

Clinical-epidemiological Profile and Waiting Times between Diagnosis and Treatment of Child and Adolescent Patients with Central Nervous System Cancer Treated in Brazilian Hospitals

<https://doi.org/10.32635/2176-9745.RBC.2023v69n4.4243>

Perfil Clínico-epidemiológico e Tempos de Espera entre o Diagnóstico e o Tratamento dos Pacientes Infantojuvenis com Câncer do Sistema Nervoso Central Atendidos nas Unidades Hospitalares Brasileiras

Perfil Clínico-epidemiológico y Tiempos de Espera entre el Diagnóstico y el Tratamiento de Pacientes Infantiles con Câncer del Sistema Nervoso Central Atendidos en Unidades Hospitalarias Brasileñas

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ABSTRACT

Introduction: Central Nervous System tumors are the most frequent group of solid tumors in the pediatric population. Children and adolescents with cancer should be treated in onco-pediatric-accredited hospitals, but actually this treatment does not occur in this type of unit in some cases. **Objective:** To describe the clinical-epidemiological profile and waiting times between diagnosis and treatment of pediatric patients with CNS cancer in accredited and non-accredited hospitals for childhood cancer. **Method:** Descriptive study of data extracted from the *Integrador RHC* on CNS tumors diagnosed between 2010 and 2017, in individuals aged 0 to 19 years. Sociodemographic and clinical variables were included to explore the differences in time between diagnosis and treatment. **Results:** 5,281 cases of CNS tumors were included. Males (54.8%) were more affected than females (45.2%). Children aged 0 to 4 years were the most prevalent (33.2%). Histology of the primary tumor (73.3%) was the main diagnostic exam. The time between diagnosis and treatment was longer in onco-pediatric non-accredited (29 days) than in accredited (17 days) hospitals. Black, Brown, Indigenous and Yellow individuals waited more since diagnosis to treatment (23 days). **Conclusion:** Differences of interval until treatment, skin color and onco-pediatric hospital accreditation were found. It is necessary to ensure equitable access to these patients within the Brazilian Health System.

Key words: central nervous system neoplasms; oncology service, hospital; epidemiology; pediatrics; time-to-treatment.

RESUMO

Introdução: Tumores do sistema nervoso central (SNC) são o grupo mais frequente de tumores sólidos na população de crianças e adolescentes que devem ser tratados em unidades habilitadas em oncopediatria, o que, em alguns casos, não ocorre nesse tipo de unidade. **Objetivo:** Comparar o perfil clínico-epidemiológico dos pacientes infantojuvenis com câncer do SNC atendidos nas unidades hospitalares habilitadas em oncologia com as habilitadas em oncologia pediátrica, e analisar o tempo entre o diagnóstico e o tratamento do câncer do SNC, segundo as variáveis clínicas e sociodemográficas. **Método:** Estudo descritivo sobre tumores do SNC diagnosticados entre 2010 e 2017, em indivíduos de 0 a 19 anos, extraídos da base de dados do Integrador RHC. Variáveis sociodemográficas e clínicas foram incluídas para explorar as diferenças no tempo entre o diagnóstico e o tratamento. **Resultados:** Foram incluídos 5.281 casos de tumores do SNC. O sexo masculino (54,8%) foi mais frequente do que o sexo feminino (45,2%). A faixa etária de 0 a 4 anos foi a mais prevalente (33,2%). O principal exame para o diagnóstico do tumor foi a histologia do tumor primário (73,3%). O tempo entre o diagnóstico e o tratamento foi maior nos hospitais não habilitados (29 dias) do que nos habilitados em oncopediatria (17 dias). Pretos, pardos, indígenas e amarelos apresentaram maior tempo até o tratamento (23 dias). **Conclusão:** Encontraram-se diferenças quanto à cor da pele, acreditação para oncopediatria e intervalo do diagnóstico até o tratamento. Destaca-se a necessidade de garantir o acesso equitativo desses pacientes dentro do Sistema de Saúde brasileiro.

Palavras-chave: neoplasias do sistema nervoso central; serviço hospitalar de oncologia; epidemiologia; pediatria; tempo para o tratamento.

RESUMEN

Introducción: Los tumores del Sistema Nervoso Central son el grupo de tumores sólidos más frecuente en la población pediátrica. Los niños y adolescentes con cáncer deben ser tratados en unidades cualificadas en oncopediatria, pero en la práctica este tratamiento, en algunos casos, no se da en este tipo de unidades. **Objetivo:** Comparar el perfil clínico-epidemiológico y los tiempos de espera entre diagnóstico y tratamiento de pacientes pediátricos con cáncer del SNC en unidades habilitadas y no habilitadas para cáncer infantil. **Método:** Estudio descriptivo de datos extraídos del Integrador RHC sobre tumores del SNC diagnosticados entre 2010 y 2017, en individuos de 0 a 19 años. Se incluyeron variables sociodemográficas y clínicas para explorar las diferencias de tiempo entre el diagnóstico y el tratamiento. **Resultados:** Se incluyeron 5281 casos de tumores del SNC, los varones (54,8%) fueron más afectados que las mujeres (45,2%), los niños de 0 a 4 años fueron los más afectados (33,2%), el principal examen para el diagnóstico del tumor fue la histología del tumor primario (73,3%). El tiempo entre el diagnóstico y el tratamiento fue mayor en los hospitales no habilitados (29 días) que en los habilitados en oncopediatria (17 días). Los negros, pardos, indígenas y amarillos presentaron mayor tiempo hasta el tratamiento (23 días). **Conclusión:** Se encontraron diferencias en cuanto al color de piel, acreditación hospitalaria e intervalo hasta el tratamiento que deben ser discutidas para el avance del Sistema Único de Salud en la atención al paciente de oncología pediátrica. Se destaca la necesidad de garantizar el acceso equitativo dentro del Sistema de Salud brasileño a estos pacientes.

Palabras clave: neoplasias del sistema nervoso central; servicio de oncología en hospital; epidemiología; pediatria; tiempo de tratamiento

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INTRODUCTION

Central nervous system (CNS) tumors are the most frequent group of solid tumors in the population of children and adolescents (0-19 years), representing approximately 26% of all childhood neoplasms¹. In addition, these tumors are the most common cause of cancer-related death in this age group². There is a gap in studies that understand the care profile of children and youth patients with CNS cancer at the national level. Several studies have conducted this analysis encompassing all types of childhood cancers and in specific hospital units, making it impossible to fully compare the Regions³⁻⁵.

The Ministry of Health Ordinance n°. 874, of May 16, 2013, establishes the National Policy for Cancer Prevention and Control, establishes comprehensive care for the user in a regionalized and decentralized manner, and determines that cancer treatment will be done in health facilities qualified as High Complexity Care Unit in Oncology (Unacon) or High Complexity Care Center in Oncology (Cacon)⁶. However, not all hospital units are qualified in specific services, such as pediatric oncology. In Brazil, there are 317 units and centers qualified in cancer treatment, of which 75 are qualified in pediatric oncology⁷.

Hospitals qualified in pediatric oncology have services for the diagnosis and treatment of solid tumors and acute and chronic malignant hemopathies of children and adolescents, with chemotherapy center, and may have radiotherapy service, in addition to palliative care⁷. These hospitals must meet the criteria described in art. 19 of Ordinance of the Ministry of Health n°. 1,399, of December 17, 2019⁷.

There are no studies that describe whether children and adolescents with CNS cancer are treated in hospitals enabled or not enabled for childhood cancer. Thus, a comparison between these two types of hospitals is necessary to ensure equity, one of the principles of the Unified Health System (SUS). This comparison is crucial because, in 2023, the National Cancer Institute (INCA) estimated 4,230 new cases of childhood cancer for males and 3,700 cases for females for each year of the 2023-2025 triennium in Brazil. These values correspond to an estimated risk of 140.50 new cases per million for males and 128.87 per million for females⁸.

Since the time between diagnosis and treatment of childhood cancer is also a relevant factor in prognosis⁹, the objective of the study is to compare the clinical and epidemiological profile of children and adolescents with CNS cancer treated in oncology-qualified hospitals with pediatric oncology-qualified hospitals and to analyze the

time between diagnosis and treatment of CNS cancer, according to clinical and sociodemographic variables.

Comparing the time between diagnosis and treatment in child and adolescent cancer treatment units and analyzing the clinical-epidemiological profile of patients allows the evaluation of care for children with cancer in Brazil, as well as the understanding of who are the children with CNS cancer in the country. The findings of the study will contribute to the discussion about access to health services, the social determinants of health and the quality of information in the Hospital Cancer Records (HCR).

METHOD

An exploratory observational study in which information on childhood CNS tumors was analyzed. These were extracted from the RHC Integrator, a system that nationally consolidates the RHC¹⁰ databases.

Before the analysis, the extracted database went through an adaptation process, through the categorization of existing variables, removal of irrelevant data, standardization, and creation of new variables. We analyzed 5,281 cases of CNS cancer in children and adolescents, from 0 to 19 years of age, from 2010 to 2017. This period was chosen, since the consolidation of the data requires time and, in more recent years, there was a lack of these data in some Units of the Federation.

To delimit the study population, it was necessary to filter the RHC Integrator database, which initially had 69,794 cases of childhood cancer. For the analysis, the so-called “analytical” cases were included, which are those in which planning, and treatment are conducted in the hospital where the tumor was registered¹⁰. “Non-analytical” cases were excluded, since they did not present data capable of evaluating the quality of care provided in the hospital unit.

The State of São Paulo was excluded from this analysis, as it uses data from HCR managed by the Oncocentro de São Paulo Foundation (Fosp), which does not collect information on variables that will be used in this research, such as “skin color”. The lack of some information from this State would bias the analysis of the Southeast Region. Cases of childhood CNS cancer in São Paulo represented 28.6% of the total. Sociodemographic and clinical variables were included in the study to explore differences in time between diagnosis and treatment.

The sociodemographic variables chosen were sex, skin color, age group, Federative Unit, and municipality of origin of the patient and Brazilian regions. Some variables were excluded due to the impossibility of analysis, such as schooling of the child, history of alcohol consumption, smoking. Staging and disease status at the end of the

first treatment could also not be analyzed because of inconsistencies in bank completion.

The clinical variables analyzed were most important exam for the diagnosis of the tumor (cytological, histological, imaging), type of CNS cancer, origin of referral, year of diagnosis, previous diagnosis, and treatment, first treatment received in the hospital, interval, in days, between diagnosis and treatment, and previous diagnosis and treatment. The CNS cancer type variable did not exist in the database, so it was created by an algorithm based on the combination of morphology and topography present in the database, using the International Classification of Childhood Cancer (ICIC)¹¹. The time-to-treatment variable was created by subtracting the treatment date from the diagnosis date. The study exposure variable is the type of hospital where the patient was treated: qualified or not in pediatric oncology, according to Ministry of Health Ordinance n. 1,399, of December 17, 2019⁷, and the variable of interest (outcome) is the time between diagnosis and treatment.

The characteristics of the clinical and sociodemographic variables were described by absolute and relative frequencies. The time interval (in days) between diagnosis and treatment initiation was described by the median central tendency measure. The *p-value* < 0.05 in the chi-square test was considered statistically significant. All analyses were performed using *STATA 15*¹² software. The graphs were produced in *Microsoft Excel* and *R Core Team*¹³ software version 2022, using the *ggplot2*¹⁴ package.

According to Resolution n. 510¹⁵, of April 7, 2016, of the National Health Council (CNS), research using public databases, without identifying patients, does not need to be evaluated by a Research Ethics Committee.

RESULTS

5,281 cases of CNS cancer were identified, 2,893 (54.8%) in males and 2,388 (45.2%) in females. The most frequent age group was 0-4 years, with 1,757 (33.3%) cases. Regarding skin color, 2,521 (47.7%) cases were black, brown, indigenous, and yellow, and 808 (15.3%) had no information on skin color (Table 1).

Most patients were treated in their State Unit of origin, 4,917 (93.1%), but in a municipality of different origin, 3,985 (75.5%). In this analysis, the highest percentage of CNS cancer cases was observed in the Northeast, 36.8%, which represents 1,929 patients (Table 1).

We identified 3,828 (72.5%) cases treated in hospitals qualified in pediatric oncology and 1,453 (27.6%) cases treated in hospitals not qualified in pediatric oncology. In both, males were more frequent, with 2,080 (54.3%) and 813 (55.9%) cases respectively, but without statistical

significance ($p = 0.292$) (Table 1).

Regarding the age group, the group from 0 to 4 years presented a higher percentage in hospitals qualified in pediatric oncology, with 1,419 (37.1%) cases. In those not qualified in pediatric oncology, the age group from 5 to 9 years was more frequent, with 420 (28.9%) cases. The age group of 15 to 19 years represented 410 (11.9%) cases in hospitals qualified in pediatric oncology and 366 (25.2%) cases in hospitals not qualified in pediatric oncology. Regarding skin color, in both types of hospitals, blacks, browns, indigenous and yellows were more frequent, with 1,751 (45.7%) patients qualified for pediatric oncology and 770 (53.0%) patients not qualified in pediatric oncology ($p < 0.01$) (Table 1).

Regarding the clinical variables, the most important exam for the diagnosis of the tumor was the histology of the primary tumor, being performed by 3,869 (73.3%) patients. In 5,142 (97.4%) patients, tumors were classified as intracranial and intraspinal unspecified neoplasia. Regarding the origin of the referral, 4,090 (77.5%) patients were referred by SUS. Combined treatment (more than one modality) was the most frequent type of treatment performed, performed in 2,294 (43.4%) patients, followed by chemotherapy, performed in 1,101 (20.9%) patients (Table 2).

It was also observed that 2,625 patients (49.7%) had no previous diagnoses and treatments and 1,610 had only the diagnosis.

Still in relation to clinical variables (Table 2), in both types of hospitals, the most important test for the diagnosis of CNS cancer was the histology of the primary tumor. It was found that 5,142 (97.4%) cases were classified as unspecified intracranial neoplasms in hospitals qualified and not qualified in pediatric oncology. In both types of hospitals, referrals occurred mainly through SUS (77.5%).

Regarding the interval between diagnosis and treatment (Table 3), the age group from 15 to 19 years presented the greatest interval (median of 33 days), compared to the other age groups. Non-whites also had a longer time (median of 23 days), compared to whites (median of 16.5 days). The South Region had the shortest interval, with a median of eight days, and the Northeast Region had the longest interval, with a median of 28 days until treatment.

Hospitals not qualified in pediatric oncology had the longest interval, with a median of 29 days, while those qualified had a median of 17 days until treatment. Regarding the origin of the referral, the shortest time between diagnosis and treatment occurred among individuals referred "on their own", with a median of 8.5 days. Patients with previous diagnosis and treatment had a median of 71 days until treatment (Table 4).

Table 1. Distribution of sociodemographic characteristics of CNS cancer cases diagnosed in children and adolescents, according to the type of hospital, from 2010 to 2017, in Brazil

Sociodemographic variables	Hospital type		Total n (%)	p
	Enabled for pediatric oncology n (%)	Not enabled for pediatric oncology n (%)		
Total	3,828 (72.5)	1,453 (27.6)	5,281 (100.0)	
Sex	Male	2,080 (54.3)	813 (55.9)	0.292
	Female	1,748 (45.7)	640 (44.1)	
Age group (years)	0 to 4	1,419 (37.1)	338 (23.3)	< 0.01
	5 to 9	1,150 (30.0)	420 (28.9)	
	10 to 14	840 (21.9)	329 (22.6)	
	15-19	419 (10.9)	366 (25.2)	
Skin color	White	1,492 (39.0)	460 (31.7)	< 0.01
	Black/ brown/indigenous/ yellow	1,751 (45.7)	770 (53.0)	
	No information	585 (15.3)	223 (15.4)	
Treatment in the state of origin	No	298 (7.8)	66 (4.5)	< 0.01
	Yes	3,530 (92.2)	1,387 (95.5)	
Treatment in the municipality of origin	No	2,927 (76.5)	1,058 (72.8)	0.006
	Yes	901 (23.5)	395 (27.2)	
Regions	North Region	194 (5.1)	164 (11.3)	0.01
	Northeast	1,104 (29.1)	825 (56.9)	
	Southeast Region	965 (25.4)	229 (15.9)	
	South Region	1,060 (27.9)	169 (11.7)	
	Midwest Region	474 (12.5)	64 (4.4)	

Caption: UF = Federative Unit.

(p) comparing the categories of sociodemographic characteristics for the total population.

Individuals referred by SUS took less time (20 days) until treatment than those who were not referred by SUS (24 days). In relation to the year, there was a decrease in the time interval between diagnosis and treatment of CNS cancer, from 22 days in 2010 to 19 days in 2017, with oscillations over the years.

Comparing the time between diagnosis and treatment, according to the type of hospital, it was observed that, for all age groups, the interval was longer in hospitals not qualified in pediatric oncology. In the age group from 0 to 4 years, this difference becomes even more visible, with the interval being 15 days longer. Regarding skin color, it was noted that, for both whites and blacks, browns, indigenous people and yellows, the interval was higher in hospitals not qualified in pediatric oncology, but still, whites had a shorter interval until treatment (Table 5).

Hospitals not qualified in pediatric oncology had a longer interval both in referrals made by SUS (30 days)

and in those that were not made by SUS (31 days). In qualified hospitals, there was a reduction from 20 to 14 days in the time between diagnosis and treatment, from 2010 to 2017, and in non-qualified hospitals, there were variations from 28 to 36 days in the respective years. In both types of hospitals, patients with a diagnosis and previous treatments had a median greater than 60 days until treatment (Table 5).

DISCUSSION

Considering that childhood cancer has different clinical, epidemiological, and biological characteristics in relation to cancer in adults^{16,17}, it is possible to observe the priority of treatment in a specialized service, which was possible to observe in this analysis, since 72.4% of the cases obtained treatment in a service qualified for pediatric oncology.

Table 2. Distribution of sociodemographic characteristics of CNS cancer cases diagnosed in children and adolescents, according to the type of hospital, from 2010 to 2017, in Brazil

Clinical variables		Enabled for pediatric oncology n (%)	Not enabled for pediatric oncology n (%)	Total n (%)	p
Total		3,828 (72.5)	1,453 (27.5)	5,281 (100.0)	
Most important test for tumor diagnosis	Clinic	13 (0.3)	12 (0.8)	25 ± 0.5	<i>p</i> < 0.01
	Clinical research	38 (1.0)	2 (0.1)	40 (0.8)	
	Imaging exam	932 (24.4)	239 (16.5)	1,171 (22.8)	
	Tumor markers	53 (1.4)	6 (0.4)	59 (1.1)	
	Cytology	47 (1.2)	28 (1.9)	75 (1.4)	
	Histology of metastasis	15 (0.4%)	4 (0.3)	19 (0.4)	
	Primary tumor histology	2,718 (71.0)	1,151 (79.2)	3,869 (73.3)	
	No information	12 (0.3)	11 (0.8)	21 (0.4)	
Type of CNS cancer	Ependymomas and choroid plexus tumor	4 (0.1)	2 (0.1)	6 (0.1)	<i>p</i> < 0.01
	Astrocytoma's	2 (0.1)	2 (0.1)	4 (0.1)	
	Intracranial and intraspinal embryonic tumors	2 (0.1)	1 (0.1)	3 (0.1)	
	Other gliomas	9 (0.2)	4 (0.3)	13 (0.3)	
	Other specified intracranial and intraspinal neoplasms	86 (2.3)	27 (1.9)	113 (2.1)	
	Other specified intracranial and intraspinal neoplasms	3,735 (97.3)	1,417 (97.5)	5,142 (97.4)	
Forwarding source	SUS	3,000 (78.4)	1,090 (75.0)	4,090 (77.5)	<i>p</i> < 0.01
	Non-SUS	332 (8.7)	207 (14.3)	539 (10.2)	
	On its own	94 (2.5)	28 (1.9)	122 (2.3)	
	No information	402 (10.5)	128 (8.8)	530 (10.0)	
Year of diagnosis	2010	233 (6.1)	105 (7.2)	338 (6.4)	<i>p</i> < 0.01
	2011	502 (13.1)	206 (14.9)	708 (13.4)	
	2012	510 (13.3)	218 (15.0)	728 (13.8)	
	2013	533 (13.9)	268 (18.4)	801 (15.8)	
	2014	468 (12.2)	214 (14.8)	682 (12.9)	
	2015	546 (14.3)	142 (9.8)	688 (13.0)	
	2016	578 (15.1)	174 (12.0)	752 (14.2)	
	2017	458 (12.0)	126 (9.0)	584 (11.1)	
First treatment	None	7 (0.2)	6 (0.4)	13 (0.3)	<i>p</i> < 0.01
	Surgery	742 (19.4)	201 (13.8)	943 (17.8)	
	Radiotherapy	354 (9.3)	463 (31.9)	817 (15.5)	
	Chemotherapy	914 (23.9)	187 (12.8)	1,101 (20.9)	
	Bone marrow transplant	4 (0.1)	0 (0.0)	4 (0.1)	
	Immunotherapy	0 (0.0)	0 (0.0)	0 (0.0)	
	Other	55 (1.4)	39 (2.7)	94 (1.8)	
	No information	5 (0.1)	10 (0.7)	15 (0.3)	
Previous diagnosis and treatment	Combined treatment	1,747 (45.6)	547 (37.7)	2,294 (43.4)	<i>p</i> < 0.01
	No diagnosis and no treatment	2,049 (53.3)	576 (39.6)	2,625 (49.7)	
	No diagnosis and no treatment	1,073 (28.0)	537 (37.0)	1,610 (30.5)	
	No diagnosis and no treatment	580 (15.2)	304 (20.9)	884 (16.7)	
	No information	126 (3.3)	36 (2.5)	162 (3.1)	

Caption: SUS = Unified Health System.

(*p*) comparing the categories of sociodemographic characteristics for the total population.

In this study, males showed no statistically significant difference in relation to females. However, some national and international studies show higher incidence rates of CNS neoplasia in male children and adolescents^{18,19}.

Skin color is also considered a preponderant factor, since, in the two types of hospitals, blacks, browns, indigenous and yellows represented the majority of cases, however, in qualified hospitals, the number of

Table 3. Median interval in days between diagnosis and treatment of cases of childhood CNS cancer diagnosed in children and adolescents, according to sociodemographic variables, from 2010 to 2017, in Brazil

Sociodemographic variables		Median (min-max)
Sex	Female	20 (18-21)
	Male	20 (18-21)
Age group (years)	0 to 4	14 (12-15)
	5 to 9	20 (18-22)
	10 to 14	23 (20-26)
	15-19	33 (28-37)
Skin color	White	16.5 (14-19)
	Black/ brown/indigenous/yellow	23 (21-26)
	No information	16 (14-20)
Regions	North Region	27 (20-32)
	Northeast	28 (26-30)
	Southeast Region	19.5 (17-22)
	South Region	8 (7-9)
	Midwest Region	14 (12-15)

Table 4. Median interval in days between diagnosis and treatment of cases of childhood CNS cancer diagnosed in children and adolescents, according to sociodemographic variables, from 2010 to 2017, in Brazil

Clinical variables		Median (min-max)
Hospital type	Qualified in pediatric oncology	17 (15-19)
	Non- qualified in pediatric oncology	29 (27-32)
Forwarding source	SUS	20 (19-21)
	Non-SUS	24 (20-27)
	By their own	8,5 (6,7-13)
	No information	18.5 (14-22.1)
Year of diagnosis	2010	22 (20-28)
	2011	18 (13.4-23)
	2012	23 (19-27)
	2013	20 (18-25)
	2014	21 (19-27)
	2015	20 (16-25)
	2016	14 (12-17)
	2017	19 (15-21.2)
First treatment	None	5 (2-93)
	Surgery	0 (0-0)
	Radiotherapy	50 (47-56)
	Chemotherapy	30 (27-33)
	Bone marrow transplant	192 (62-322)
	Combined treatment	16 (14-19)
	Other	26 (7-40)
	No information	33 (9-41.7)
Previous diagnosis and treatment	No diagnosis and no treatment	1 (1-2)
	No diagnosis and no treatment	37 (35-39)
	No diagnosis and no treatment	71 (67-76)
	No information	18 (12-26)

Caption: SUS = Unified Health System.

Table 5. Median interval in days between diagnosis and treatment of cases of childhood CNS cancer diagnosed in children and adolescents, according to sociodemographic variables, from 2010 to 2017, in Brazil

Variables	Hospital type		
	Enabled for oncopediatrics (min-max)	Not enabled for pediatric oncology (min-max)	
Age group (years)	0 to 4	12 (10-14)	27 (18.5-29.5)
	5 to 9	19 (17-21)	25 (19.4-31)
	10 to 14	21 (18-24)	27 (22.4-31)
	15-19	27 (19-33.1)	40 (33-47)
Skin color	White	15 (12-18)	26 (19-31)
	Black/ brown/indigenous/yellow	20 (19-22)	29.5 (26-33)
	No information	12 (9-14)	32 (27-38)
Forwarding source	SUS	17 (15-19)	30 (27-33)
	Non-SUS	20 (18-24)	31 (23.8-37)
	On its own	8 (5 - 11)	17 (7.6-25)
	No information	14.5 (12-20)	25 (17.3-33.6)
Year of diagnosis	2010	20 (18-27)	28 (20-40)
	2011	19 (14-23)	14 (6-29)
	2012	18 (13-21)	39 (32-54)
	2013	19 (15-22.6)	27.5 (20-32.6)
	2014	20 (17-25)	27 (19-32)
	2015	17 (14-21)	34 (25-51)
	2016	12 (9-14)	28 (20.2-34.9)
	2017	14 (13-18.5)	36 (25-44)
Treatment in the municipality of origin	No	16 (14-18)	31 (28-34)
	Yes	20 (18-24)	25 (18.5-28)
Treatment in the state of origin	No	13 (9.6-14)	24 (3.5-40)
	Yes	18 (16-19)	29 (27-32)
Previous diagnosis and treatment	No diagnosis and no treatment	2 (1-2)	0 (0-0)
	No diagnosis and no treatment	37 (34-40)	38 (34-42)
	No diagnosis and no treatment	66 (62-72)	78.5 (72-94)
	No information	14 (10.5-21)	33 (22-37)

Captions: UF= Federative Unit; SUS = Unified Health System.

patients with this characteristic was lower compared to non-qualified hospitals. However, when the interval until treatment was analyzed, they presented the greatest interval compared to those with declared white skin color. This result is consistent with the study by Santos et al.²⁰ that points to the persistence of inequalities related to skin color in accessibility to health goods and services. It is noteworthy that socioeconomic inequalities influence the accessibility to cancer care, especially in early diagnosis²⁰.

Regardless of the type of cancer and the forms of diagnosis and treatment, studies show that mainly black patients (black plus brown) have barriers in accessing

cancer care for social and economic reasons. The SUS needs to ensure equitable access to all social groups^{20,21}.

Regarding the origin of the patients, most of them were not treated in their municipalities of origin. Despite being the second most common type of cancer in the pediatric population, CNS cancer is a rare disease, so the insertion of pediatric oncology services in each municipality is not feasible, given that there would be no demand and specialized clinical staff. This is even more relevant due to the need for a pediatric neurosurgeon.

In Brazil, SUS relies on Treatment Outside the Home (TFD), a benefit granted to people with cancer who

need to move to other Regions to undergo therapeutic treatment. In these cases, the legislation requires the government to provide financial aid to cover the costs of transportation and accommodation. If there is a need for an escort, he will also be entitled to this assistance.

It is necessary to emphasize that, in the case of childhood cancer, the companion is crucial and that, due to a long treatment, the patient and his companion need accommodation that, in many cases, is also offered by support houses around Brazil. A study²² highlighted that several family members of children with cancer report multiple sources of “financial toxicity”, which is the impact of the disease on family finances, and one of these sources is related to the trip to the treatment site.

In this study, the histology of the primary tumor was the most important test for the diagnosis of CNS cancer, which could guarantee greater specification of the type of cancer, since the histopathological examination evaluates, under a microscope, a tissue fragment to confirm a diagnosis or diagnostic hypothesis, and the sample is obtained by incisional biopsy, excisional biopsy or organ fragments collected on microscopic examination²³.

However, when analyzing the variable that specifies the type of cancer in the light of ICIC¹¹, the classification of “Unspecified intracranial and intraspinal neoplasia” is mostly observed, which can demonstrate a problem in the accurate diagnosis²⁴, or also the lack of filling out the information in the medical record, affecting the filling out of the tumor registration form.

The information available in the HCR has immense potential for analysis, which allows us to observe the institutional patterns of cancer care overtime²⁵. It is noteworthy that there is a need to improve information, especially in the classification of the histological type of the tumor.

It was observed that patients from hospitals not qualified in pediatric oncology had the longest time until treatment, in addition to this time having presented variability over the years studied. In hospitals qualified in pediatric oncology, the interval decreased over time. This study is the first to describe these time interval differences between diagnosis and treatment. Delay in the initiation of treatment of childhood cancer is known to be associated with epidemiological and clinical characteristics of cancer patients³.

Most intervals, except for bone marrow transplant patients (192 days) and those with previous diagnosis and treatment (71 days), were less than 60 days. This shows compliance with Law n°. 12.732/2012, which assures cancer patients the right to start treatment in the SUS within 60 days after diagnosis²⁶. It is noteworthy that excisional biopsy is considered a diagnostic and

therapeutic procedure, and patients undergoing this procedure are included in the category of “previous diagnosis and treatment”, which may justify the longer periods observed in this category.

As a limitation of this study, there was difficulty in classifying tumors using the ICIC11, mainly due to the lack of histological type. However, even so, it remains relevant, due to the national scope, the number of cases and the number of variables analyzed.

CONCLUSION

This study allowed us to map the clinical-epidemiological profile of children and adolescents' cases of cancer of the CNS in Brazil, making a comparison between hospitals qualified and not qualified for pediatric oncology, in addition to allowing an analysis of the time between diagnosis and treatment. In view of the above, it was noticed that there is a difference in the profile of patients treated in each type of unit. Regarding the interval between diagnosis and treatment, compliance with the Law of 60 days was attested in all elements analyzed, except for bone marrow transplantation.

This research made it possible to know nationally the characteristics of children and youth patients with CNS cancer (excluding São Paulo), in addition to raising discussions about equal access among patients in several types of hospitals. This initial study will provide specific discussions on social determinants of health, geographic access of patients, coordination between municipalities and Federation Units, ensuring comprehensive care, the importance of specifying the diagnosis of the type of tumor and a greater understanding of the reality in future analyzes.

CONTRIBUTIONS

Samara Velloso Espósito contributed substantially to the design and planning of the study; in the collection, analysis, and interpretation of data; in the writing and critical review. Marcell de Oliveira Santos and Marianna de Camargo Cancela contributed substantially to the design and planning of the study; data collection, analysis, interpretation; and critical review of the manuscript. All authors approved the last version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

FUNDING SOURCES

None.

REFERENCES

- American Cancer Society [Internet]. Atlanta: ACS; 2019. Types of cancer that develop in children. [acesso 2023 nov 30]. Disponível em: <https://www.cancer.org/cancer/cancer-in-children/types-of-childhood-cancers.html>
- Instituto Nacional de Câncer [Internet]. Rio de Janeiro: INCA; 2022. Câncer infantojuvenil. [acesso em 2023 nov 30; atualizado em 2023 jan 13]. Disponível em: <https://www.gov.br/inca/pt-br/assuntos/cancer/tipos/infantojuvenil>
- Mutti CF, Cruz VG, Santos LF, et al. Perfil clínico-epidemiológico de crianças e adolescentes com câncer em um serviço de oncologia. *Rev Bras Cancerol.* 2018;64(3):293-300. doi: <https://doi.org/10.32635/2176-9745.RBC.2018v64n3.26>
- Araújo MAS, Jurema GL, Silva AD, et al. Câncer infantil: perfil epidemiológico em população atendida por hospital de referência no Piauí. *REAS.* 2020;12(12):e4817. doi: <https://doi.org/10.25248/reas.e4817.2020>
- Diniz AB, Regis CA, Brito NP, et al. Perfil epidemiológico do câncer infantil em população atendida por uma unidade de oncologia pediátrica em Salvador-Bahia. *R Ci méd biol.* 2005;4(2):113-7. doi: <https://doi.org/10.9771/cmbio.v4i2.4185>
- Ministério da Saúde (BR). Portaria nº 874 de 16 de Maio de 2013. Política Nacional para a Prevenção e Controle do Câncer na rede de atenção à saúde das pessoas com doenças crônicas no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União, Brasília, DF. 2013 maio 17. [acesso 2023 nov 30]. Disponível em: <https://bvsms.saude.gov.br/bvs/saudelegis/gm/2013/prt087416052013.html>
- Ministério da Saúde (BR). Portaria nº 1.399 de 17 de dezembro de 2019. Redefinição dos critérios e parâmetros referenciais para a habilitação de estabelecimentos de saúde na alta complexidade em oncologia no âmbito do SUS. Diário Oficial da União, Brasília, DF. 2019 dez 17. [acesso 2023 nov 30]. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/saes/2019/prt1399_19_12_2019.html
- Instituto Nacional de Câncer. Estimativa 2023: incidência do Câncer no Brasil [Internet]. Rio de Janeiro: INCA; 2022. [acesso 2023 nov 30]. Disponível em: <https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/estimativa-2023.pdf>
- Silva VB, Lucena NNN, Pinto RNM, et al. Fatores associados ao tempo entre o diagnóstico e o início do tratamento do câncer infantojuvenil. *Saud Pesq.* 2022;15(3):e-10894. doi: <https://doi.org/10.17765/2176-9206.2022v15n3.e10894>
- Instituto Nacional de Câncer. Registros hospitalares de câncer: planejamento e gestão. Rio de Janeiro: INCA; 2010.
- Steliarova-Foucher E, Stiller C, Lacour B, et al. International Classification of Childhood Cancer, 3. ed. *Cancer.* 2005;103(7):1457-67. doi: <https://doi.org/10.1002/cncr.20910>
- SATA: Stata Statistical Software [Internet]. Versão 15. College Station: StataCorp LLC; 2017. [acesso 2023 set 14]. Disponível em: <https://www.stata.com/stata15/>
- R: The R Project for Statistical Computing [Internet]. Versão 2022 [sem local]: The R foundation. 2022 nov 15. [acesso 2023 set 14]. Disponível em: <https://www.R-project.org>
- Wickham H. *ggplot2: elegant graphics for data analysis.* New York: Springer-Verlag; 2016.
- Conselho Nacional de Saúde (BR). Resolução nº 510, de 7 de abril de 2016. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais cujos procedimentos metodológicos envolvam a utilização de dados diretamente obtidos com os participantes ou de informações identificáveis ou que possam acarretar riscos maiores do que os existentes na vida cotidiana, na forma definida nesta Resolução [Internet]. Diário Oficial da União, Brasília, DF. 2016 maio 24. [acesso 2023 nov 30]; Seção I:44. Disponível em: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2016/res0510_07_04_2016.html
- Petrilli AS, Carneiro Jr. JL, Cypriano M, et al. Diferenças clínicas, epidemiológicas e biológicas entre o câncer na criança e no adulto. *Rev Bras Cancerol.* 1997;43(3):191-203. doi: <https://doi.org/10.32635/2176-9745.RBC.1997v43n3.2853>
- Kattner P, Strobel H, Khoshnevis N. et al. Compare and contrast: pediatric cancer versus adult malignancies. *Cancer Metastasis Rev.* 2019;38:673-82. doi: <https://doi.org/10.1007/s10555-019-09836-y>
- Gasparini B, Monteiro GTR, Koifman S. Mortalidade por tumores do sistema nervoso central em crianças e adolescentes no Rio de Janeiro, Brasil, 1980-2009. *Cad. saúde colet.* 2013;21(3):272-80.
- Gittleman H, Kromer C, Ostrom QT, et al. Is mortality due to primary malignant brain and other central nervous system tumors decreasing? *J Neurooncol.* 2017;133(2):265-75. doi: <https://doi.org/10.1007/s11060-017-2449-1>
- Paulista JS, Assunção PG, Lima FLT. Acessibilidade da população negra ao cuidado oncológico no Brasil: revisão integrativa. *Rev Bras Cancerol.* 2020;65(4):e-06453. doi: <https://doi.org/10.32635/2176-9745.RBC.2019v65n4.453>
- Souza ABC, Guedes HG, Oliveira VCB, et al. High incidence of prostate cancer metastasis in afro-brazilian men with low educational levels: a retrospective observational study. *BMC Public Health.* 2013;13:537. doi: <https://doi.org/10.1186/1471-2458-13-537>
- Kelada L, Wakefield CE, Vetsch J, et al. Financial toxicity of childhood cancer and changes to parents' employment after treatment completion. *Pediatr Blood Cancer.*

2020;67(7):e28345. doi: <https://doi.org/10.1002/pbc.28345>

23. Junqueira L, Carneiro J. Histologia básica I. 12. ed. Rio de Janeiro: Guanabara Koogan; 2013.
24. Instituto Nacional de Câncer José Alencar Gomes da Silva. Incidência, mortalidade e morbidade hospitalar por câncer em crianças, adolescentes e adultos jovens no Brasil. Rio de Janeiro: Inca; 2016.
25. Instituto Nacional de Câncer José Alencar Gomes da Silva. Informação dos registros hospitalares de Câncer como estratégia de transformação [Internet]. Rio de Janeiro: Inca; 2012. [acesso 2023 nov 20]. Disponível em: <https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/informacao-dos-registros-hospitalares-de-cancer-como-estrategia-de-transformacao.pdf>
26. Ministério da Justiça, Ministério da Saúde (BR). Lei nº 12.732 de 22 de novembro de 2012. Dispõe sobre o primeiro tratamento de paciente com neoplasia maligna comprovada e estabelece prazo para seu início. Diário Oficial da União, Brasília, DF. 2012 nov 22. Disponível em: https://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/12732.htm

Recebido em 25/7/2023
Aprovado em 14/12/2023