

# Clinical and Epidemiological Profile of Children and Adolescents with Cancer in an Oncology Service

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*Perfil Clínico-epidemiológico de Crianças e Adolescentes com Câncer em um Serviço de Oncologia*

Perfil Clínico Epidemiológico de Niños y Adolescentes con Cáncer en un Servicio de Oncología

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## Abstract

**Introduction:** Progress in cancer control in the last 50 years is undeniable, however, in Brazil it still represents the second cause of death in the child and adolescent population and studies have not shown a decline in this data. **Objective:** To analyze the clinical-epidemiological profile of children and adolescents with cancer in an Oncology Service. **Method:** Retrospective documentary study, with search of data in medical records of children and adolescents, with diagnosis of cancer in the period from 2008 to 2014. Data were collected from May to August 2015, stored in a computerized database and submitted to statistical analysis descriptive. This study was approved by the Research Ethics Committee of the Federal University of Tocantins (protocol 116/2014). **Results:** The mean age at diagnosis was 8 years, the majority of which were male and the most frequent types of cancer were Leukemia, Lymphomas and Central Nervous System Tumors. The use of chemotherapy predominated among the treatments used. Regarding the situation-outcome, they were discharged for cure (11%); in treatment (14%); post-treatment follow-up (31%) and died (29%). **Conclusion:** The profile of children and adolescents with cancer in this study denoted the complexity and biopsychosocial dimension that involved the treatment of childhood and adolescence cancer, translated by the expressive number of hospital admissions and deaths in children under 5 years of age. It is recommended that health professionals be trained to perform the early diagnosis and for the excellence of multi-professional treatment, seeking not only cure but also quality of life. **Key words:** Neoplasms; Child; Adolescent; Epidemiology.

## Resumo

**Introdução:** O progresso no controle do câncer nos últimos 50 anos é inegável; entretanto, no Brasil, ele ainda representa a segunda causa de morte na população infantojuvenil, e estudos não têm evidenciado declínio desses dados. **Objetivo:** Analisar o perfil clínico-epidemiológico de crianças e adolescentes com câncer em um Serviço de Oncologia. **Método:** Estudo documental retrospectivo, com busca de dados em prontuários de crianças e adolescentes, com diagnóstico de câncer no período de 2008 a 2014. Os dados foram coletados no período de maio a agosto de 2015, armazenados em banco de dados informatizado e submetidos à análise estatística descritiva. Este estudo foi aprovado pelo Comitê de Ética em Pesquisa da Universidade Federal do Tocantins (protocolo 116/2014). **Resultados:** A idade média ao diagnóstico foi de 8 anos, sendo a maioria do sexo masculino; e os tipos de câncer mais frequentes foram as leucemias, linfomas e os tumores do sistema nervoso central. O uso da quimioterapia predominou entre os tratamentos utilizados. Referente à situação-desfecho, obtiveram alta por cura (11%); em tratamento (14%); acompanhamento pós-tratamento (31%); e foram a óbito (29%). **Conclusão:** O perfil de crianças e adolescentes com câncer deste estudo denotou a complexidade e a dimensão biopsicossocial, que envolveram a terapêutica do câncer infantojuvenil, traduzidas pelo número expressivo de internações hospitalares e óbitos em crianças menores de 5 anos. Recomenda-se a capacitação dos profissionais de saúde para a realização do diagnóstico precoce e para a excelência do tratamento multiprofissional em busca não só da cura, mas também da qualidade de vida. **Palavras-chave:** Neoplasias; Criança; Adolescente; Epidemiologia.

## Resumen

**Introducción:** el progreso en el control del cáncer en los últimos 50 años es innegable, sin embargo, en Brasil todavía representa la segunda causa de muerte en la población infantojuvenil y los estudios no han evidenciado la declinación de esos datos. **Objetivo:** analizar el perfil clínico-epidemiológico de niños y adolescentes con cáncer en un Servicio de Oncología. **Método:** estudio documental retrospectivo, con búsqueda de datos en prontuarios de niños y adolescentes, con diagnóstico de cáncer en el período de 2008 a 2014. Los datos fueron recolectados en el período de mayo a agosto de 2015, almacenados en banco de datos informatizado y sometidos al análisis estadístico descriptivo. Este estudio fue aprobado por el Comité de Ética en Investigación de la Universidad Federal de Tocantins (protocolo 116/2014). **Resultados:** La edad media al diagnóstico fue de 8 años, siendo la mayoría del sexo masculino y los tipos de cáncer más frecuentes fueron las Leucemias, Linfomas y los Tumores del Sistema Nervioso Central. El uso de la quimioterapia predominó entre los tratamientos utilizados. En cuanto a la situación de desenlace, se obtuvieron altas por cura (11%); en tratamiento (14%); seguimiento post-tratamiento (31%) y fueron a muerte (29%). **Conclusión:** El perfil de niños y adolescentes con cáncer de este estudio denotó la complejidad y la dimensión biopsicossocial que involucraron la terapéutica del cáncer infantojuvenil traducidas por el número expresivo de internaciones hospitalarias y muertes en niños menores de 5 años. Se recomienda la capacitación de los profesionales de salud para la realización del diagnóstico precoz y para la excelencia del tratamiento multiprofesional, en busca no sólo de la cura, sino también de la calidad de vida. **Palabras clave:** Neoplasias; Niño; Adolescente; Epidemiología.

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## INTRODUCTION

According to the World Health Organization (WHO), in 2012 there were 14.1 million new cancer cases in the world and 8.2 million deaths from the disease. It is estimated that by 2030 the global numbers will reach 23.6 million new cases of cancer. Meanwhile, the estimate in Brazil for the two-year period 2016-2017 was 600 thousand new cancer cases, with high incidence and mortality rates<sup>1,2</sup>.

As with cancer in adults, childhood and adolescent cancer is defined as a group of diseases characterized by the disordered multiplication of atypical cells and location anywhere in the body<sup>3</sup>. It is considered a spectrum of different malignant neoplasms that vary according to histological type, primary site, gender, age, and race. Pediatric neoplasms differ from tumors in adults in their morphology, clinical behavior, and primary site and should thus be studied separately<sup>4</sup>. The differences are related to prognosis, histological characteristics, and tumor location. The neoplasms with the highest incidence in childhood are leukemias, tumors of the central nervous system (CNS), and lymphomas. In adults, the incidence is highest for non-melanoma skin cancer, prostate tumors, and breast cancer<sup>1</sup>.

The Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA) estimates that in the two-period 2018-2019 there will be 420 thousand new cancer cases in the country, not including non-melanoma skin cancer. Children and adolescents account for 3% of the cancer cases in Brazil. Thus, there will be 12,500 new cancer cases in children and adolescents up to 19 years of age. The Southeast and Northeast are the regions of Brazil with the highest numbers of new cases (5,300 e 2,900, respectively), followed by the Central-West with 1,800, the South with 1,300, and the North with 1,200<sup>5</sup>.

In Brazil, cancer ranked eighth among causes of death in children 0 to 4 years of age and was the leading cause from 5 to 19 years of age in 2014, according to the Ministry of Health's Mortality Information System (SIM)<sup>6</sup>. Data on cancer mortality in the populations of the United States and Argentina are consistent with the Brazilian data, as the second leading cause of mortality in children 0 to 14 years of age and 5 to 14 years of age, respectively, exceeded only by external causes<sup>3,6</sup>.

The diagnosis of childhood cancer, constant hospitalizations, and painful treatments change the routine of the child and family and pose a challenge for the multidisciplinary health team<sup>7</sup>. In this context, early detection of childhood cancer and rapid initiation of treatment are significantly important for the child's prognosis and are directly related to proper development

of the treatment and positive outcomes such as cure of the cancer<sup>8</sup>.

However, diagnosis in early-stage cancer is complex. The child often displays nonspecific signs and symptoms that are present in other common diseases of children, including fever, vomiting, weight loss, bleeding, enlarged lymph nodes, generalized bone pain, and pallor<sup>9</sup>.

It is thus indispensable to develop qualified care, aimed at early diagnosis and timely treatment. According to studies in developed countries, strides in clinical and biological diagnosis, use of adequate therapies based on the risk, and optimization of supportive care result in a dramatic increase in cure rates in children with cancer<sup>10,11</sup>.

However, in various regions of Brazil, the curability of childhood cancer is jeopardized by the shortage of hospitals specialized in pediatric oncology, lack of specialized physicians, and failure to diagnose the disease in primary care<sup>12</sup>.

Increased knowledge of a population's reality and context, as well as data on incidence and the specificities of cancer in the country or in certain areas, can serve as tools to support planning and follow-up of health interventions aimed at a positive impact on preventive and therapeutic measures<sup>13</sup>. The current study thus proposed to analyze the clinical and epidemiological profile of children and adolescents with cancer in an oncology service in the North of Brazil.

## METHOD

This was a retrospective document study based on data recorded in the patient charts of children and adolescents treated from March 2008 to December 2014 in the oncology department of a public hospital located in the North of Brazil. The department is a referral service for the state of Tocantins and neighboring areas such as the south of Pará, Maranhão, and Bahia states. The hospital has a state-level administration and provides inpatient and outpatient care with medium and high complexity<sup>14</sup>.

Data were collected in the oncology service from May to August 2015. The children's and adolescents' charts were identified by consulting an electronic spreadsheet provided by the administrative department of the oncology service and included the following variables that were analyzed in this study: name, age, sex, home city, accompanying person, type of cancer, number of hospitalizations, outcome, and deaths.

Data from the patient charts were organized according to the study's objectives, using an original data collection instrument containing items related to the children's and adolescents' sociodemographic and clinical characteristics. The records were stored in an electronic databank and

submitted to descriptive statistical analysis and presented as simple frequencies and percentages.

The types of cancer analyzed in the study were categorized according to the International Classification of Childhood Cancer, 1996 (ICCC-3), based on morphological type<sup>15</sup>.

A total of 160 patient charts were analyzed according to the selection criteria: patient charts with diagnostic confirmation of cancer and age 0 to 18 years. A total of 14 patient charts were excluded that did not contain the minimum information such as age at diagnosis of the disease.

The study was approved by the hospital's Teaching and Research Department and the Institutional Review Board of the Federal University of Tocantins (UFT), under case review number 116/2014.

## RESULTS

According to the sample of patient charts, only 39 (24.4%) of the children and adolescents lived in the same city as the oncology service. Most of the families thus had to travel long distances to obtain cancer treatment. Some came from cities and towns in the states of Pará and Maranhão, traveling more than a thousand kilometers to reach the oncology service at this public hospital.

Based on the charts, cancer incidence was highest in children up to 5 years of age (54; 36.97%) and in males (94; 64%). Mean age at the start of treatment was 8.11 years (Table 1).

According to ICCC-3<sup>15</sup>, the main types of childhood and adolescent cancer in this study were leukemias (69; 47.26%), followed by lymphomas (27; 18.49%) (Table 2).

As for treatment modalities, 65 (45%) received exclusive chemotherapy, and in 56 patients (38%) it was associated with other modalities such as radiotherapy (25; 17%), surgery (22; 15%), hematopoietic stem cell transplantation (3; 2%), and radiotherapy and surgery (6; 4%). When necessary, the children and adolescents were

referred to other specialized centers for radiotherapy and hematopoietic stem cell transplantation.

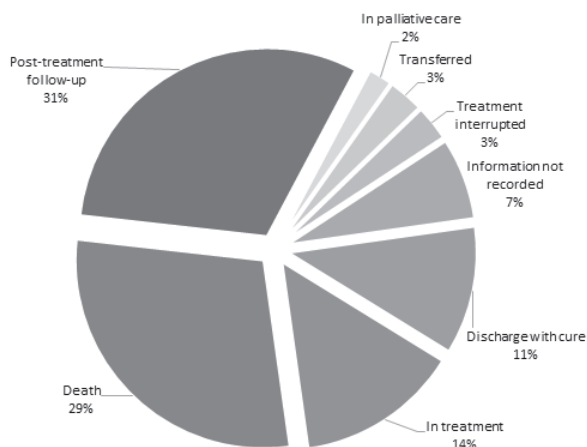
Of the 146 cases, 106 (72.60%) required hospitalization, 70 (47.94%) of which in hospital wards; 7 (0.47%) in intensive care units alone (ICU); and 29 (19.86%) in both. There were 1,051 hospitalizations in total, of which 1,007 in hospital wards and 44 in the ICU, in approximately seven years. Among patients that required inpatient treatment in wards, the number of hospitalizations ranged from 1 to 28, but of those who required treatment in the ICU, the number of hospitalizations ranged from 1 to 4. In 116 cases (72.5%), the patient's mother was the accompanying person.

**Table 2.** Distribution of types of cancer in children and adolescents in an oncology service from 2008 to 2014, Brazil, 2015 (N=146)

Types of cancer	f	%
<b>Leukemias</b>		
Acute lymphoblastic leukemia	54	36.98
Acute myeloid leukemia	10	6.84
Chronic myeloid leukemia	3	2.05
Biphenotypic leukemia	2	1.36
<b>Lymphomas</b>		
Hodgkin's lymphoma	13	8.90
Burkitt's lymphoma	7	4.79
Non-Hodgkin's lymphoma	4	2.73
Other lymphomas	3	2.05
<b>Central nervous system, intracranial, and intramedullary neoplasms</b>		
Ependymomas	5	3.42
Medulloblastoma	4	2.73
Astrocytoma	3	2.05
Primitive neuroectodermic tumor	2	1.36
Other gliomas	4	2.73
<b>Tumors of the sympathetic nervous system</b>		
Neuroblastoma	6	4.10
<b>Renal tumors</b>		
Wilms tumor	3	2.05
<b>Hepatic tumors</b>		
Hepatoblastoma	1	0.68
Hepatic cell carcinoma	1	0.68
<b>Malignant bone tumors</b>		
Osteosarcoma	5	3.42
<b>Soft tissue sarcomas</b>		
Rhabdomyosarcoma	5	3.42
Soft tissue alveolar sarcoma	1	0.68
Soft tissue tumor	1	0.68
<b>Germ cell, trophoblastic, and gonadal tumors</b>		
Yolk sac tumor	2	1.36
Metastatic choriocarcinoma	1	0.68
Ovarian carcinoma	1	0.68
<b>Other carcinomas</b>		
	5	3.42

**Table 1.** Sociodemographic characteristics of children and adolescents with cancer treated at the oncology service in a public hospital in the North of Brazil, 2015 (N=146)

Variables	f	%
<b>Age (years)</b>		
≤ 1 ano	14	9.58
2 e ≤ 5	40	27.39
6 e ≤ 9	36	24.65
10 e < 12	14	9.58
12 e < 15	20	13.69
15 e ≤ 18	22	15.06
<b>Sex</b>		
Female	52	35.6
Male	94	64.4



**Graph 1.** Characterization of outcomes in children and adolescents with cancer diagnosis in an oncology service from 2008 to 2014, Brazil, 2015

At the end of the data collection, there were 16 cases (11%) of cure; 46 (31%) were in post-treatment follow-up; 20 (14%) were still in treatment; three (2%) were receiving palliative care; four (3%) had been transferred to another oncology service; four (3%) had their treatment interrupted; and 43 had evolved to death (29%). Among the four cases with treatment interrupted, three were due to the lack of a specialized health professional, and one case was an adolescent who had become pregnant. There were six cases (3.7%) of metastatic disease (Graph 1).

The majority of the deaths were in boys (69.76%) and with a diagnosis of leukemia (21; 48.83%) from 2 to 5 years of age (Table 3).

## DISCUSSION

The study showed a predominance of cancer in male children and adolescents, similar to results in other studies in Brazil and in other countries including the United States, Colombia, and Bolivia<sup>13,16-19</sup>.

A study on the incidence of these tumors in the United States showed a higher proportion in males than in females, although adolescents 15 to 19 years of age were more affected by neoplasms than children 0 to 14 years of age<sup>19</sup>.

Corroborating these findings, another study in oncology services in Brazil in the states of Rio Grande do Sul and Piauí found a higher proportion of male patients and children under 10 years of age<sup>18</sup>. The current study's results are similar to those of the other Brazilian studies cited above, with most cases in children under 10 years of age.

Information on the clinical and sociodemographic profile of a given patient population, such as type and location of the tumor, extent of the disease, age, parents'

**Table 3.** Characteristics of fatal cancer cases in children and adolescents in an oncology service, from 2008 to 2014, Brazil, 2015 (N=43)

Characteristics	f	%
<b>Age (years)</b>		
≤ 1	2	4.65
2 ≤ 5	10	23.25
6 ≤ 9	7	16.27
10 < 12	4	9.30
12 < 15	9	20.93
15 ≤ 18	7	16.27
NR	4	9.20
<b>Sex</b>		
Female	13	30.23
Male	30	69.76
<b>Type of cancer</b>		
Leukemias	21	48.83
Central nervous system tumors	6	13.95
Lymphomas	5	11.62
Neuroblastoma	3	6.97
Bone tumors	2	4.65
Soft tissue tumors	2	4.65
Renal tumors	2	4.65
Hepatic tumors	1	2.32
Others	1	2.32

schooling, and distance to treatment centers are factors that can influence the time elapsed between the first symptoms until diagnosis of the cancer in children and adolescents<sup>20</sup>.

Assessment of the incidence, mortality, and hospital morbidity is important for elucidating the cancer profile and effective surveillance for extensive use of the information in order to translate it into effective measures for cancer control in children, adolescents, and young adults<sup>21</sup>.

The predominant types of childhood and adolescent cancers in this study were leukemias, followed by lymphomas and CNS tumors. Thus, leukemias, and especially acute lymphocytic leukemia, were the most frequent neoplasms in this sample of patients under 19 years of age, a result consistent with other studies in Brazil and elsewhere in the world<sup>13,16-18,22</sup>

In the United States, the most frequent types of childhood and adolescent cancers were leukemias, followed by CNS tumors and lymphomas<sup>19</sup>. In Cali, Colombia, the order was leukemias. CNS tumors, lymphomas, and soft tissue sarcomas<sup>19</sup>. In Cochabamba, Bolivia, the order was leukemias, retinoblastomas, and lymphomas<sup>17</sup>.

Studies in cancer centers in Brazil have also shown a predominance of leukemias and variation in the other types of cancer. In the state of Paraná, the order was leukemias, lymphomas, retinoblastomas, and CNS tumors. In the state of Espírito Santo, leukemias were



followed by lymphomas, CNS tumors, and renal tumors<sup>23</sup>, and in Piauí, leukemias were followed by lymphomas, bone tumors, renal tumors, and CNS tumors<sup>18</sup>.

Our study and the study in the state of Paraná identified chemotherapy as the most widely used modality in pediatric cancer patients<sup>24</sup>, used alone or in association with other treatments. Chemotherapy produces opposing and conflicting feelings in the child's family. While fear and sadness emerge due to the side effects, there is also hope and expectation of cure through the treatment<sup>25</sup>.

In this study, when radiotherapy was used, it was always associated with other modalities, such as chemotherapy and/or surgery. The literature has shown that radiotherapy should be used with caution, and that it has been used less and less in children and adolescents due to its late adverse effects<sup>20</sup>.

As with any other treatment, cancer therapies have side effects. Cancer treatment is known to have hematological, gastrointestinal, and dermatological toxicities. There are also cases of chemotherapy with infectious complications, the leading cause of morbidity and mortality in immunocompromised children and adolescents undergoing cancer treatment<sup>20</sup>.

Children with chronic diseases generally require prolonged and repeated hospitalizations, which alters their routine and triggers feelings of fear, anxiety, and premature maturity and places limitations on their lives<sup>26</sup>. The effects of hospitalization extrapolate the disease itself and end up causing changes in the family's daily routine and structure<sup>8</sup>.

This study's data identify the mother as the child's principal accompanying person during treatment, participating either alone or with other family members and/or third parties. This pattern is similar to the one found in other studies addressing family issues in pediatric cancer cases<sup>23,25-28</sup>.

Childhood and adolescent cancer involve overload and tension, because the accompanying person's basic needs such as personal hygiene, meals, and sleep are altered and jeopardized, since the family focuses its attention and comprehensive care on the child or adolescent<sup>29</sup>.

The finding that stood out in this study was the high proportion of deaths, 29% of the participants. Most of the deaths occurred in younger children rather than adolescents, and there were more deaths in boys than in girls. Another study, in two municipalities (counties) in Northeast Brazil, found an increase in mortality rates<sup>7</sup>. These findings corroborate the current study's data, which showed that mortality from childhood and adolescent cancers in North and Northeast Brazil increased by 2% to 3% a year, while in the South, Southeast, and Central-West it decreased by 0.5% to 1.5% a year<sup>30</sup>.

As in other studies in Brazil, most of the patients that died had a diagnosis of leukemia, CNS tumor, or lymphoma<sup>7,13,24,31</sup>. An analysis of the age bracket of the patients that died showed that this study differed from one in the state of Paraná, where adolescent cancer patients showed a three-fold higher risk of death compared to children<sup>31</sup>.

Factors associated with the increase and the high number of pediatric cancer deaths in the states of North and Northeast Brazil feature socioeconomic issues, the use of public versus private health services, and distance from the family's home to medical centers, besides the small number of oncology services and medical oncologists<sup>3,32</sup>.

Another factor related to high mortality was diagnostic delay, since advanced-stage disease tends to be associated with lower odds of cure and higher frequency and severity of sequelae due to the more aggressive treatment. Since 2011, the Brazilian Ministry of Health has implemented protocols that assist health care professionals in managing suspected and confirmed cases, within a line of care that determines flows and interventions from basic to high-complexity care<sup>5</sup>.

According to a study with primary care professionals in Campinas, São Paulo state<sup>33</sup>, the professionals felt insecure in relation to this diagnosis, since recognizing signs and symptoms in childhood and adolescent cancer was considered complex. Besides, for them, early diagnosis has proceeded, since it is not limited to a diagnostic taxonomy, but also involves establishing a relationship that goes beyond the physician/patient bond, including indispensable subjective characteristics. Health care professionals working in pediatric oncology face the challenge of reducing the consequences of cancer treatment, besides providing care that includes the patient and family in a comprehensive approach<sup>34</sup>.

The study's limitations included the impossibility of identifying the time elapsed between the initial signs and symptoms, diagnosis, and the start of treatment, presence of other health conditions, availability of medications, and possible associations between the number of deaths and other variables. In addition, since this was a document-based study, it only analyzed information recorded on the patient charts.

It is thus important for health care professionals to be trained to complete the patient charts properly, since such information can be used to help establish preventive and therapeutic interventions.

## CONCLUSION

The clinical and epidemiological profile of children and adolescents with cancer treated at an oncology service in a public hospital located in the North of Brazil showed

a predominance of leukemias, lymphomas, and CNS tumors in male children up to five years of age.

In addition, the complexity and biopsychosocial dimension of treatment in childhood and adolescent cancer were expressed in the high number of hospitalizations, indicating the need for specialized multidisciplinary health care.

The data from this study corroborated other studies in Brazil and elsewhere in the world. However, the current study showed alarming data on mortality. In the city studied here, there was no specific pediatric oncology service, which may have contributed to the high number of deaths.

Urgent action is recommended in training health care professionals to perform early diagnosis and provide information to the population, aimed at the identification and association of signs and symptoms related to childhood cancer, as well as the importance of specialized care and/or referral to specialized centers as quickly as possible.

This study's findings were intended to contribute to health interventions focused on specialized care for these patients and their families, aimed at improving survival, quality of life, and prognosis. This involves specialized multidisciplinary treatment for childhood and adolescent cancer, seeking not only cure, but also quality of life for these children and adolescents.

### CONTRIBUTIONS

Cintia Flôres Mutti worked on the research project's conception and planning, data collection and analysis, writing and critical revision of the manuscript, and approval of the final version for publication. Vanessa Gomes da Cruz worked on the research project's conception and planning, data collection and analysis, and writing of the manuscript. Leidiene Ferreira Santos, Daiana de Araújo, Silvana Bastos Cogo, and Eliane Tatsch Neves worked on the writing and critical revision of the manuscript and approval of the final version for publication.

### CONFLICT OF INTEREST

None.

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None.

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