Hospital-Based Cancer Registries in Brazil: Distribution and Completeness of Information on Childhood Cancer, from 2000 to 2022

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Registros Hospitalares de Câncer no Brasil: Distribuição e Completude das Informações sobre o Câncer Infantojuvenil, de 2000 a 2022

Registros de Cáncer Hospitalarios en el Brasil: Distribución y Completitud de la Información sobre Cáncer Infantil, de 2000 a 2022

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ABSTRACT

Introduction: Cancer is a set of diseases with aggressive characteristics that can spread throughout the body's organs. It is considered one of the main public health issues, being identified as the predominant cause of death in most of the population. **Objective:** To characterize childhood cancer and verify the completeness of information in the hospital-based cancer registries (HBCRs) database in Brazil and its geographic regions, from 2000 to 2022. **Method:** Observational, retrospective study of secondary basis, with a quantitative approach. The sample comprised 91,233 cases registered in different cancer registries, contained in the Integrating Module of hospital-based cancer registries of the National Cancer Institute, with information on children and adolescents aged 0 to 19 years. **Results:** Childhood cancer was more prevalent in males (54.2%; n=49,448), in children between 0 and 4 years old (31.5%; n=28,686), and residents in the Southeast region (44.7%; n=40,801). The hematopoietic and reticuloendothelial system was most affected (29.5%; n=26,859) and chemotherapy was the most administered therapy (44.8%; n=40,916). In 78.8% (n=71,891) of cases, specialized services have met the legal deadline for starting cancer treatment. Most of the variables were classified as excellently completed, however, 20% were considered poorly completed, with the Southeast region being the one with the greatest incompleteness of information. **Conclusion:** Neoplasms of the hematopoietic and reticuloendothelial systems were the most frequent, affecting mainly younger children and males, showing excellent completion for most of the variables analyzed.

Key words: Child; Adolescent; Neoplasms/epidemiology ; Records/statistics & numerical data.

RESUMO

Introdução: O câncer configura-se como um conjunto de doenças com características agressivas e passíveis de disseminação pelos órgãos do corpo. É considerado um dos principais problemas de saúde pública, sendo apontado como causa predominante de morte na maioria da população. **Objetivo:** Caracterizar o câncer infantojuvenil e verificar a completude das informações na base dos Registros Hospitalares de Câncer (RHC) no Brasil e em suas Regiões geográficas no período de 2000 a 2022. **Método:** Estudo observacional, retrospectivo, de base secundária, com abordagem quantitativa. A amostra foi composta de 91.233 casos registrados em diferentes registros de câncer, contidos no Módulo Integrador dos RHC do Instituto Nacional de Câncer, com informações de crianças e adolescentes de 0 a 19 anos. **Resultados:** O câncer infantojuvenil foi mais prevalente no sexo masculino (54,2%; n=49.448), nas crianças entre 0 e 4 anos (31,5%; n=28.686) e residentes na Região Sudeste (44,7%; n=40.801). O sistema hematopoiético e reticuloendotelial foi o mais acometido (29,5%; n=26.859) e a quimioterapia foi a terapêutica mais administrada (44,8%; n=40.916). Em 78,8% (n=71.891) dos casos, os serviços especializados cumpriram o prazo estabelecido por lei para início do tratamento oncológico. A maioria das variáveis foi classificada de excelente preenchimento, porém 20% foram consideradas de ruim preenchimento, sendo a Região Sudeste a com maior incompletude de informações. **Conclusão:** Neoplasias do sistema hematopoiético e reticuloendotelial foram as mais frequentes, acometendo principalmente crianças mais jovens e do sexo masculino, evidenciando-se excelente preenchimento para a maioria das variáveis analisadas.

Palavras-chave: Criança; Adolescente; Neoplasias/epidemiologia; Registro/estatística & dados numéricos.

RESUMEN

Introducción: El cáncer es un conjunto de enfermedades con características agresivas y capaces de propagarse por los órganos del cuerpo. Es considerado uno de los principales problemas de salud pública, identificándose como la causa predominante de muerte en la mayoría de la población. **Objetivo:** Caracterizar el cáncer infantil y juvenil y verificar la integridad de las informaciones contenidas en la base de datos de Registros de Cáncer Hospitalarios (RCH) en el Brasil y sus regiones geográficas, en el período de 2000 a 2022. **Método:** Estudio observacional, retrospectivo, de base secundaria, con enfoque cuantitativo. La muestra estuvo conformada por 91 233 casos registrados en diferentes registros de cáncer, contenidos en el Módulo Integrador de Registros de Cáncer Hospitalarios del Instituto Nacional del Cáncer, con información de niños y adolescentes de 0 a 19 años. **Resultados:** El cáncer infantil y juvenil fue más prevalente en el sexo masculino (54,2%; n=49 448), en niños entre 0 y 4 años (31,5%; n=28 686) y en residentes de la región Sudeste (44,7%; n=40 801). El sistema hematopoyético y reticuloendotelial fue el más afectado (29,5%; n=26 859) y la quimioterapia fue la terapia más administrada (44,8%; n=40 916). En el 78,8% (n=71 891) de los casos, los servicios especializados han cumplido el plazo establecido por la ley para iniciar el tratamiento del cáncer. La mayoría de las variables fueron clasificadas como excelentemente llenadas, sin embargo, el 20% fue considerado mal llenado, siendo la región Sudeste la que presenta mayor incompletitud de informaciones. **Conclusión:** Las neoplasias del sistema hematopoyético y reticuloendotelial fueron las más frecuentes, afectando principalmente a niños de menor edad y al sexo masculino, mostrando un excelente llenado en la mayoría de las variables analizadas.

Palabras clave: Niño; Adolescente; Neoplasias/epidemiología; Registros/estadística & datos numéricos.

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INTRODUCTION

Cancer is configured as a set of diseases with aggressive characteristics and susceptible to dissemination through the organs of the body. It is one of the main public health issues, pointed out as the predominant cause of death in the majority of the population[1]. Among children and adolescents, cancer is considered worrisome, because it is a disease of little-known causality and distinct characteristics, which hinders its prevention[2]. An estimated 400 thousand cases[3] worldwide are expected for this pathology, with an estimated 7,930 new cases for each year of the 2023-2025 triennium[1].

The proportion of morbimortality in developed countries translates the effectiveness of access to diagnosis and treatment because, despite the increase in the number of cases, the mortality rate has decreased over time[4]. However, 90% of children and adolescents with cancer live in low- and medium-income countries, where health services are often precarious and inadequate. Additionally, the existence of under records that do not express reality compromise disease control strategies[5]. Developing countries face numerous challenges in diagnosis, treatment, and follow-up of children and adolescents with cancer, given that information concerning those cases is ignored and, most times, data on this type of cancer are statistically omitted or grouped with adult neoplasms[6]. Even with the presence of cancer records in these countries, the information is underreported, making it necessary to rely on data from other sources for epidemiological understanding[5,7].

In Brazil, the monitoring of cancer cases is systematized and made available by the Cancer Registries (RCBP)[8], Cancer Hospital Records (RHC)[9] and the Mortality Information System (SIM)[10], which are responsible for the epidemiological description of the disease[11].

It is necessary to highlight that, depending on the information, these reflect the profile and magnitude of the disease, as well as the quality of the care provided, becoming essential in the planning, implementation, and monitoring of public policies, development of health strategies and decision-making, benefiting more appropriate actions considering the needs of the population[11].

Considering the above, this study addresses the information of the RHC, since it is essential to verify the gaps and quality of information on cancer in the Brazilian territory, essential to know the care profiles of the cancer treatment reference centers, and contribute to the planning and execution of more assertive strategies in coping with childhood cancer. There are few studies on childhood cancer in Brazil, and the existing ones address short periods, in some cases dealing with specific types of neoplasms, with epidemiological profiles or trends of data incompleteness. Based on that scenario, this research presents unprecedented knowledge about childhood cancer in Brazil and its Regions, with characterization and data incompleteness of 22 years of follow-up.

Therefore, the present study aims to characterize childhood cancer and verify the completeness of information on the RHC bases in Brazil and its Geographic Regions, from 2000 to 2022.

METHOD

This is an observational, retrospective, secondary-based study with a quantitative approach, which presents part of the doctoral thesis of one of the authors, whose central theme is childhood cancer in Brazil[12]. The study data was collected from the information contained in the Integrator Module of the RHC[9], made available by the National Cancer Institute (INCA). The publicly available information was downloaded on May 18, 2024.

The study population consisted of 118,348 records on cancer of children and adolescents aged 0 to 19, from 2000 to 2022. Data was collected until 2022, the most recent year with records in every month.

The study included 91,233 cases recorded in different cancer records, and only those cases registered as analytical (with diagnosis and treatment in hospitals with RHC) were considered eligible for no overestimation of records[13], those who had their first cancer diagnosis in the period 2000 to 2022, and those who informed their State of residence.

The variables analyzed were extracted from the tumor record sheet and grouped according to their classification into: Demographic variables (sex, age, skin color, federation unit (FU) of the patient's residence), care, and tumor diagnosis variables (the most important basis for diagnosis, location of the primary tumor, histological type, date of first diagnosis), and variables related to treatment (starting date of first tumor-specific treatment at the hospital, reason for not undergoing first treatment at the hospital, first treatment received at the hospital, disease status at the end of first treatment at the hospital).

For a better understanding of the behavior of childhood cancer, the conversion of eligible cases was performed, based on the International Classification of Childhood Cancer, 3rd revised edition (ICCC-3)[14].

The variable "time between diagnosis and treatment" was also created, and the time interval between the date of diagnosis and the date of treatment initiation was calculated, but information that did not have any of the dates or was mistyped resulting in negative time was considered incomplete.

The information contained in the database that presented as a response "no information," "number 0", "information and/or date unknown" or the absence of information were grouped in the category "no

information" for data completeness analysis. In the variable "first treatment received at the hospital," the records of patients who presented more than one therapeutic modality were grouped into "two or more therapeutic modalities."

The data analyzed were tabulated and organized in a Microsoft Excel™ spreadsheet enabling statistical analysis in the public domain R software. The variables were described using absolute frequencies (n) and relative frequencies (%). The data were evaluated for their incompleteness, i.e., the determination of the percentage of information ignored or not filled. The degree of completion was classified according to a system of scores[15], stratified as follows: Excellent (incompleteness <5%), Good (5%≤ incompleteness <10%), Regular (10%≤ incompleteness <20%), Poor (20%≤ incompleteness <50%), and Very poor (incompleteness ≥50%).

Since this study uses free publicly available secondary data, it does not require consideration of a Research Ethics Committee, according to Resolution no. 510[16] of April 7, 2016, of the National Health Council.

RESULTS

The study obtained a sample of 91,233 cases recorded in different cancer records with oncopediatric information (0 to 19 years old), distributed by the following Regions: North (8.2%; n=7,498), Northeast (25.9%; n=23,633), Middle West (5.1%; n=4,610), Southeast (44.7%; n=40,801) and South (16.1%; n=14,691). Most of the information belonged to male individuals (54.2%; n=49,448), with the North having greater representativeness (56.6%; n=4,244). The mean age observed was 9.27 years (±6.2), with a median of 9 years, and the most prevalent age group was 0 to 4 (31.5%; 28,686), while the brown skin color was the most frequent (29.0%; n=26,429), being more present in the Northeast (59.2%; n=13,994) (Table 1).

At a national level, it is possible to highlight data incompleteness in the variable skin color (40.7%; n=37,166), being classified as poor completion. The Southeast (65.4%; n=26,685) and Middle West (42.8%; n=1,974) regions showed the most lack of information in this variable, thus classified as very poor and poor completion, respectively.

Table 2 shows that microscopic confirmation prevailed for cancer diagnosis when compared to the other resources available (90.4%; n=82,491), with the Southeast Region being the one that most used this diagnostic device (92.3%; n=37,659). The hematopoietic and reticuloendothelial system was observed to be the most affected (29.5%; n=26,859), and according to the ICCC-3, leukemias, myeloproliferative diseases and myelodysplastic diseases (27.9%; n=25,431), lymphomas and reticuloendothelial neoplasms (16.4%; n=14,920), CNS tumors and miscellaneous intracranial and intraspinal neoplasms (11.1%; n=10.135) were the most portrayed pathologies.

Table 1. Demographic characteristics of childhood cancer in the Brazilian Regions, Brazil, 2000-2022

Variables		North		Northeast		Middle West		Southeast		South		Brazil	
		n	%	n	%	n	%	n	%	n	%	n	%
Sex	Male	4,244	56.6	12,688	53.7	2,458	53.3	21,995	53.9	8,063	54.9	49,448	54.2
	Female	3,254	43.4	10,945	46.3	2,152	46.7	18,806	46.1	6,627	45.1	41,784	47.8
	No information	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0	1	0.0
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,691	100.0	91,233	100.0
Age group	0-4 years old	2,483	33.1	7,280	30.8	1,630	35.4	12,435	30.5	4,858	33.1	28,686	31.5
	5-9 years old	1,662	22.2	4,862	20.6	897	19.4	7,877	19.3	2,702	18.4	18,000	19.7
	10-14 years old	1,523	20.3	5,045	21.3	926	20.1	8,768	21.5	2,915	19.8	19,177	21.0
	15-19 years old	1830	24.4	6446	27.3	1157	25.1	11721	28.7	4216	28.7	25,370	27.8
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,691	100.0	91,233	100.0
Skin color	White	832	11.1	3,735	15.8	920	19.9	6,663	16.4	12,209	83.1	24,359	26.7
	Black	139	1.8	864	3.7	96	2.1	1,196	2.9	315	2.1	2,610	2.9
	Yellow	30	0.4	285	1.2	10	0.2	58	0.1	56	0.4	439	0.5
	Brown	3,788	50.5	13,994	59.2	1,584	34.4	6,181	15.2	882	6.0	26,429	29.0
	Indigenous	117	1.6	27	0.1	26	0.6	18	0.0	42	0.3	230	0.2
	No information	2,592	34.6	4,728	20.0	1,974	42.8	26,685	65.4	1,187	8.1	37,166	40.7
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0

Source: Based on data from Hospital Cancer Records (RHC): 2000-2022[9].

As for the missing data in this section, the variables "basis for diagnosis" and "location of the primary tumor" were classified as having excellent completion (0.5%; n=399; 0.0%; n=01), respectively.

According to Table 3, the variable "reason for not performing the first treatment" has the subcategory "does not apply", which translates the possibility of the patient undergoing full treatment, being the most frequently observed in the RHC of all Brazilian Regions, around 90% of the cases, the Southeast being the region with the highest adherence (95.6%; n=38,978). Chemotherapy (44.8%; n=40,916), surgery (13.1%; n=12,309), and radiotherapy (3.1%; n=2,806%) were the most frequently performed therapeutic modalities in the first treatment received at the hospital. The specialized services for oncological treatment have met, for the most part, the deadline established by law for the onset of oncological treatment (78.8%; n=71,891). All Brazilian Regions stood out with more than 70% of cases starting treatment up to 60 days after proven diagnosis. Complete remission (15.4%; n=13,993) and disease stability (14.3%; n=13,011) prevailed after this first stage in the hospital environment. Finally, the South Region (30.5%; n=4,483) has presented the highest percentage of patients with total disease remission.

The variable "disease status at the end of the first treatment at the hospital" (47.4%; n=43,224) presented the highest percentage of incomplete information from this session, being classified as poor completion and the Southeast presented most of these information losses (71.4%; n=29,132), standing out as very poor completion. The variable "reason for not performing the first treatment at the hospital" showed excellent completion (3.3%; n=3,007), but only good completion for the South (6.3%; n=925) and Northeast (5.7%; n=1,339) Regions. Meanwhile, all Regions presented excellent completion for the variable "first treatment received at the hospital," and good completion for the "time between diagnosis and treatment" variable.

DISCUSSION

The present study observed that most children and adolescents with cancer are male, brown-skinned, aged 0 to 4 years old. It also verified that their hematopoietic and reticuloendothelial system was the most affected and that most patients underwent antineoplastic treatment, which started within the deadline determined by Law 12.732/12[17]. Most of the studied variables have excellent data completeness. Depending on the characteristics, these were also seen in other studies with RHC from different Brazilian Regions[18-21]. However, 20% were classified as having poor completion, with the Southeast Region having the most incomplete information.

The predominance of males was observed in the present study as well as in other studies that looked at different Regions of the country[12-28] and abroad[29,30]. Despite the lack of understanding about the higher incidence of childhood cancer in males, scholars point to genetic factors and immunological conditions as possible causes[31,32].

A higher number of records were identified in the age group of 0-4 years, corroborating other Brazilian[21,24,27,28] and international[6,33] studies. Age is an important analysis factor, since the occurrence of some tumors is higher in certain age groups, and patients in the early years of life are the most affected[34].

The present study showed a predominance of individuals with brown skin color, which is in line with studies developed in the States of Minas Gerais[23], Alagoas[24], Acre[27], and Piauí [35]. Some studies[18,26,28] observed white individuals as the most affected by childhood cancer, which can be explained by the differences in human groups distributed in the country, with the North and Northeast regions concentrating the majority of brown-skinned individuals[36].

When analyzing information completeness in demographic variables throughout the Brazilian territory, the sex and age variables were noticed to have excellent completion, corroborating other national studies[19,37,38]. The correct filling of such information is relevant because they are objective and easy-to-understand characteristics[19], as well as essential for health surveillance and for planning disease control actions[39]. However, the skin color variable showed poor completion, considering the completeness of the Southeast Region as very poor. Brazilian studies[19,21] share the increase in the lack of data for this characteristic, a fact that needs better attention, considering that it may not be just a biological difference, but a sociocultural construction capable of contributing to inequality in access to diagnosis and antineoplastic treatment[19-21].

Regarding the tests used for the diagnosis of childhood cancer, studies developed in the states of Minas Gerais[23] and Piauí [35] revealed a greater use of microscopic examinations. These findings are also present in this research and are evident in all Brazilian Regions. Therefore, microscopic examinations are essential to guide the responsible professional when childhood cancer is suspected, and thus, enable referral to oncology-specialized centers capable of providing a definitive diagnosis.

The present study shows a greater number of cases of the hematopoietic and reticuloendothelial system in all regions of Brazil, corroborating studies of different Brazilian Regions[23,35]. However, it is worth highlighting

Table 2. Characteristics of care and diagnosis of childhood cancer in the Brazilian Regions, Brazil, 2000-2022

Variables		North		Northeast		Middle West		Southeast		South		Brazil	
		n	%	n	%	n	%	n	%	n	%	n	%
Basis for diagnosis	Clinic	73	1.0	210	0.9	69	1.5	254	0.6	315	2.2	921	1.0
	Non-microscopic features	571	7.6	1,903	8.0	518	11.2	2,796	6.9	1,634	11.1	7,422	8.1
	Microscopic confirmation	6,829	91.1	21,384	90.5	3,966	86.1	37,659	92.3	12,653	86.1	82,491	90.4
	No information	25	0.3	136	0.6	57	1.2	92	0.2	89	0.6	399	0.5
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0
Location of primary tumor	Hematopoietic and reticuloendothelial system	3,077	41.1	7,335	31.0	1,219	26.5	10,849	26.6	4,379	29.8	26,859	29.5
	Lymph nodes	796	10.6	2,760	11.7	480	10.4	4,322	10.6	1,656	11.3	10,014	11.0
	Brain	596	7.9	2,311	9.8	583	12.6	4,626	11.3	1,506	10.2	9,622	10.6
	Bones, joints, and joint cartilage of limbs	527	7.0	1,776	7.5	294	6.4	2,521	6.2	780	5.3	5,898	6.5
	Kidney	393	5.3	1,293	5.5	261	5.7	2,127	5.2	708	4.8	4,782	5.2
	Connective tissue, subcutaneous tissue, and other soft tissues	215	2.9	917	3.9	211	4.6	1,595	3.9	558	3.8	3,496	3.8
	Eyes and attachments	292	3.9	802	3.4	212	4.6	1,545	3.8	379	2.6	3,230	3.5
	Bones, joints, and joint cartilage of other unspecified joints	171	2.3	578	2.4	126	2.7	952	2.3	394	2.7	2,221	2.4
	Adrenal gland	86	1.1	289	1.2	108	2.3	1,043	2.6	483	3.3	2009	2.2
	Others	1,345	17.9	5,572	23.6	1,116	24.2	11,221	27.5	3,847	26.2	23,101	25.3
	No information	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0	1	0.0
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0
Cancer Classification (ICCC-3)	Leukemia, myeloproliferative diseases, and myelodysplastic diseases	2,913	38.9	6,932	29.4	1,169	25.4	10,267	25.2	4,150	28.2	25,431	27.9
	Lymphomas and reticuloendothelial neoplasms	1,135	15.1	3,830	16.2	697	15.1	6,812	16.7	2,446	16.6	14,920	16.4
	central nervous system and miscellany of intracranial and intraspinal neoplasms	606	8.1	2,272	9.6	598	13.0	5,105	12.5	1,554	10.6	10,135	11.1
	Neuroblastoma and other tumors of peripheral nerve cells, tumors of the sympathetic nervous system	190	2.6	807	3.4	183	4.0	1,808	4.4	649	4.4	3,637	4.0
	Retinoblastoma	242	3.2	687	2.9	187	4.1	1,344	3.3	306	2.1	2,766	3.0
	Renal tumors	378	5.0	1,252	5.3	258	5.6	2,211	5.4	716	4.9	4,815	5.3
	Liver tumors	80	1.1	223	0.9	49	1.1	426	1.1	143	1.0	921	1.0
	Malignant bone tumors	663	8.8	2,169	9.2	371	8.0	3,138	7.7	1,031	7.1	7,372	8.1
	Soft tissues and other extraosseous sarcomas	357	4.8	1,394	5.9	313	6.8	2,858	7.0	796	5.4	5,718	6.3
	Germ cell tumors, trophoblastic tumors, and gonadal neoplasms	369	4.9	1,262	5.3	311	6.7	2,766	6.8	989	6.7	5,697	6.2
	Other malignant epithelial neoplasms and other malignant melanomas	425	5.7	2,184	9.2	357	7.7	3,585	8.8	1,612	11.0	8,163	8.9
	Other malignant and non-specified neoplasms	138	1.8	415	1.8	103	2.2	381	0.9	267	1.8	1,304	1.4
	Clinically malignant tumor (without microscopic examination)	02	0.0	205	0.9	14	0.3	100	0.2	29	0.2	350	0.4
	No information	00	0.0	01	0.0	00	0.0	00	0.0	03	0.0	04	0.0
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,691	100.0	91,233	100.0

Source: Based on data from Hospital Cancer Records (RHC): 2000-2022[9].

Table 3. Characteristics of the treatment of childhood cancer in the Brazilian Regions, Brazil, 2000-2022

Variables		North		Northeast		Middle West		Southeast		South		Brazil	
		n	%	n	%	n	%	n	%	n	%	n	%
Reason for not undergoing the first treatment at the hospital	Treatment refusal	12	0.2	12	0.0	04	0.1	42	0.1	19	0.1	89	0.1
	Advanced disease, lack of clinical conditions, and/or associated diseases	55	0.7	75	0.3	18	0.4	188	0.5	31	0.2	367	0.4
	Treatment abandonment	20	0.3	114	0.5	10	0.2	54	0.1	31	0.2	229	0.3
	Death	143	1.9	471	2.0	62	1.4	508	1.2	305	2.1	1,489	1.6
	Other reasons or complications of treatment or treatment performed out of hospital	119	1.6	493	2.1	164	3.5	748	1.8	276	1.9	1,800	2.0
	Not applicable	6,903	92.0	21,129	89.4	4,138	89.8	38,978	95.6	13,104	89.2	84,252	92.3
	No information	246	3.3	1,339	5.7	214	4.6	283	0.7	925	6.3	3,007	3.3
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0
First treatment received at the hospital	None	260	3.5	460	1.9	178	3.9	1,207	3.0	299	2.0	2,404	2.6
	Surgery	619	8.3	2,756	11.7	726	15.8	5,880	14.4	2,328	15.8	12,309	13.5
	Radiotherapy	195	2.6	1,024	4.3	234	5.1	805	2.0	548	3.7	2,806	3.1
	Chemotherapy	4,090	54.5	11,577	49.1	2,129	46.2	15,969	39.2	7,151	48.8	40,916	44.8
	Hormone therapy	08	0.1	26	0.1	06	0.1	19	0.0	29	0.2	88	0.1
	Bone marrow transplant	07	0.1	21	0.1	02	0.0	55	0.1	16	0.1	101	0.1
	Immunotherapy	03	0.0	11	0.0	01	0.0	26	0.1	11	0.1	52	0.1
	Two or more therapeutic modalities	2,111	28.2	7,238	30.6	1,224	26.5	16,407	40.2	4,083	27.8	31,063	34.1
	Others	166	2.2	419	1.8	63	1.4	413	1.0	151	1.0	1,212	1.3
	No information	39	0.5	101	0.4	47	1.0	20	0.0	75	0.5	282	0.3
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0
Time between diagnosis and treatment	≤ 60 days	5,407	72.1	17,547	74.2	3,693	80.1	33,705	82.6	11,539	78.5	71,891	78.8
	> 60 days	1,512	20.2	3,823	16.2	603	13.1	4,756	11.7	1,859	12.7	12,553	13.8
	No information	579	7.7	2,263	9.6	314	6.8	2,340	5.7	1,293	8.8	6,789	7.4
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0
State of the disease at the end of the first treatment at the hospital	Complete remission	507	6.8	4,580	19.4	1,164	25.3	3,259	8.0	4,483	30.5	13,993	15.4
	Partial remission	652	8.7	1,199	5.1	186	4.0	1,344	3.3	1,717	11.7	5,098	5.6
	Stable disease	2,140	28.5	4,808	20.3	532	11.6	3,347	8.2	2,184	14.9	13,011	14.3
	Disease in progression	733	9.8	1,378	5.8	248	5.4	1,284	3.1	868	5.9	4,511	4.9
	Oncological therapeutic support	77	1.0	283	1.2	45	1.0	229	0.6	231	1.6	865	0.9
	Death	1,219	16.2	3,609	15.3	481	10.4	1,487	3.6	1,253	8.5	8,049	8.8
	Not applicable	305	4.1	893	3.8	191	4.1	719	1.8	374	2.5	2,482	2.7
	No information	1,865	24.9	6,883	29.1	1,763	38.2	29,132	71.4	3,581	24.4	43,224	47.4
	Total	7,498	100.0	23,633	100.0	4,610	100.0	40,801	100.0	14,690	100.0	91,233	100.0

Source: Based on data from Hospital Cancer Records (RHC): 2000-2022[9].

a greater proportion of the involvement of such a system in the North Region, which may be related to greater availability of diagnostic resources for hematological neoplasms because the disease-confirming tests are less complex and more accessible.

When considering ICCC-3, results consistent with other national[18,24-26] and international investigations were identified in the present study[6,7,30] which considered leukemias, lymphomas, and central nervous system (CNS) tumors as the most frequent neoplasms. For

international studies, CNS tumors come second, followed by lymphomas[7,29].

Regarding the "most important basis for the diagnosis", this had excellent completion, as observed in other studies that used RHC[19,20,37,38,40]. The variable "location of the primary tumor" was classified as having excellent completion, which is a key feature for understanding the health-disease process[37].

The study in question also shows that about 90% of individuals diagnosed with childhood cancer underwent the first antineoplastic treatment at the hospital. Given this finding, it is necessary to establish early diagnosis to accelerate the beginning of treatment with chances of cure[6].

According to the data analyzed, there was a predominance of chemotherapy in all Brazilian Regions, followed by surgery and radiotherapy as the first treatment received at the hospital. These findings are corroborated by other studies conducted in the Northeast[24] and Southeast[23] Regions, as well as a study at the national level[29], while those developed in the North of the country show radiotherapy as the second most widely used modality[22]. Given the need to implement cancer control policies, Law No. 12,732[17] was published in 2012, which establishes the maximum period of 60 days for the beginning of treatment, after diagnostic proof of cancer. Thus, the present study identified that 70% or more of the population with cancer started treatment in specialized services up to the deadline stipulated by law, ranging from 0 to 4,772 days, with a median of 8 and an average of 42.4 days.

It was possible to visualize the time between diagnosis and treatment in a study conducted with all the RHC in Brazil, between 2000 and 2015, with an interval between 1 and 1,455, with a median of 2 and a mean of 15 days[18]. In another study, conducted in João Pessoa, State of Paraíba (PB), it was found that pediatric patients with solid tumors showed an interval of 0 to 77 days from diagnosis to the beginning of treatment, while this interval was of 0-37 days for children with hematological neoplasms[41]. These differences can be explained from the territorial dimension studied, in addition to the services involved in oncopediatric treatment, since João Pessoa has a High Complexity Oncology Assistance Center (Cacon) with pediatric oncology service. It should be noted that some states, mainly from the North and Northeast Regions, do not have specialized childhood cancer centers, which can contribute to the delay in diagnosis and adequate treatment.

It is also noticed that 15.4% of the patients presented complete remission of cancer after the first treatment at the hospital, followed by disease stability. The South and Middle West Regions presented the highest percentage of complete remission. At the same time, the North Region recorded a higher number of cases with the progression of the disease at the end of the first treatment and the most deaths. A study conducted in the State of Minas Gerais corroborates, in part, the results of the present study, since it shows a greater number of individuals with disease stability followed by complete remission[23].

Regarding data completeness, the variable "reason for not undergoing the first treatment at the hospital" showed excellent completion, ranging from the greatest loss of information in the South Region (good completion) and the lowest incompleteness in the Southeast Region (excellent completion). A study developed in the South Region[40] shows excellent completeness concerning this variable, while other studies expose variations in the classification of complete data[18-20,37]. The variable "first treatment received at the hospital" showed excellent completeness at the national level and compared to other Brazilian Regions. Comparable results have been observed in some studies[18-20], which highlight the need for information to follow up on the antineoplastic treatment, as well as for evaluating the quality of the care provided to patients.

Finally, the variable "disease state at the end of the first treatment at the hospital" obtained the worst rating of the study, poor completion. When analyzed by Region, the Southeast obtained very poor completeness. Studies conducted with RHC data showed comparable results, considering the poor completion variable[18-20,37,40], which exposes the fragility of this information that is essential in the evaluation of hospital care provided to individuals with cancer.

In summary, the completeness of the data available in RHC, for the most part, was considered excellent to good completion according to the classification adopted, but it is necessary to consider the differences in filling perceived between the Brazilian Regions and the extensive data loss of some variables for the Southeast Region.

The lack of information on important variables can occur due to the lack of knowledge of information by the patient's caregiver, but also the lack of training of the registrars, the difficulty of backfeeding the system experienced by health professionals, and the difference in clinical and epidemiological records contained in the patient's medical records[39].

Thus, the improvement of data collection and correct filling of cancer records has been a challenge since it can affect the interpretation of the disease situation and the identification of factors that contribute to its development.

The limitations of the present study include the use of secondary data and possible biases of information and

selection. Follow-up for an extended period (22 years) may cause changes in the standardization of data collection, in the classifications used for filling, and in the turnover of professionals responsible for the records[13]. Moreover, the visible decline in the number of cases recorded over the last years due to delays in updating the RHC data is highlighted. Another noteworthy aspect is the lack of patients' personal information, which makes it impossible to relate the data to other databases and make the information complete. Some of the variables presented a high level of incompleteness. This was noticeable for the Southeast Region, considering a great lack of information in the State of São Paulo, which warns of the lack of integration of the SisRHC system. The potentialities of this study include the size of the sample analyzed and the territorial scope, providing knowledge of oncopediatric care in the country and its Geographic Regions.

Analyzing the information contained in the RHC allowed a better understanding of the distribution of childhood cancer in Brazil and its Geographic Regions, identifying possible weaknesses in access to treatment for this population. Such information contributes not only to scientific knowledge but also to the improvement of public policies and the application of specific and assertive strategies according to the reality of each locality, assisting in decision-making by managers and professionals involved in pediatric oncological patient care.

CONCLUSION

By analyzing the cases recorded in different cancer records, it was found that the majority belonged to children and adolescents of the male sex, brown-skinned, in the age group of 0 to 4 years. The hematopoietic and reticuloendothelial system was the most affected, and most individuals underwent the first treatment at the hospital, with chemotherapy being the most used modality. All Brazilian Regions have complied with the deadline set by the Law of 60 Days in more than 70% of cases.

It was also verified that most variables had excellent completeness, but the information on "skin color" and "disease status at the end of the first treatment at the hospital" presented the highest percentage of missing data, being considered poor completion, and the Southeast Region presented the highest incompleteness of information.

CONTRIBUTIONS

Nyellisonn Nando Nobrega de Lucena, Luiz Medeiros Araujo Lima Filho and Ana Maria Gondim Valença contributed substantially to the study design, planning, data acquisition and interpretation, wording, and critical review. Lecidamia Cristina Leite Damascena and Ynnaiana Navarro de Lima Santana Quintans contributed substantially to data analysis and interpretation, wording, and critical review. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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