’ chemotherapy competencies, St. Jude designed a basic chemotherapy course aimed at nursing professionals and technicians using the Cure4Kids web platform. Since 2015, St. Jude and APHON have worked together to provide the certified APHON chemotherapy and biotherapy program—adapted to the cultural context and translated into Spanish—to nurses in Latin America and the Caribbean.

Several quality improvement projects focusing on patient safety and chemotherapy administration have been promoted in the region, according to local needs.

**Figure A9. St. Jude Global Initiative logo**



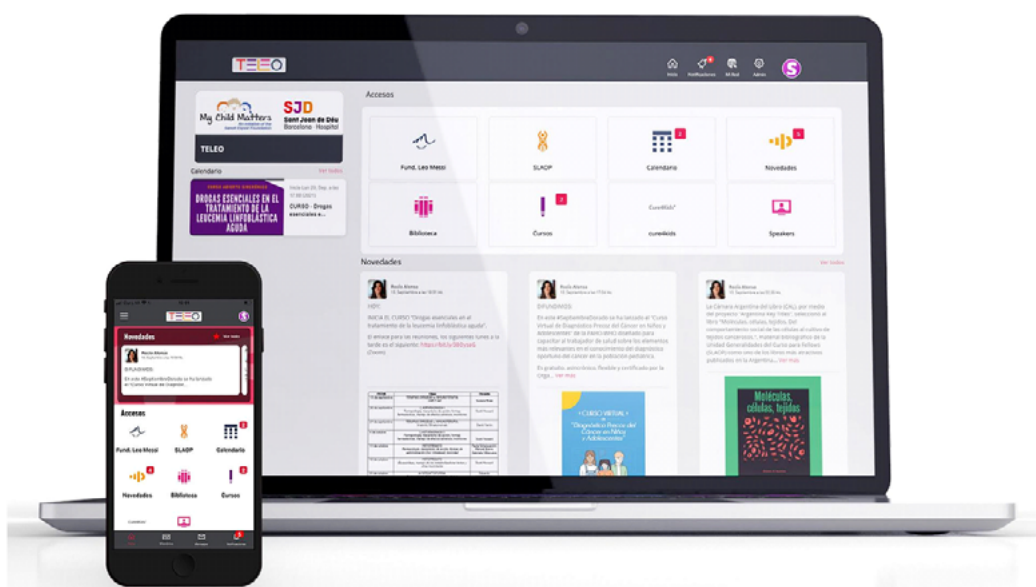
### Case 11. TELEO: Tele-education in pediatric oncology (My Child Matters)

This project—developed within the framework of the Sanofi Espoir Foundation’s My Child Matters initiative by San Juan de Dios Hospital (Barcelona) and the Latin American Society of Pediatric Oncology—aimed to provide access to Spanish training resources and specialized content, created by the best local experts, in the multidisciplinary area of pediatric oncology. The project also provided a meeting space for all staff.

Three nursing projects were carried out:

- Approaches to Pediatric Oncology Nursing. This intensive course was aimed at nursing professionals in their first five years of oncology practice. It consisted of simultaneous classes, with a total duration of 21 hours, and a final exam. 211 registration applications were received and 42 people attended the full course, 32 of whom passed the final exam. The attending nurses came from Argentina, Bolivia, Chile, Colombia, the Dominican Republic, Ecuador, Guatemala, Haiti, Honduras, Mexico, and Peru.
- Approaches to Pediatric Oncology Nursing. This self-managed course, including eight units with recorded classes and specific material, also enabled participants to contact the teaching team to resolve any doubts. The course enrolled 250 nurses from Argentina, Brazil, Chile, Colombia, the Dominican Republic, Ecuador, Guatemala, Honduras, Mexico, Nicaragua, Peru, and Uruguay.
- Coffee Talks: Opening Borders. This knowledge exchange aimed to improve the quality of pediatric oncology patient care in Latin America. It consisted of monthly one-hour meetings, held on the second Thursday of each month. In these meetings, an expert colleague presented the theory behind a topic, and participants were encouraged to interact, share and deepen knowledge, and generate debate. Between 25 and 35 participants attended each meeting.

Figura A10. TELEO Platform



**Case 12. Development and implementation of educational nursing material for parents of children with cancer in Peru (Global Initiative for Childhood Cancer, PAHO/WHO)**

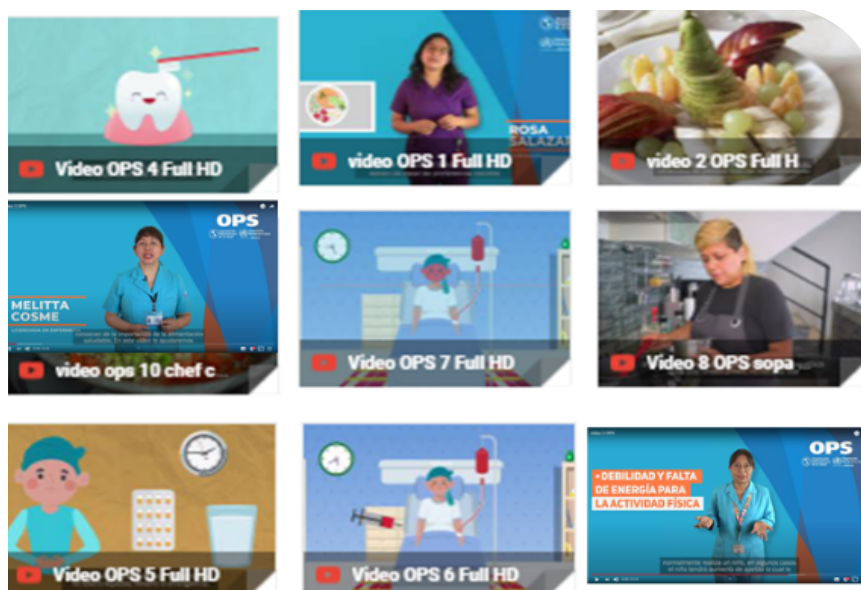
Educating parents and caregivers of children with cancer is one of the fundamental roles of nursing. It helps to avoid complications, provide quality care, promote treatment adherence, and maintain basic standards of care. The study's objective was to design educational material for parents and caregivers of children with cancer, offering general information about cancer and its care.

Within the framework of the WHO Global Initiative for Childhood Cancer in Peru, in May 2020, a multicenter working group was established with head nurses, education coordinators, nurse educators, and other multidisciplinary teams. In June and July 2020, a comprehensive assessment of the needs of parents and caregivers of children with cancer was carried out. For this, an online and in-person survey was conducted at several institutions, aimed at examining the preferred models and content of online and in-person educational talks, as well as audiovisual and printed material. A questionnaire was used to assess understanding of the material.

A total of 365 parents and caregivers were included in the study. The median age was 37.9 years. Most respondents (49.7%) were parents of children in active treatment. Up to 45% of parents had only primary or secondary education. Cancer treatment and side effects (25%), nutrition (15%), warning signs (12.5%), and home pediatric care (8.2%) were the topics on which parents thought it most important to receive information. Most respondents said they preferred to receive information through talks (70.9%) and educational videos (64.7%). From August to October 2020, pilot educational material (online conferences and seven educational videos) was developed and presented at online educational conferences at each institution. The content and structure of this material were modified over time. None of the parents had difficulty understanding the material.

Assessing the educational needs of parents and caregivers of children with cancer provides a starting point for designing educational strategies.

**Figure A11. Educational videos about pediatric oncology nursing in Peru**



### **Case 13. Building sustainable local capacity to diagnose, treat, and manage pediatric cancers and blood disorders (SickKids-Caribbean Initiative)**

In 2013, the SickKids-Caribbean Initiative (SCI) was created with the support of the Hospital for Sick Children (SickKids) Centre for Global Child Health, in partnership with the University of the West Indies (UWI), Ministries of Health, hospitals, and institutions from six Caribbean countries: Bahamas, Barbados, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago. The SCI aims to develop sustainable local capacity to accurately diagnose, treat, and care for pediatric cancers and blood disorders. One of the initiative's key focus areas is to provide training and education based on the needs expressed by Caribbean partners.

Nurses are at the forefront of managing and delivering patient care and leading the implementation of evidence-based practices. By investing in nurses through specialized education, the SCI strives to promote pediatric nursing practice and develop clinical competency to provide the highest-quality compassionate care to children with cancer and blood disorders.

In 2016, the SCI, in partnership with the University of the West Indies School of Nursing (UWISoN), created the Postgraduate Diploma in Pediatric Hematology/Oncology Nursing—the first of its kind in the Caribbean—at St. Augustine Campus, Trinidad and Tobago. This one-year program was jointly taught by SickKids educators and teachers at UWISoN using a variety of teaching methods, including e-learning, case-based classroom learning, and clinical practices. Since its inception, 41 nursing students (divided into three classes) from five SCI partner countries have successfully completed the program. UWISoN is currently assessing the integration of the pediatric hematology and oncology nursing curriculum into its other programs.

Individuals who obtain the Postgraduate Diploma in Pediatric Hematology/Oncology Nursing are leaders who provide quality care, carry out quality improvement initiatives, and mentor their colleagues. In 2019, a survey of graduates from the first two classes showed that 96% (26/27) of graduates had remained in their home countries.

Graduates continue to meet bimonthly through the SCI community of nursing practice, which was created in 2020. Nurses and other health professionals at partner sites also have access to online education sessions and patient education materials, developed and presented within the SCI framework.

More information about the SickKids-Caribbean initiative can be found at the following link:

<https://www.sickkids.ca/en/care-services/centres/global-child-health/capacity-building/#caribbean>

**Figure A12. SickKids-Caribbean initiative logo**



### Case 14. Strategies for developing pediatric oncology nursing competencies (Teletón Children's Cancer Hospital [ITO], Mexico)

The Teletón Children's Cancer Hospital (HITO) opened in 2013 to provide specialized and quality nursing care to pediatric cancer patients and their families. Its challenge was to establish a care model, consolidate a team, standardize procedures, and develop competencies.

In 2021, a survey was conducted among oncology nursing professionals working in Mexico. It revealed that 0.68% are specialized in pediatric oncology; 6.18% are specialized in general oncology; and 4.4% have a related diploma. These data align with those of the competency analysis of 64 nursing professionals who entered HITO between 2019 and 2021. It concluded that 82% had no pediatric oncology knowledge. This limitation was crucial to the article "An ethical imperative: safety and specialization as nursing priorities of WHO Global Initiative for Childhood Cancer",<sup>3</sup> published in 2019, setting a precedent in the HITO nursing department to formulate strategies aimed at developing competencies. These strategies include: 1) orientation programs for new nursing professionals and continuous education including the screening and care of patients with clinical worsening or in a critical condition (Early Warning Score [EWS], Pediatric Advanced Life Support [PALS], and The Golden Hour), academic conferences, a hematopoietic stem cell (HSC) transplantation program, a blood bank, nuclear medicine, infection control, infusion therapy, and wound treatment; 2) a safe environment thanks to the provision of protective equipment and proper disposal, care supplies, biotechnology, and promotion of an adequate work environment; 3) recognition of good practices and participation in quality improvement projects.

**Figure A13.** Pediatric cancer care in Mexico



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<sup>3</sup> *Ibidem.*

## Annex B. Review protocol

### 1. Objective

A scoping review was used to support recommendations on the scope of pediatric oncology nursing practice in Latin America and the Caribbean. Its objective was to identify, systematize, and consolidate available evidence on the scope of pediatric oncology nursing practice in the region from the point of view of essential core competencies, in order to incorporate them into clinical practice, teaching, and research.

### 2. Methodology

#### 2.1. Study design

This study consists of a scoping review. Its aim is to systematically identify the key concepts of a particular research field, clarify conceptual boundaries and definitions, as well as identify evidence, analyze knowledge gaps, and examine how research is conducted in a given field, providing a description and analysis of the studies reviewed.<sup>4-5</sup>

This review is based on the extension Preferred Reporting Items for Systematic Review and Meta-Analysis for Scoping Reviews (PRISMA-ScR).<sup>2,6</sup> It is in line with the JBI Manual for Evidence Synthesis,<sup>2</sup> which contains the following steps: 1) defining and aligning the objectives and research question; 2) developing the inclusion criteria in line with the objectives and guiding question; 3) describing the planned approach to evidence searching, selection, data extraction, and presentation of the evidence; 4) searching for the evidence; 5) selecting the evidence; 6) extracting the evidence; 7) analysis of the evidence; 8) presentation of the results; and 9) summarizing the evidence in relation to the purpose of the review, making conclusions, and noting any implications of the findings.

In order to ensure data reliability and methodological transparency of this review, the data protocol was evaluated and registered in the Center for Open Science (United States of America) Open Science Framework (OSF), and was approved on 15 August 2021 (Registration ID: osf.io/24sv9; DOI: 10.17605/OSF.IO/87GDF).

The PCC<sup>7</sup> strategy was used to formulate the review question, where P = Population (registered pediatric oncology nurse), C = Concept (essential core competencies in pediatric oncology), C = Context (clinical practice, education, and research). This strategy facilitated structured critical reasoning on the topic and formulation of the following question: “What are the essential competencies of pediatric oncology nursing in the context of clinical practice, educational training, and research environments in Latin America?”, as described in Table B1.

<sup>4</sup> Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32. Available from: <https://doi.org/10.1080/1364557032000119616>.

<sup>5</sup> Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, & Khalil H. Chapter 11: Scoping reviews (2020 version). In Atomataris E, Munn Z (editors). *JBI Manual for Evidence Synthesis*. Adelaide: JBI; 2020. Available from: <https://doi.org/10.46658/JBIMES-20-12>.

<sup>6</sup> Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun, H, Levac, D, Straus S, et al. E. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*; 2018;169(7):467–473. Available from: <https://doi.org/10.7326/M18-0850>.

<sup>7</sup> See note 2 to this Annex..

● **Table B1.** Description of the strategy to formulate the research question

Acronym	Definition	Description
P	Patient/Population or Problem	Registered pediatric oncology nurse
C	Concept	Essential core competencies in pediatric oncology
C	Context	Clinical practice, education, and research

## 2.2. Search strategy

A systematic study search was conducted in eight electronic databases: Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Cochrane Library, EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Scopus, ScienceDirect, and Latin American and Caribbean Literature on Health Sciences (LILACS). The study search strategy consisted of combining controlled descriptors (indexers in the respective databases) and keywords, according to the indication offered in each electronic database. The search strategy was not restricted by date or language. In addition to the aforementioned electronic databases, secondary searches were conducted in various other sources, such as ProQuest Dissertations & Theses Global, The British Library, Google Scholar, Preprints for Health Sciences (medRxiv), ClinicalTrials.gov, and International Clinical Trials Registry Platform (ICTRP). Furthermore, the list of final references appearing in the primary studies included was manually analyzed to find relevant studies that could be added. Two PhD nurse researchers—with knowledge and practical and research experience in pediatric oncology—developed the search strategy independently, as recommended by the Joanna Briggs Institute (JBI).<sup>8</sup> First, we identified the index of subject-specific headings in each database (such as MeSH terms, CINAHL Subject Headings, Emtree terms, and DeCS) and their synonyms (keywords). The search terms were then combined using the Boolean operators “AND” and “OR”.<sup>9 - 10</sup>

The search strategy combining MeSH controlled descriptors and keywords used in MEDLINE was as follows:

<sup>8</sup> See note 2 to this Annex.

<sup>9</sup> Lopes-Júnior LC, Rosa, MARP, & Lima, RAG. Psychological and psychiatric outcomes following PICU admission: a systematic review of cohort studies. *Pediatr Crit Care Med*; 2021a;19(1):e58–e67. Available from: <https://doi.org/10.1097/PCC.0000000000001390>.

<sup>10</sup> Lopes-Júnior LC, Siqueira PC, & Maciel E. School reopening and risks accelerating the COVID-19 pandemic: a systematic review and meta-analysis protocol. *PLoS One*; 2021a;16(11):e0260189. Available from: <https://doi.org/10.1371/journal.pone.0260189>.

## P-POPULATION:

# 1 ((Oncology nursing [MeSH terms] OR "Nursing, Oncology" [All fields] OR "Oncology nursing" [All fields] OR "Oncology nursing" [All fields] OR "Nursing, cancer" [All fields] OR "Oncology nursing" [All fields] OR "Registered oncology nurse" [All fields]))

# 2 ((("Pediatric nursing" [MeSH terms] OR "Nursing, pediatric" [All fields] OR "Pediatric oncology nurses" [All fields] OR "Pediatric oncology nursing" [All fields] OR "Pediatric oncology/hematology nurses" [All fields]))

# 3 # 1 AND # 2

## C- CONCEPT:

# 4 ((Clinical competency [MeSH terms] OR Competency, Clinical [All fields] OR "Competency, Clinical" OR "Clinical competency" [All fields] OR "Clinical competencies" [All fields] OR "Competencies, Clinical" [All fields] OR "Clinical skills" [All fields] OR "Skills, clinical" [All fields] OR "Professional competency" [MeSH terms] OR "Professional competency" [All fields] OR "Generalization of experience" [All fields] OR "Technical experience" [All fields] OR "Technical experience" [All fields] OR "Competency-based education" [MeSH terms] OR "Competency-based education" [All fields] OR "Competency-based education" [All fields] OR "Education, competency-based" [All fields]))

## C: CONTEXT:

# 5 ((Study plan [MeSH terms] OR Study plan [All fields] OR "Training programs" [All fields] OR "Program, training" [All fields] OR "Programs, training" [All fields] OR "Literacy programs" [All fields] OR "Literacy program" [All fields] OR "Program, literacy" [All fields] OR "Programs, literacy" OR Vocational education [All fields] OR "Education, nursing" [MeSH terms] OR "Nursing education" [All fields] OR "Education, nursing, continuous" [MeSH terms] OR "Post-registration nursing education" [All fields] OR "Post-basic nursing education" [All fields] OR "Education, post-basic nursing" [All fields] OR "Post-basic nursing education" [All fields] OR "Continuous nursing education" [All fields] OR "Continuous nursing education" [All fields] OR "Education, nursing, postgraduate" [MeSH terms] OR "Nursing education, graduate" [All fields] OR "Postgraduate nursing education" [All fields] OR "Postgraduate nursing education" [All fields] OR "Research in nursing education" [MeSH terms] OR "Research, nursing education" [All fields] OR "Research nursing education" [All fields] OR "Research in education, nursing" OR "Research, nursing education" [All fields] OR "Research in nursing" [MeSH terms] OR "Research nursing" [All fields] OR "Advanced practice nursing" [MeSH terms] OR "Nursing, advanced practice" [All fields] OR "Nursing practice, advanced" [All fields] OR "Role of the nurse" [MeSH terms] OR "Role, nurses" [All fields] OR "Scope of nursing practice" [All fields])) "Education" [All fields] OR "Research education in nursing" [All fields] OR "Research in education, nursing" OR "Research, education in nursing" [All fields] OR "Research in nursing" [MeSH terms] OR "Research in nursing" [All fields] OR "Advanced practice nursing" [MeSH terms] OR "Nursing, advanced practice" [All fields] OR "Practice nursing, advanced" [All fields] OR "Role of the nurse" [MeSH terms] OR "Role, nurses" [All fields] OR "Scope of nursing practice" [All fields])) "Education" [All fields] OR "Research education in nursing" [All fields] OR "Research in education, nursing" OR "Research, education in nursing" [All fields] OR "Research in nursing" [MeSH terms] OR "Research in nursing" [All fields] OR "Advanced practice nursing" [MeSH terms] OR "Nursing, advanced practice" [All fields] OR "Nursing practice, advanced" [All fields] OR "Role of the nurse" [MeSH terms] OR "Role, nurses" [All fields] OR "Scope of nursing practice" [All fields])) Nurses [All fields] OR "Scope of nursing practice" [All fields])) "Nurses" [All fields] OR "Scope of nursing practice" [All fields]))

# 6 # 3 AND (# 4 OR # 5)

The EndNote™ reference manager was used in this phase of the search strategy to store, organize, and exclude duplicates, to ensure a systematic, complete, and manageable search.



### 2.3. Eligibility criteria and study selection

- Inclusion criteria: primary studies, experience reports, guides, manuals, dissertations, and theses related to the essential skills to support international pediatric oncology nursing practice, primarily in Latin America and the Caribbean. Study selection was not restricted by date or language.
- Exclusion criteria: studies focusing on oncology nursing practice with adult and older populations were excluded.

Two reviewers—both PhD nurse researchers with practical and research experience in pediatric oncology (LCL) and EBSM—also participated in study selection independently and blindly. Following selection, a third reviewer—also a PhD nurse researcher with practical and research experience in pediatric oncology (RAGL)—was tasked with analyzing and deciding on the inclusion/exclusion of each article—primarily those on which no consensus had been reached. We used the Rayyan™<sup>11</sup> application as an auxiliary tool to archive, organize, and select articles comprising the sample during this article inclusion and exclusion step.

### 2.4 Data collection

The same two reviewers (LCL) and EBSM) independently extracted data from each study included as per the extraction forms presented above.<sup>12</sup>

### 2.5. Methodological assessment of the studies included

Assessing the studies' methodological quality was seen as essential to establishing internal validity. Accordingly, possible biases and the reliability of the evidence identified were checked. The hierarchy of evidence was used to classify the selected studies.<sup>13</sup> This classification was chosen due to its widespread and effective use in the health field to classify scientific evidence for scoping reviews. The classification is divided into seven hierarchical levels, as described in Table B2.

<sup>11</sup> Ouzzani M, Hammady H, Fedorowicz Z, & Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Systematic Reviews*. 2016;5(1):1-10. Available from: <https://doi.org/10.1186/s13643-016-0384-4>. <https://doi.org/10.1186/s13643-016-0384-4>.

<sup>12</sup> Lopes-Júnior LC, Urbano IR, Schuab S, Pessanha RM, Rosa GS, & Lima RG. Effectiveness of complementary therapies for the management of symptom clusters in palliative care in pediatric oncology: a systematic review. *Rev Esc Enferm USP*; 2021;55:03709. Available from: <https://doi.org/10.1590/S1980-220X2020025103709.a>.

<sup>13</sup> Fineout-Overholt E, Melnyk BM, Stillwell SB, & Williamson KM. Evidence-based practice step by step: critical appraisal of the evidence: part I. *Am J Nurs*; 2010;110(7):47–52. Available from: <https://doi.org/10.1097/01.NAJ.0000383935.22721.9c>.

● **Table B2.** Hierarchy of evidence

Level of evidence	Study design
I	Evidence derived from systematic reviews or meta-analysis of randomized controlled clinical trials.
II	Evidence derived from a well-designed randomized controlled clinical trial.
III	Evidence derived from a well-designed non-randomized controlled clinical trial.
IV	Evidence derived from a well-designed case-control, cohort, or cross-sectional study.
V	Evidence derived from a systematic review of qualitative and descriptive studies.
VI	Evidence derived from a single descriptive or qualitative study.
VII	Evidence derived from expert opinions or specialist reports.

The three reviewers (LCL, EBSM, and RAGL) were responsible for independently checking the studies' methodological quality, using specific JBI methodological assessment instruments.<sup>14</sup>

## 2.6. Data analysis and presentation

Results are presented using narrative summaries and tables, and are assessed based on the guiding question, the type of data identified, and the results. The significance of these findings was also considered according to their relationship with the guiding question, and with the objective of consolidating available evidence on the scope of pediatric oncology nursing practice in Latin America and the Caribbean based on essential core competencies, in order to incorporate them into clinical practice, education, and research.

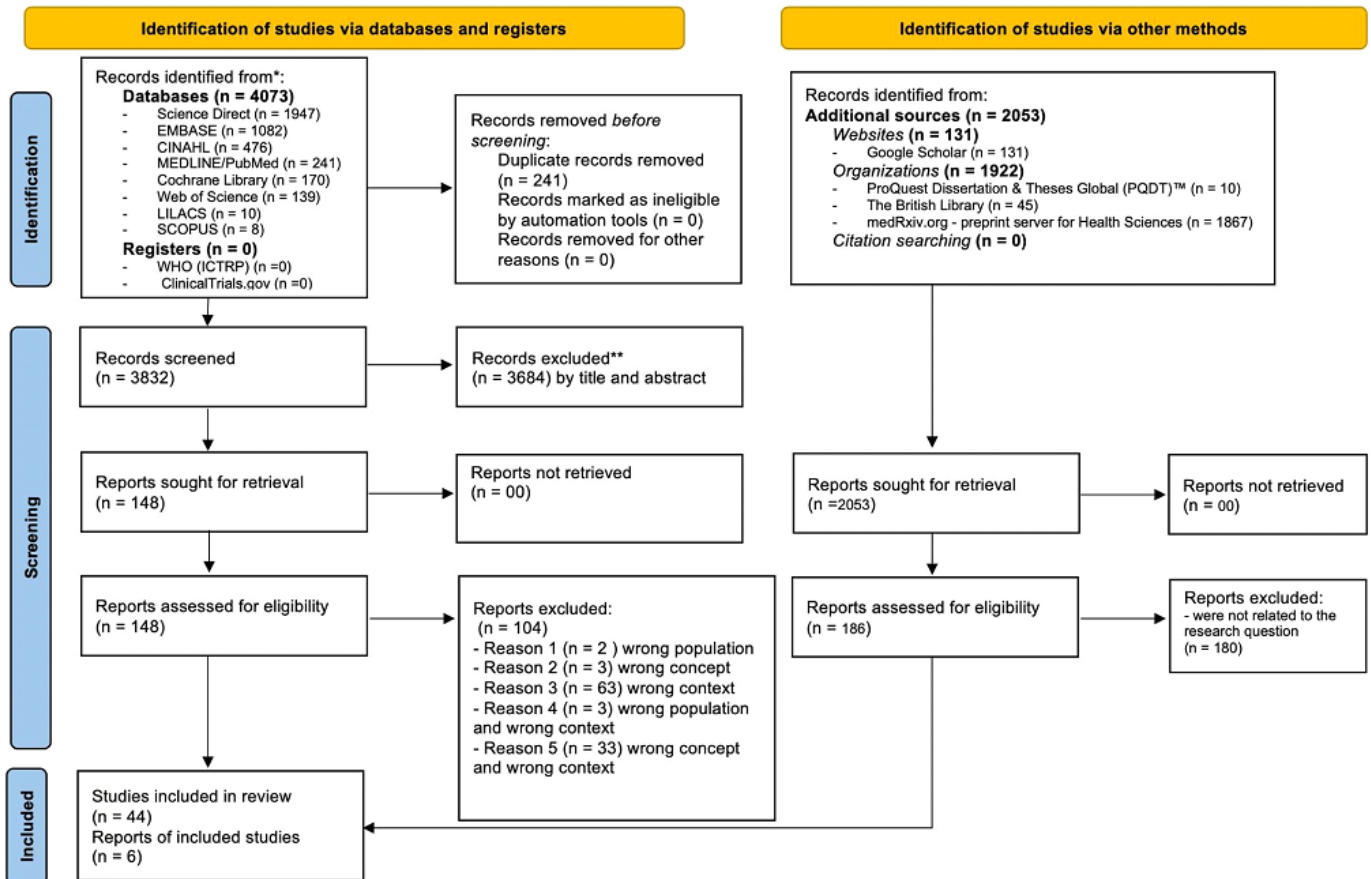
<sup>14</sup> Joanna Briggs Institute. *Critical Appraisal Tools*. JBI; 2017 [accessed on: 1 December 2022]. Available from: <https://jbi.global/critical-appraisal-tools>.

### 3. Results

#### 3.1. Study selection

Studies were included in this scoping review of pediatric oncology nursing practice in Latin America and the Caribbean according to the PRISMA algorithm (Figure B1).

Figure B1. PRISMA Algorithm



#### 3.2. Study characterization

The studies included in this scoping review were published between 1987 and 2021. Most have a quantitative or critical-reflective approach (n = 46), while four are qualitative studies. Among the studies, 21 (42%) are related to “Clinical Practice”; 16 (32%) were classified under “Education”, and 13 (26%) under “Research” (Table B3).

● **Table B3.** Characteristics of the studies included in the scoping review

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
<b>CLINICAL PRACTICE</b>						
Bakke, King, 2000 <sup>16</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To study strategies for developing optimal communication and healthy professional care relationships in the pediatric oncology setting.	N/A	VII
Munet-Vilaró, 2004 <sup>2</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To analyze selected cultural factors—such as language and interpretation, services, beliefs, health care practices, and communication styles of Latino families—that can increase and improve nurses’ ability to work with children with cancer and their families.	N/A	VII
Rushton, 2005 <sup>3</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Descriptive study (case report)	To present case studies of two children during the course of a life-threatening disease and death.	Y	VII
Carlson, 2005 <sup>4</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To study the expansion of the role of nursing in clinical trials, the multidisciplinary challenges of investigational therapies, and the development of an innovative approach to patient care in phase I or II studies.	N/A	VII

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Hollis, 2005 <sup>5</sup>	European Journal of Cancer (JCR: 9,16)	United Kingdom of Great Britain and Northern Ireland	Expert opinion	To analyze the role of pediatric oncology nurse practitioners in the United Kingdom	N/A	VII
Skinn, 2006 <sup>6</sup>	Doctoral thesis	United States of America	Cross-sectional study	To evaluate the Skinn Model of Cultural Competence (SMCC), a theoretical framework developed by this	Y	IV
Black, 2007 <sup>7</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Systematic review	To identify whether the use of standardized telephone triage practices can provide opportunities to improve pediatric oncology patient care or whether this standardization should be balanced with the intuitive knowledge and experience of the nurses involved.	N/A	V
Cantrell, 2007 <sup>8</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To analyze the art of pediatric oncology nursing practice and its influence on treatment outcomes.	N/A	VII
Andam y Silva, 2008 <sup>9</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Systematic review	To describe this institution's journey in developing a comprehensive program that includes the didactic and practical validation of chemotherapy administration in the pediatric population.	N/A	V

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Ruccione, 2009 <sup>10</sup>	Journal of Pediatric Oncology Nursing (JCR: 1.63)	United States of America	Expert opinion	To describe the contributions of pediatric oncology nursing to advancing the study of survival and improving survivors' quality of care, as well as to highlight areas of ongoing challenge and future directions suggested by thought leaders in our specialty.	N/A	VII
Foster et al., 2010 <sup>11</sup>	Seminars in Oncology Nursing (JCR = 2,31)	United Kingdom of Great Britain and Northern Ireland	Systematic review	To describe selected components of pediatric palliative care from diagnosis to cure or end of life, which combine to help nurses and other medical professionals	N/A	V
Monteiro et al., 2012 <sup>12</sup>	Revista da Escola Anna Nery (JCR = -)	Federative Republic of Brazil	Qualitative study	To comprehensively analyze nursing care for hospitalized children suffering from cancer that is as yet incurable.	Y	VI
Warnock, 2013 <sup>13</sup>	European Journal of Oncology Nursing (JCR = 2,39)	United Kingdom of Great Britain and Northern Ireland	Descriptive study	To identify and compare the opinions of administrative staff and nurses on the ideal and current role of nurses in delivering late-effects care.	Y	VI

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Day et al., 2007 <sup>14</sup>	Pediatric Nursing (JCR = 3,16)	Republic of Guatemala	Quasi-experimental study	To evaluate the impact of the International Extension Nursing Program on the quality of nursing care by evaluating the quality standards selected by Joint Commission International (JCI) in the National Pediatric Oncology Unit of Guatemala.	Y	III
Martins et al., 2016 <sup>15</sup>	European Journal of Oncology Nursing (JCR = 2,39)	United Kingdom of Great Britain and Northern Ireland	Qualitative study	To describe the development and introduction of the key role of nurse practitioners in 18 children's cancer centers in the United Kingdom, and to extract important success factors to inform future development of the role across a range of specialties.	Y	VII
Currie et al., 2018 <sup>16</sup>	Seminars in Oncology Nursing (JCR = 2,31)	United States of America	Expert opinion	To describe pediatric palliative care (PPC) in pediatric oncology, and the importance and implications of PPC for pediatric oncology.	N/A	VII
Bovero et al., 2018 <sup>17</sup>	European Journal of Oncology Nursing (JCR = 2,39)	Switzerland	Descriptive study	To describe the approach taken to include advanced nursing practice (ANP) in a pediatric hematology and oncology unit.	Y	VII

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Oliveira et al., 2019 <sup>18</sup>	Enfermagem em Foco (JCR = -)	Federative Republic of Brazil	Comprehensive review	To identify the competencies of pediatric nurses working in oncology.	N/A	V
Newman et al., 2020 <sup>19</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United Kingdom of Great Britain and Northern Ireland	Qualitative study	To support nurses' descriptions of prognostic communication and how they experience this communication in their daily practice.	S	VII
Chan et al., 2020 <sup>20</sup>	Cancer Nursing (JCR = 2,59)	Australia	Expert opinion	To argue the importance of capacity-building in the oncology nursing workforce to provide high-quality self-management support (SMS) for cancer survivors.	N/A	VII

## RESEARCH

Hinds et al., 1990 <sup>21</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Cross-sectional study	To have pediatric oncology nurses identify and rate thematic priorities for clinical nursing research in the specialty and determine whether nurses in a pediatric oncology center identified different priorities to their nursing colleagues in other settings.	Y	IV
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Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Hinds et al., 1994 <sup>22</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Cross-sectional study	To have APON members identify and rank pediatric oncology nursing research priorities.	Y	IV
Birenbaum et al., 1995 <sup>23</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To use a recently completed study to: 1) identify the benefits of multicenter qualitative research, 2) describe the measures taken to facilitate these benefits, 3) identify critical decisions in the research process, and 4) develop recommendations for future multicenter qualitative research.	N/A	VII
Fochtman y Hinds, 2000 <sup>24</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Cross-sectional study	To discover patient care concerns or other clinical trial-related issues in pediatric oncology nursing.	Y	IV
Hare et al., 2004 <sup>25</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To study research challenges and research agenda-related opportunities for the future of children and adolescents with cancer.	N/A	VII

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Reaman et al, 2004 <sup>26</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To analyze the areas able to benefit from a transdisciplinary research model, as well as the challenges of this form of collaboration.	N/A	VII
Kazak et al., 2004 <sup>27</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To outline four broad priority research areas related to family assessment and intervention in pediatric oncology.	N/A	VII
Hare et al, 2005 <sup>28</sup>	Seminars in Oncology Nursing (JCR = 2,31)	United States of America	Expert opinion	To compare and contrast the research priorities developed at the State of Science Summit II for Pediatric Oncology Nursing (SOS II) with those developed at a working group meeting held in August 2003, entitled "Moving the research agenda forward for children and adolescents with cancer".	N/A	VII

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Hawks et al., 2006 <sup>29</sup>	Journal of Pediatric Oncology Nursing (JCR: 1,63)	United States of America	Expert opinion	To review the study development process within the Children's Oncology Group (COG), explore alternative and complementary medicine research initiatives within the COG, and discuss the multidimensional role of the nurse as an implementing physician and collaborating researcher in research into this type of medicine.	N/A	VII
Maru et al., 2013 <sup>30</sup>	Cancer Nursing (JCR = 2,59)	Japan	Expert opinion	To analyze the globalization of pediatric oncology nursing research.	N/A	VII
<b>EDUCATION</b>						
McGee et al., 1987 <sup>31</sup>	Oncology Nursing Forum (JCR: 2,17)	United States of America	Cross-sectional study	To identify the competencies required of clinical oncology nurse practitioners, using a modified Delphi survey.	Y	IV
Calzone et al., 2002 <sup>32</sup>	Oncology Nursing Forum (JCR: 2,17)	United States of America	Cross-sectional study	To determine core competencies in cancer genetics for advanced practice nurses (APNs) in oncology.	Y	IV

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Tomlinson, 2004 <sup>33</sup>	Journal of Clinical Nursing (JCR: 3,03)	Scotland	Qualitative study	This paper addresses this deficit by developing a comprehensive framework for a small and widespread specialty.	Y	VII
Day, 2008 <sup>34</sup>	Pediatric Nursing (JCR: -)	United States of America	Expert opinion	To provide recommendations in the areas of education, staffing, compensation, and communication of International Outreach Program (IOP) staff at St. Jude Children's Research Hospital.	N/A	VII
Challinor et al., 2014 <sup>35</sup>	Cancer Nursing (JCR = 2,59)	Republic of South Africa	Cross-sectional	Phase 1: To identify the educational priorities of nurses in low- and middle-income countries (LMICs) providing cancer care. Phase 2: To request educational strategies from expert pediatric oncology nurses. Phase 3: To develop a culturally adaptable modular curriculum framework based on the priorities of LMIC nurses	Y	IV
Day et al., 2014 <sup>36</sup>	Lancet Oncology (JCR = 41,31)	United States of America	Expert opinion	To present reference standards for pediatric oncology nursing care in low- to middle-income countries.	N/A	VII

Reference	Type of publication and JCR2020 impact factor	Country	Design	Objective	Ethical aspects	Level of evidence
Beaver et al., 2016 <sup>37</sup>	Journal for Nurses in Professional Development (JCR = 0,53)	United States of America	Expert opinion	To describe a successful approach to standardizing nursing practice in geographically distant academic and community sites	N/A	VII
Baileys et al., 2018 <sup>38</sup>	Clinical Journal of Oncology Nursing (JCR: 1,02)	United States of America	Expert opinion	To identify the current responsibilities of the Oncology Nurse Navigator (ONN) and differentiate novice from expert practice.	N/A	VII
Esplen et al., 2020 <sup>39</sup>	Supportive Care in Cancer (JCR = 3,60)	Canada	Descriptive study	To develop the relevant framework among regulated health professionals involved in cancer care to ensure the robust set of core and shared competencies required for oncology practice.	Y	VII
Sullivan et al., 2021 <sup>40</sup>	Pediatric Blood & Cancer (JCR = 3,16)	Latin America	Expert opinion	To describe the development, expansion, and impact of a sustainable network approach to pediatric oncology nursing education in Latin America.	N/A	VII

Y: Yes; N/A.: Not applicable.

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### *3.3. Methodological assessment of the studies included in the scoping review*

Most of the quantitative or critical-reflective studies (n = 40; 86.9%) included in this review were classified between 62.5% and 100% according to the Joanna Briggs Institute (JBI) Critical Appraisal Checklist Tools for quantitative studies. In other words, they were methodologically well-founded. The four qualitative studies were all well-founded, with ratings between 60% and 80% according to the JBI Critical Appraisal Checklist Tools for qualitative studies.





One of the main aims of the WHO Global Initiative for Childhood Cancer and the CureAll Americas framework is to strengthen centers of excellence and promote the training of the health workforce, especially pediatric oncology nurses, specialized in nursing care for children and adolescents with cancer and their families. These health personnel provide compassionate, non-traumatic, complex, continuous, ethical, conscious patient- and family-centered care in order to meet the physical, emotional, psychosocial, and cultural needs of the people involved.

This publication is aimed at health administration teams, hospital management teams, and professional pediatric oncology nursing groups. Its objective is to identify, systematize, and consolidate available evidence on the scope of pediatric oncology nursing practice in Latin America and the Caribbean based on core competencies, in order to incorporate them into clinical practice, teaching, and research.

The preparation process included a systematic review aimed at finding the best evidence on this subject. Patient- and family-centered care and the conceptual model of competencies for teenagers and young adults with cancer, developed by the Teenage Cancer Trust with the support of the Royal College of Nursing, were the theoretical foundations supporting the systematization of recommendations.

