



## Childhood cancer survival: Emerging reflections on pediatric oncology nursing

Sobrevivência ao câncer infantojuvenil: reflexões emergentes à enfermagem em oncologia pediátrica

Supervivencia al cáncer infantojuvenil: reflexiones emergentes a la enfermería en oncología pediátrica

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### ABSTRACT

The aim of this study is to analyze and critically reflect on childhood cancer survival, including conceptual aspects, repercussions, survival care, and challenges. This is a theoretical and reflective study, based on the scientific literature on the subject and on the researchers' experience. Childhood cancer survival is conceptualized as the process of living beyond the oncological diagnosis. A person is considered a cancer survivor from the diagnosis until the end of life and is at high risk of experiencing physical, psychosocial, and economic effects. Therefore, survival care shall minimize, as far as possible, these impacts throughout life. Such care includes an action plan to track and treat the persistent effects of therapy, preventing diseases and promoting healthy behaviors, not being restricted to monitoring oncological recurrence. In the national setting, challenges persist, such as the scarcity of policies to guide comprehensive, good quality, and coordinated survival care. Despite these challenges, the nurse occupies a privileged position and is competent to implement survival care and manage the effects related to cancer treatment.

### DESCRIPTORS

Cancer Survivors; Child; Adolescent; Oncology Nursing.

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## INTRODUCTION

Pediatric oncology has changed significantly over the past 40 years<sup>(1)</sup>. The treatment of childhood cancer is one of the great oncology stories of success<sup>(2)</sup>. During a period of history, cancer was considered an incurable disease and the survivors were the family members of the cancer patient who had died. However, as a result of improvements in cancer therapy, children and adolescents started to live for decades after the end of treatment<sup>(3)</sup>.

A total of 65,850 cancer survivors aged zero to 14 years (children) and 47,760 survivors aged 15 to 19 years (adolescents) living in the United States on January 1, 2019 is estimated. Leukemia survivors represent approximately one third of all cancer survivors under the age of 20<sup>(1)</sup>. Data on the number of survivors in Brazil and in the world are still scarce<sup>(4)</sup>.

However, this success in increasing the number of survivors comes at a price, with a very high prevalence of chronic diseases in this population, conditions known as late effects<sup>(5)</sup>. Children and adolescents who survive are exposed to prolonged and intensive treatment protocols to eliminate childhood cancer<sup>(2)</sup>. Even in long-term survival, late effects may appear as they mature, seriously affecting functioning in adulthood<sup>(6)</sup>. Evidence shows that 60% of adult survivors to childhood cancer will develop at least one chronic condition and about one third will have a serious, life-threatening condition<sup>(7)</sup>.

With the population of survivors to childhood cancer growing rapidly, there is a great need for research that discusses survival issues and the potential effects of treatments on the lives of children and adolescents. However, this is a topic that is still little debated in the national oncology nursing literature, with discussions still incipient and the urgent need to expand them, which warrants the relevance of the present study. Additionally, evidence in the literature shows that health care professionals tend to direct their care to patients undergoing active treatment for cancer<sup>(8)</sup>. However, it is necessary to think about care in the post-treatment period, since cancer survival involves much more than just being alive<sup>(6)</sup>.

Presenting a reflective discussion about how survival applied in the context of childhood cancer is an important contribution to the pediatric oncology nursing practice, as it offers nurses new possibilities of providing guidance, support, and care to improve this population's condition of being survivors, aiming at successful survival. Thus, based on the

scientific literature and the researchers' experience, this study aims to describe and critically analyze the survival to childhood cancer, including conceptual aspects, repercussions, survival care, and challenges.

## METHOD

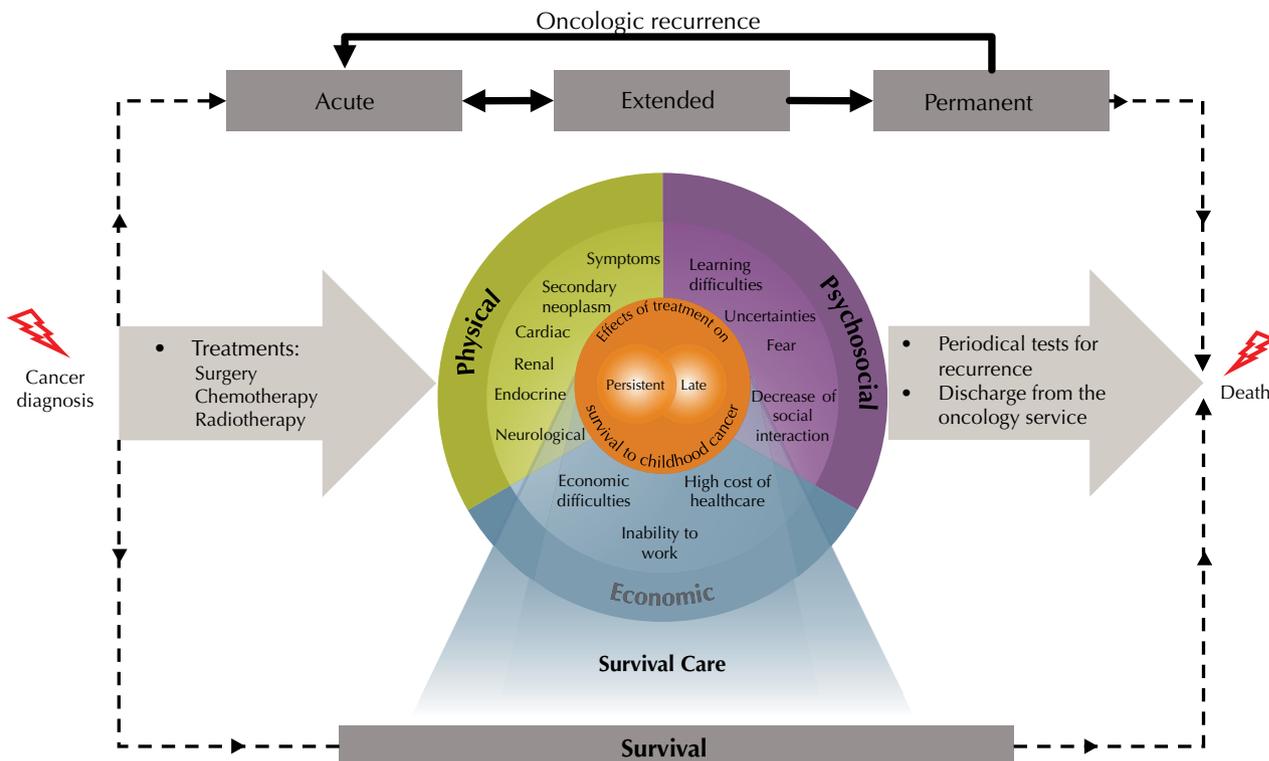
This theoretical-reflective study was based on the relevant literature identified through searches with the following keywords: "sobrevivente/survivor", "sobrevivência/survival", "câncer/cancer", "infância/childhood" and "enfermagem oncológica/oncology nursing". The search was limited to publications in English and Portuguese and, to ensure a historical and current understanding of the phenomenon of childhood cancer survival, no time limit was defined. The databases searched were PubMed, CINAHL, SCOPUS, Web of Science, and Google Scholar. In addition, manual searches were carried out to identify references published by prestigious oncology societies and associations, such as: American Cancer Society (ACS), National Coalition for Cancer Survivorship (NCCS) and National Cancer Institute (NCI). The reference lists in the included literature were also manually reviewed for studies not retrieved from the databases consulted.

## RESULTS

Based on the results of the literature captured and analyzed, a diagram was created to help elucidate the key components of childhood cancer survival (Figure 1), with conceptual aspects, repercussions of survival, and their care being highlighted.

### DEFINING SURVIVAL IN THE CONTEXT OF CHILDHOOD CANCER

The word survival stems from the verb survive<sup>(4)</sup>; in the dictionary, it is defined as an act or effect of surviving, of continuing living or existing<sup>(9)</sup>. The term survival first appeared in the medical literature in the 1960s, not linked to oncology, but to people who survived myocardial infarction. Later, in the 1970s, this concept emerged in the cancer-related literature<sup>(10)</sup>, particularly in pediatric oncology<sup>(11)</sup>. After the development of protocols for the treatment of childhood cancer, pediatric oncologists discovered that many children remained in remission for prolonged periods and that they needed to be followed up in the post-treatment period<sup>(12)</sup>. This was the beginning of survival care for childhood cancer<sup>(11)</sup>.



**Figure 1** – Key components of childhood cancer survival - Ribeirão Preto, SP, Brazil, 2020.

Cancer survival took on a new meaning in 1985, with the publication by Dr. Fitzhugh Mullan in the *New England Journal of Medicine*, in which this physician, also a cancer patient, described his own personal reflections on survival. In this work highly referenced in studies related to cancer survival<sup>(11)</sup>, Mullan divided survival into three distinct “seasons of survival”: acute, extended, and permanent survival. The first one begins with the diagnosis of cancer and includes treatment, in which the focus is on removing and reducing cancer and treatment acute effects. Fear and anxiety are constant during this phase. The next one is the extended phase, which begins when the patient completes the course of primary treatment or goes into remission of the disease. This is the season of “watchful observation” with periodic examinations, in which the fear of recurrence is the predominant feeling. Finally, we have permanent survival, which is very close to the “cure” described in the literature. However, the binary concept of “cured” and “not cured” is avoided by Mullan when he describes survival, since there is no moment of cure, but a progression to a stage where the probability of recurrence is small enough and cancer can be considered controlled<sup>(13)</sup>. This definition by Mullan shows that survivors experience uncertainties and need to deal with specific emotions in the different stages of cancer survival.

Consistent with Mullan’s concept of survival, the NCCS defined survival as the process of living after the diagnosis of cancer<sup>(14)</sup>. A person becomes a cancer survivor the moment he/she receives the diagnosis and remains so until the end of his/her life<sup>(15)</sup>. The definition has been expanded to include these individuals’ family members, friends, and

caregivers<sup>(16)</sup>. This perspective aims to recognize the person, and not just the patient, as well as their needs, and not just their treatments.

The experience of cancer survival encompasses a number of trajectories that only end with the survivor’s death<sup>(15)</sup>. This means that survival is an ongoing process for the rest of the survivor’s life. This is especially important when considering that around 80% of children and adolescents will live years beyond the diagnosis of childhood cancer<sup>(1)</sup>. The trajectories<sup>(15)</sup> that can be experienced by these people in the course of cancer survival are described in Chart 1. Although a survivor’s experience may have characteristics that are similar to that of another, and, to some extent, trajectories in common, this event is uniquely experienced by each patient.

**Chart 1** – Different trajectories of cancer survival - Ribeirão Preto, SP, Brazil, 2020.

Living cancer-free after treatment for the remainder of life
Living cancer-free after treatments for many years, but experiencing one or more serious late treatment complications
Living cancer-free after treatment for many years, but dying after a late recurrence
Living cancer-free after the first cancer is treated, but developing a second cancer
Living with intermittent periods of active disease requiring treatment
Living with cancer continuously, with or without treatment, without a disease-free period

In the oncological scientific literature, there has still been a wide discussion about the use of the term survival, specifically about when it actually starts in cancer situations<sup>(10)</sup>. For a long time, the term survival has been frequently used related to time since diagnosis and measured in five-year increments, with no recurrence episodes<sup>(11)</sup>. However, important associations, such as the NCCS and the ACS, adopted the definition described by Mullan to conceptualize cancer survival<sup>(14)</sup>. Although the most widely accepted definition is that survival begins at the time of diagnosis and continues throughout life, this lack of a conceptual definition regarding the term “cancer survivor” is a challenge that can make it difficult for health professionals to identify potential survivors in their health services, besides impairing the development of health care plans that meet their needs.

Survival is not a single condition, but multiple conditions<sup>(13)</sup>; it is not a single moment or a specific phase after treatment, but a sequence of events<sup>(4)</sup>. To understand how the concept of survival is applied in the context of childhood cancer, a study identified this concept associated with the following attributes: 1) individual perception of the experience of childhood cancer; 2) multifaceted experience from the repercussions in different dimensions of life; 3) uncertainty due to the possibility of disease recurrence; 4) new normal after treatment; 5) the need for constant negotiation; 6) search for constant information, decision making, own rights (advocacy); and 7) partnerships, with the family as a constant source of support<sup>(11)</sup>.

#### EFFECTS OF TREATMENT ON CHILDHOOD CANCER SURVIVAL

In the oncology field, pediatric oncology was the precursor in the dissemination of knowledge about survival issues related to cancer treatment and its effects, due to the early implementation of treatment protocols to fight childhood cancer in the 1970s. As the number of survivors increased, the researchers were able to study the relationships between specific aspects of the therapy and its effects<sup>(12)</sup>. Childhood cancer treatment involves a single set of therapies that can lead to a number of effects<sup>(2)</sup>. These effects result from the combination of surgical, radiotherapy, and chemotherapy treatments, and generally depend on factors such as patient's age, degree of the disease, dose, treatment schedule, and exposed body part<sup>(2,12)</sup>.

There can be physical changes during development, from childhood to adulthood, and they are especially influenced by agents that inhibit tissue growth and differentiation, as well as by radiation and certain specific types of drugs. Children, unlike adults, can be severely affected by these agents and, since they were the first beneficiaries of combined therapy, it was possible, from an early age, to know the effects after childhood cancer treatment<sup>(12)</sup>.

These effects can affect all aspects of the life of the survivors and their families. Cancer survival is characterized by being a multifaceted experience, since the side effects of cancer and its treatment can occur before, during,

and many years after diagnosis, treatment, and remission<sup>(11)</sup>. They can also be categorized in several ways, as permanent or late effects. The permanent ones are chronic sequelae persisting after the end of treatment and can include symptomatic physical adverse effects, such as pain, fatigue, and neuropathy. The late effects, depending on their particularities, can appear months or years after the end of treatment<sup>(6)</sup>. The latter can still be directly observable, such as amputation of a limb, or functional, such as cognitive impairment<sup>(2)</sup>.

Besides fatigue, pain, neuropathy and cognitive impairment, children and adolescents may experience other physical effects, such as infertility, cardiac toxicity, renal failure, hearing loss, endocrine disorders, and the development of secondary neoplasia<sup>(7,17)</sup>. The two late physical effects associated with a higher risk of premature mortality in childhood cancer survivors are cardiac toxicity<sup>(18)</sup> and the development of secondary neoplasia<sup>(19)</sup>. The risk of breast cancer in survivors to childhood cancer at 50 years of age is comparable to that of women with a BRCA gene mutation<sup>(19)</sup>. Children who have been exposed to anthracycline chemotherapy and/or have received radiation in a field that includes the heart area are at high risk for cardiac toxicity<sup>(20)</sup>. Chart 2 summarizes some of the late effects most commonly associated with childhood cancer.

**Chart 2** - Late effects of childhood cancer - Ribeirão Preto, SP, Brazil, 2020.

System	Possible effects
Cardiac	Valve disease
	Pericarditis
	Myocardial infarction
	Congestive heart failure
	Sudden death
Renal	Renal insufficiency or failure
	Hydronephrosis
Endocrine	Growth retardation
	Pituitary, thyroid, and adrenal disease
	Ovarian or testicular failure
	Late puberty
	Infertility
	Obesity
Neurological	Learning difficulties
Secondary neoplasm	Solid tumors
	Leukemia
	Lymphoma
	Brain tumors
Symptoms	Fatigue
	Pain
	Neuropathy

Childhood cancer treatment has the potential to affect surviving children and adolescents not only physically, but also psychosocially throughout the course of their lives<sup>(21)</sup>. Some emotional effects that can affect the survivor include anxiety, fear, sadness, depression, and uncertainty<sup>(22)</sup>. Survivors face a number of consequences until many years after the end of cancer treatment, such as learning difficulties, as well as difficulty to keep an active and independent life, to socially interact, and make friends<sup>(21,23)</sup>. In addition, they are more vulnerable to the development of post-traumatic stress disorder<sup>(24)</sup>. Fear of tumor recurrence is also a significant psychological effect on the lives of survivors and their families<sup>(2)</sup>.

In addition to the physical and psychosocial sequelae of cancer therapy, survivors of childhood cancer have a high long-term risk of facing economic difficulties, which can result in material, psychological, and behavioral consequences, including high cost of health care and treatment, and limitations or inability to work. They are also more likely to be unable to work or to miss work due to health problems<sup>(25)</sup>. Moreover, cancer financial burden can extend for decades after diagnosis. When revealing the cancer history, childhood cancer survivors may face difficulties in accessing personal and insurance loans<sup>(26)</sup>.

#### COMPREHENSIVE CARE IN CHILDHOOD CANCER SURVIVAL: POSSIBILITIES AND CHALLENGES

The promising increase in the number of children living beyond the diagnosis of cancer has brought another challenge, that of taking care of the treatment long-term effects<sup>(6)</sup>. Even when the number of survivors was not as significant as it is today, it was recognized that curing a child from cancer was not enough. Pediatric oncology nurses were the first to identify the need to offer specific care to these survivors in the post-cancer treatment period<sup>(27)</sup>.

In 2003, the Institute of Medicine (IOM) published the report entitled *Childhood Cancer Survivorship: Improving Care and Quality of Life*, in which they make a number of recommendations for the provision of comprehensive care for survival. These recommendations go beyond those normally suggested for adult cancer survivors, which are directed to emphasizing recurrence monitoring. In child and adolescent survival care, the guidelines emphasize the importance of tracking and treating persistent and late effects, of reducing the risk of second cancers, when possible, and of promoting the adoption of healthy behaviors and lifestyles<sup>(2)</sup>. This report represents a milestone for assistance to survivors, as it describes in an unprecedented way the practical recommendations for survival care.

Several variables can affect cancer survival care: the type of cancer and the treatment received; the patient's age at diagnosis; the years since diagnosis and racial, ethnic, and socioeconomic aspects<sup>(28)</sup>, as well as personal skills, such as coping and support. This leads to a very different survival experience for each individual, although everyone has similar diagnoses. What the child understands about his/her

experience with cancer and subsequent survival can differ significantly from the adolescent's or young adult's perception of that same experience<sup>(11)</sup>.

Survival care shall be based on individual assessments and contain planned guidelines on a case-by-case basis. However, it is recognized throughout the literature, based on the essential components of the IOM, that survival care shall include the following components: a) prevention, screening, and interventions for recurrence, long-term and late effects; early detection of new cancers; b) evaluation, support, management, and provision of information related to physical, psychological, social, and spiritual needs; c) monitoring, information, and promotion of healthy living and disease prevention behaviors; d) coordination of care among providers to communicate general health needs<sup>(2)</sup>.

Children and adolescents, when completing their primary cancer treatment, shall receive a summary of their treatment history and a comprehensive follow-up plan. This document shall include the history of cancer treatment, since the diagnosis, treatments received (such as type, dosages, dates, procedure, and radiated fields) and potential consequences, covering problems found during treatment and their possible future impacts<sup>(17)</sup>. The follow-up plan, in its turn, shall contain the recommended follow-up time, evaluation and treatment of late and prolonged effects; education on possible prolonged effects; recommended wellness plans (prevention practices and health behaviors); assessment of psychosocial distress; sharing of information about sources of support; and evaluation of economic issues<sup>(6)</sup>.

As a result of increasing awareness about care needs of survivors to childhood cancer, some institutions have initiated long-term effects follow-up programs, which have a multidisciplinary team at the helm to monitor and support survivors. Team composition generally includes pediatric and radiological oncologists, a pediatric oncology nurse, a social worker, a health educator, and a psychologist. They keep a close working relationship with endocrinologists, cardiologists, and other specialists whose services are necessary for some survivors<sup>(2)</sup>. However, this is not a reality in part of the centers for pediatric cancer treatment in several countries, including Brazil<sup>(29)</sup>, which still focus exclusively on curing the disease and seem unconcerned about the late effects of cancer survival<sup>(2)</sup>. In Brazil, the National Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases<sup>(30)</sup> suggests a model of care for cancer patients based on prevention and early detection, access to diagnostic confirmation, adequate treatment, and timely and palliative care, without, however, mentioning guidelines for survival care.

Brazilian health care is notoriously heterogeneous. Structured and well-equipped cancer centers are located mainly in the southeastern and southern states of the country. Unfortunately, 83 million people live in areas where public health lacks specialized professionals and essential technology. The management of survivors to childhood cancer is still very diverse; most of the country still struggles with the

screening and early detection of childhood cancer<sup>(29)</sup>. Thus, the comprehensive provision of survival care assisted by a multidisciplinary team is still a challenge to be overcome. This challenge is even greater for children and adolescents living in regions of the country where access to health services is limited.

Survival care has been discussed upon since 1980. In the United States, most pediatric cancer centers offer programs with this care<sup>(29)</sup>. In Brazil, while children and adolescents with cancer are being treated, their care is performed by specialized health professionals, in inpatient and outpatient units of the main tertiary hospitals. After treatment, the responsibility for health care returns to the primary care physician, internist, and pediatrician, with the tertiary center being responsible only for the follow-up and detection of tumor recurrence<sup>(29)</sup>. Thus, the childhood cancer survivor and his/her family feel lost in the transition between specialized care and primary care, lacking the necessary survival care. Primary care has the potential to play a key role in providing quality and effective follow-up and care to survivors and their families living with and beyond a cancer diagnosis, but this is still a distant reality in the Brazilian health system.

Much progress has been made since the first discussions on survival care emerged, but more efforts are needed to ensure that all survivors have access to quality, comprehensive, and coordinated care. Cancer survivors usually have specific medical and non-medical needs related to their cancer experience. In the case of the treatment of childhood cancer, the provision of comprehensive care can help children and adolescents live with quality and in well-being.

Nursing is in a good position to implement survival care, since managing effects related to cancer and its treatment falls within the scope of nursing practice, regardless of the scenario. Nurses are like catalysts, internists, educators, researchers, and administrators who are in excellent positions to provide effective, comprehensive care focused on the well-being and care planning for survivors<sup>(6,27)</sup>. Although the urgent discussions presented in this study are aimed at pediatric oncology nurses, they have the potential to extrapolate this field and raise reflections for changes also in the scope of general nursing practice, whose professionals provide care to surviving children and adolescents at different health care levels.

Finally, it is up to decision makers to develop health guidelines and policies specific for survivors, as our health

system still lack them. Meeting the unique and complex needs of the growing population of cancer survivors is a challenge that can only be responded to with an equitable and accessible survival care model. These policies shall also provide for the training of health professionals, for them to acquire knowledge, skills, and attitudes that are appropriate to quality care for survivors.

## FINAL CONSIDERATIONS

This study discussed and analyzed the scientific literature on childhood cancer survival, specifically on the definition of the concept of survival, effects of treatment on survival, and challenges and possibilities in the implementation of survival care.

Cancer survival experience encompasses a series of trajectories that begin with the diagnosis and only end with the death of the survivor. The results presented in this study help to understand how survival is applied in the context of childhood cancer and will help nurses to accurately identify survivors to childhood cancer during clinical practice, so that they can provide the necessary care, support, and guidance to these people. In addition, a presented definition of survivor has the potential to guide the selection of subjects for future research related to survival, which are still scarce on the national setting.

Children and adolescents who survive childhood cancer are at high risk of experiencing physical, psychosocial, and economic effects throughout their lives. This population, unlike adults, is at greater risk of experiencing secondary physical effects as well, as they are in full growth and development.

Therefore, survival care shall be provided to minimize these repercussions throughout life. Recommendations for survival care includes an action plan for tracking and treating the persistent effects of therapy, preventing diseases and promoting healthy behaviors, not being restricted to monitoring oncological recurrence. In the national setting, many challenges persist, such as the scarcity of policies to guide comprehensive, good quality, and coordinated survival care. However, even in the face of these challenges, nurses, in their clinical practice, adopt a privileged position to implement survival care and manage the effects related to cancer treatment.

## RESUMO

O objetivo deste estudo é analisar e refletir criticamente sobre a sobrevivência ao câncer infantojuvenil, incluindo aspectos conceituais, repercussões, cuidados de sobrevivência e desafios. Estudo teórico e reflexivo, fundamentado na literatura científica sobre a temática e na experiência dos pesquisadores. A sobrevivência ao câncer infantojuvenil é conceituada como o processo de viver além do diagnóstico oncológico. Uma pessoa é considerada sobrevivente de câncer desde o diagnóstico até o final da vida e tem risco elevado de desenvolver efeitos físicos, psicossociais e econômicos. Portanto, cuidados de sobrevivência devem minimizar, na medida do possível, essas repercussões ao longo da vida. Esses cuidados incluem um plano de ações para rastreamento e tratamento dos efeitos persistentes da terapêutica, prevenção de doenças e promoção de comportamentos saudáveis, não se restringindo ao monitoramento da recorrência oncológica. No contexto nacional, desafios persistem, como a escassez de políticas que orientem os cuidados de sobrevivência de qualidade, abrangentes e coordenados. Apesar destes desafios, o enfermeiro ocupa posição privilegiada e é competente para implementar cuidados de sobrevivência e gerenciamento dos efeitos relacionados ao tratamento oncológico.

## DESCRITORES

Sobreviventes de Câncer; Criança; Adolescente; Enfermagem Oncológica.

## RESUMEN

El objetivo de este estudio es analizar y reflexionar críticamente acerca de la supervivencia al cáncer infantojuvenil sobre todo en los aspectos conceptuales, repercusiones, cuidados de supervivencia y desafíos. Se trata de estudio teórico y reflexivo sobre el tema con fundamentación en la literatura científica y en la experiencia de los investigadores. La supervivencia al cáncer infantojuvenil se define como el proceso de vivir más allá del diagnóstico oncológico. A uno se le considera superviviente de cáncer desde su diagnóstico hasta el final de su vida con riesgos elevados de desarrollar efectos físicos, psicosociales y económicos. Por lo tanto, cuidados de supervivencia deben minimizar, cuando posible, esas repercusiones a lo largo de la vida. Esos cuidados incluyen un plan de acciones para búsqueda y tratamiento de los efectos persistentes de la terapéutica, prevención de enfermedades y fomento de comportamientos sanos, sin restricción del monitoreo de la recurrencia oncológica. En el contexto nacional persisten desafíos como la escasez de políticas que orienten los cuidados de supervivencia con calidad y que sean amplios y ordenados. A pesar de ello, el enfermero ocupa posición privilegiada y es competente para implementar cuidados de supervivencia y supervisión de los efectos del tratamiento oncológico.

## DESCRIPTORES

Supervivientes de Cáncer; Niño; Adolescente; Enfermería Oncológica.

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