Epidemiological Characteristics of Families and Patients with Cancer in the State of São Paulo, their Difficulties and Challenges in Accessing the Barretos Children's Cancer Hospital

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Características Epidemiológicas de Famílias e Pacientes com Câncer do Estado de São Paulo, suas Dificuldades e Desafios para Acesso ao Hospital de Câncer Infantojuvenil de Barretos

Características Epidemiológicas de Familias y Pacientes con Cáncer en el Estado de São Paulo, sus Dificultades y Desafíos en el Acceso al Hospital Oncológico Infantil de Barretos

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ABSTRACT

Introduction: Cancer corresponds to abnormal proliferation of cells and, although it can be considered rare in children, adolescents and young adults, is the leading cause of death from disease up to the age of 29. **Objective:** To investigate the epidemiological characteristics of patients and families, by region of the State of São Paulo, with a contextual analysis of the first care and the difficulties in arriving at the Barretos Children's Cancer Hospital. **Method:** Cross-sectional, ambispective study, from January 2015 to January 2023, using questionnaires and descriptive analysis of data with quantitative variables median (variation in days) and qualitative variables (absolute and/or relative frequency), using Student's t, Kruskal-Wallis and ANOVA or Bonferroni variance tests and chi-square or Fisher's exact. **Results:** 650 patients were analyzed, most of whom were male (54%), white (68.1%), living in urban areas (95.4%) and with an average family income (67.7%). Considering all patients, the first consultation was most frequent in the public service (57.1%), in the National Health System office (30.8%) with the need for one more consultation after the first evaluation (37.2%). Residents of regions far from the oncology center had their first consultation in a private office (32.4%) and four or more consultations in more than 25% of cases. The biggest barrier was related to the health system (16.8%), with slow procedures. Hematological neoplasms were more frequent (33.7%). **Conclusion:** The health system was the greatest obstacle for patients, suggesting inequity of access related to sociodemographic and economic factors of the population. **Key words:** Neoplasms/epidemiology; Access to Primary Care; Barriers to access health service; Diagnosis.

RESUMO

Introdução: O câncer corresponde à proliferação anormal de células e, embora possa ser considerado raro em crianças, adolescentes e adultos jovens, constitui a primeira causa de mortalidade por doença até os 29 anos. Objetivo: Investigar características epidemiológicas de pacientes e famílias, por Regiões do Estado de São Paulo, com análise contextual do primeiro atendimento e das dificuldades de chegada ao Hospital de Câncer Infantojuvenil de Barretos. Método: Estudo transversal, ambispectivo, de janeiro de 2015 a janeiro de 2023, com uso de questionários e análise descritiva dos dados com variáveis quantitativas mediana (variação em dias) e variáveis qualitativas (frequência absoluta e/ou relativa), com uso de testes t de Student, Kruskal-Wallis e de variância ANOVA ou Bonferroni e teste de qui-quadrado ou exato de Fisher. Resultados: Foram analisados 650 pacientes, a maioria do sexo masculino (54%), cor branca (68,1%), residentes na zona urbana (95,4%) e com média renda familiar (67,7%). Considerandose todos os pacientes, o primeiro atendimento foi mais frequente no serviço público (57,1%) no consultório do Sistema Único de Saúde (30,8%) e com necessidade de mais uma consulta após a primeira avaliação (37,2%). Houve moradores de Regiões distantes do centro oncológico com primeira consulta no consultório particular (32,4%) e quatro ou mais consultas em mais de 25% das vezes. A maior barreira relacionou-se ao sistema de saúde (16,8%), com morosidade em procedimentos. Neoplasias hematológicas foram mais frequentes (33,7%). Conclusão: A maior dificuldade dos pacientes esteve presente no sistema de saúde sugerindo iniquidade de acesso relacionada a fatores sociodemográficos e econômicos da população. Palavras-chave: Neoplasias/epidemiologia; Acesso à Atenção Primária; Barreiras ao acesso aos cuidados de saúde; Diagnóstico.

RESUMEN

Introducción: El cáncer significa la proliferación anormal de células y, aunque puede considerarse raro en niños, adolescentes y adultos jóvenes, es la primera causa de mortalidad por enfermedad hasta los 29 años. Objetivo: Investigar las características epidemiológicas de los pacientes y sus familiares, por regiones del estado de São Paulo, con análisis contextual de la primera atención y de las dificultades para llegar al Hospital Infantil de Cáncer de Barretos. Método: Estudio transversal, retrospectivo y prospectivo, de enero de 2015 a enero de 2023, mediante cuestionarios y análisis descriptivo de datos con variables cuantitativas -mediana (variables en días)- y variables cualitativas (frecuencia absoluta y/o relativa), utilizando las pruebas t de Student, Kruskal-Wallys y ANVA o de Bonferroni, prueba de ji al cuadrado o exacta de Fisher. Resultados: 650 pacientes fueron analizados, la mayoría masculina (54%), blanca (68,1%), residente en zona urbana (95,4%) y con ingresos familiares medios (67,7%). Considerando el total de pacientes, la primera consulta fue más frecuente en el servicio público (57,1%) en el consultorio del Sistema de Salud Único (30,8%) y con necesidad de una consulta más después de la primera evaluación (37,2%). Residentes de regiones alejadas del centro oncológico con su primera consulta en consultorio privado (32,4%) y cuatro o más consultas más del 25% de las veces. La mayor barrera estuvo relacionada con el sistema de salud (16,8%), con trámites lentos. Las neoplasias hematológicas fueron las más frecuentes (33,7%). Conclusión: La mayor dificultad de los pacientes estuvo presente en el sistema de salud, sugiriendo inequidad de acceso relacionada con factores sociodemográficos y económicos de la población.

Palabras clave: Neoplasias/epidemiología; Acceso a Atención Primaria; Barreras de acceso a los servicios de salud; Diagnóstico.

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INTRODUCTION

Cancer corresponds to a group of diseases with abnormal and uncontrolled proliferation of cells. While the disease is still considered to be rare in people aged 0 to 29 years old, data from the International Agency for Research on Cancer (IARC) for 2022 show an incidence of over 605 thousand cancer cases with mortality over 200 thousand people, being the most common cause of death from disease in this age group in countries like the United States¹⁻³. In Brazil, the National Cancer Institute (INCA) estimates 7,930 new cases of childhood cancer for each year of the 2023-2025 period, and 2,289 deaths in this age group in 2020, representing the top cause of death from disease in children and adolescents in all Brazilian Regions⁴.

The State of São Paulo (SSP) has the greatest population in Brazil with around 47 million people, with a projection of over 11 million children and adolescents aged 0 to 19 years old for 2024 and 18 million people, if considered the age group from 0 to 29 years⁵. In 2023, 1,850 new cases of childhood cancer were estimated in SSP⁴. The histological confirmation was performed in 93% of cases from 2014 to 2018⁶, and the *Fundação Oncocentro de São Paulo* (Fosp) cancer foundation indicates that, in the 2000-2020 period, leukemias and myeloproliferative diseases were the most frequent in children up to 14 years old (29.5%) and lymphomas (23.6%), the most frequent in people aged 15 to 19 years old⁷.

In Brazil, healthcare must be equal and universal, ensured by the National Health System (SUS), which offers integral care to the needs of patients⁸. The healthcare model follows a hierarchy that starts with primary care, able to treat fewer complex conditions, with follow-up to specialized services according to gravity. SUS operates under territorialization and regionalization guidelines, being financed by government taxes^{9,10}. Alternatively, the population can turn to the private system, directly paying health insurance operators. This structure aims at ensuring broad and adequate access to health services¹¹.

The path patients follow to cancer diagnosis and treatment may be long and filled with obstacles in access to healthcare, related to sociodemographic and economic characteristics of families, health professionals and teams in the local healthcare system, with bureaucratic barriers and shortage of services¹².

The objective of this study is to investigate the epidemiological characteristics of patients and families, by Regions of the SSP, with contextual analysis of the first consultation and difficulties in accessing the Barretos Children's Cancer Hospital (HCIJB in the Brazilian Portuguese abbreviation), an oncology center focused on children that exclusively cares for SUS patients. Understanding those characteristics and identifying the obstacles in healthcare access may help develop government strategies to reduce barriers in pediatric oncology assistance in the SSP, in a scenario with shortage of information from patients and their families cared in oncology reference centers such as the HCIJB.

METHOD

Since 2015, HCIJB has instituted an in-person survey to collect epidemiological data from patients and their families, any difficulties found within the healthcare network to access the necessary services, data on time to disease diagnosis and treatment, with follow-up upon recurrence, healing and death, with the objective of structuring a database for scientific research.

The present study was cross-sectional. Ambispective, that is, used previously collected data stored in the REDCap¹³ program (January 2015 to July 2021) and data collected prospectively from August 2021 to January 2023. This study has been approved by the HCIJB Research Ethics Committee, report number 7133590 (CAAE (submission for ethical review): 38702114.6.1001.5437), in compliance with Resolution number 466¹⁴, December 12, 2012, of the National Health Council.

Patients were selected by convenience. That way, all patients who were present at the HCIJB (for consultations, ambulatory procedures or hospitalization) were invited to participate in the study in established periods for the survey application. After clearing doubts on the study and asking patients to fill out the Informed Consent Form (ICF), the survey was applied to the legal guardian who accompanied the child/adolescent, in case the patient was under 18 years old at the beginning of the illness who brought them to the HCIJB.

The inclusion criteria were patients residing in the SSP when the symptoms that brought them to HCIJB started that were included from January 2015 to January 2023. The exclusion criteria were patients coming from other States or who refused to participate in the survey. From March 2020 to January 2021, it was not possible to apply the survey due to the COVID-19 pandemic restrictions. A small percentage of young adults aged 20 to 29 years old (5.8%) was included in our analyses, since this age group is usually cared for in the HCIJB and included in scientific studies if eligible, because the approach from specialized pediatric oncology services usually improves the prognosis and survival of this population¹⁵⁻¹⁷.

The study came from the Regional Healthcare Departments (RHD), grouped in three Regions according to proximity to HCIJB. The fact that oncology care referral



should be regional to result in a smaller influx of patients from farther Regions was considered. The Barretos, Franca, Ribeirão Preto and Araraquara RHD form the North Region; Araçatuba and São José do Rio Preto constitute the Northwest Region; and the remaining RHD (Presidente Prudente, Marília, Bauru, Piracicaba, São João da Boa Vista, Sorocaba, Registro, Campinas, Grande São Paulo, Baixada Santista and Taubaté) form the Distant Region (DR). This grouping is aimed at optimizing statistical analysis.

Patients' characteristics such as sex, skin color and age at the start of the pathology who brought them to HCIJB were assessed. Skin color was self-declared by the patient or their legal guardian during the survey application. The following data from the families were collected: parents education level, place of residence, number of siblings and total number of people in the residence. The analyses included the type of first consultation, place of consultation and which medical specialist conducted the first consultation, in addition to the number of new consultations after the first one. The difficulties in accessing HCIJB were listed, and the first neoplasms were studied, grouped individually, and data were related to the patients original Regions in the SSP. Data on the treatment, disease remission, survival, disease recurrence or death were not assessed, given that this study focused on the patients' journey to access the hospital's services.

The parents' education level was grouped into three categories: low (illiterate or who study for up to 8 years), medium (9 to 11 years of study) and high education level (\geq 12 years of study). The average family income was grouped in monthly gains levels, such as low (up to 1 minimum-wage (MW)), medium (2 to 5 MW) and high (>5 MW).

The socioeconomic index for health and social research (GeoSES)¹⁸ of the patients' original municipality was used in the study due to its wider scope in dimensions related to accessibility to the healthcare system. The GeoSES is composed of seven dimensions (education, income, poverty, wealth, residential segregation, mobility and deprivation of access to resources or services) being represented by values that range from worse (-1) to better (1) socioeconomic status.

A descriptive analysis of epidemiological data from patients and their families is presented here, quantitative variables summarized in median (variation in days) and qualitative variables summarized by absolute and/or relative frequencies. The T tests (or Mann-Whitney) were used, and for comparison of three or more independent groups, the Kruskal-Wallis's test was used. In case the factor possessed more than two categories, the variance analysis technique (ANOVA) or Bonferroni was used. To verify the association between categorical variables, the chi-square test (or Fisher's exact test) was used. A significant level of 5% was adopted and analyses were performed using the SPSS, $v21.0^{19}$ software.

Due to the cross-sectional, ambispective nature of this study, some variables do not contemplate all the patients included, given that in some situations the interest variable was included after the start of the analyzed period. However, there was no loss of information, since the survey was totally answered in a single in-person interview, with data on diagnosis being later aggregated during the consistency check of information by the HCIJB.

RESULTS

A total 0f 650 patients were included from January 2015 to January 2023. Considering the SSP Regions, 334 were from the North Region (51.4%), 208 from the Northwest region (32%) and 108 from the DR (16.6%) (Figure 1).

Male sex patients were predominant (351/54%) and white skinned patients predominated in all Regions (440/68.1%). The age group where childhood cancer was most frequent in the studied population was 0 to 4 years old (162/24.9%), varying across Regions. The skin color, sex and age group characteristics of patients did not vary significantly between Regions.

The most frequent father and mother education levels were low in every Region. Fathers' low education ranged from 55.4% (154 fathers) in the North Region to 44.1% (41 fathers) in the DR, while mothers' low education level represented 61.1% in the North Region (55 mothers) and 50% in the Northwest Region (34 mothers). Families lived predominantly in urban areas (95.4%), with a medium family income around 2 to 5 MW (134/67.7%) in all Regions, with no significant variation between them.

In 335 families (53.6%), the patients' guardians also cared for other dependents in the home, with one vulnerable (person who needs constant care) in 7.2% of families in the North and Northwest Regions and 9.3% in the DR. Patients from the North Region and DR had more frequently two siblings, and most families were composed of four people in all Regions. The sociodemographic data of patients and relatives are presented in Table 1. The number of siblings in families did not vary significantly with family income.

Before accessing the HCIJB, the first most frequent consultation happened in the public healthcare system, more frequently in the North (159/59.8%) and Northwest (94/56.3%) Regions, while the DR presented a similar percentage of first consultations in public and private systems (50% each). The most frequent location





Figure 1. Patients from the State of São Paulo (n/%) grouped in three Regions according to their residence municipality at the start of the symptoms who brought them to Barretos Children's Cancer Hospital (HCUB) Source: Geociências, Instituto Brasileiro de Geografia e Estatística (IBGE).

Variables/Regions	North	Northwest	Distant	Total	р
			n (%)		
Patients	334 (51.4)	208 (32.0)	108 (16.6)	650 (100)	
Gender n: 650					0.376*
Male	189 (56.6)	108 (51.9)	54 (50.0)	351 (54.0)	
Female	145 (43.4)	100 (48.1)	54 (50.0)	299 (46.0)	
Color n: 646					0.071*
White	217 (65.2)	153 (74.3)	70 (65.4)	440 (68.1)	
Brown	93 (27.9)	37 (18.0)	25 (23.4)	155 (24.0)	
Black	18 (5.4)	7 (3.4)	7 (6.5)	32 (5.0)	
Yellow	4 (1.2)	9 (4.4)	4 (3.7)	17 (2.6)	
Red (indigenous)	1 (0.3)	0	1 (0.9)	2 (0.3)	
Age group n: 650					0.451**
0-4 years-old	89 (26.6)	49 (23.6)	24 (22.2)	162 (24.9)	
5-9 years-old	75 (22.5)	51 (24.5)	24 (22.2)	150 (23.1)	
10-14 years-old	77 (23.1)	48 (23.1)	20 (18.5)	145 (22.3)	
15-19 years-old	74 (22.2)	52 (25.0)	29 (26.8)	155 (23.8)	
20-29 years-old	19 (5.7)	8 (3.8)	11 (10.1)	38 (5.8)	
Father education level n: 539					0.167**
Low	154 (55.4)	82 (48.8)	41 (44.0)	277 (51.3)	
Medium	99 (35.6)	62 (36.9)	42 (45.1)	203 (37.6)	
High	25 (9.0)	24 (14.3)	10 (10.7)	59 (10.9)	

Table 1. Sociodemographic data of patients and families related to the first consultation of patients in the Barretos Children's Cancer Hospital, by Regions of the State of São Paulo

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Table 1. Continuation

Variables/Peaions	North	Northwest	Distant	Total	р
Valiables/ Regions			n (%)		
Mother education level n: 191					0.251**
Low	55 (61.1)	34 (50.0)	21 (63.6)	110 (57.5)	
Medium	25 (27.8)	20 (29.4)	10 (15.8)	55 (28.7)	
High	10 (11.1)	14 (20.6)	2 (3.1)	26 (13.6)	
Place of residence n: 194					
Urban area	98 (96.1)	50 (94.3)	37 (94.9)	185 (95.4)	0.819***
Rural area	4 (3.9)	3 (5.7)	2 (5.1)	9 (4.6)	
Family income n: 198					0.201***
Up to 1 MW⁰	21 (20.4)	9 (16.1)	9 (23.1)	39 (19.7)	
2 to 5 MW	69 (34.8)	41 (20.7)	24 (12.1)	134 (67.7)	
Over 5 MW	13 (6.5)	6 (3.0)	6 (3.0)	25 (12.6)	
Guardian cares for other people in the house n: 625					0.597***
None	154 (48.0)	86 (43.4)	50 (47.2)	290 (46.4)	
Children/elders/others	167 (52.0)	112 (56.6)	56 (52.8)	335 (53.6)	
Number of vulnerables ^b in the residence including siblings and/or elders n: 71	300 (89.8)	187 (89.9)	92 (85.2)	579 (89.1)	0.635***
1	24 (7.2)	15 (7.2)	10 (9.3)	49 (7.5)	
2	5 (1.5)	5 (2.4)	3 (2.8)	13 (2.0)	
3	4 (1.2)	1 (0.5)	3 (3.8)	8 (1.2)	
4	1 (0.3)	0	0	1 (0.2)	
Number of siblings of the ill child/ adolescent n: 185	236 (70.7)	158 (76.0)	71 (65.7)	465 (71.6)	0.316**
0	11 (3.3)	6 (2.9)	5 (4.6)	22 (3.3)	
1	26 (7.8)	20 (9.6)	9 (8.3)	55 (8.4)	
2	37 (11.1)	12 (5.8)	10 (9.3)	59 (9.0)	
3	16 (4.8)	10 (4.8)	8 (7.4)	34 (5.2)	
4 or over	8 (2.3)	2 (1.0)	5 (4.6)	15 (2.3)	
Total number of people at home n: 198	231 (69.2)	152 (73.1)	69 (63.9)	452 (69.6)	0.666**
2	9 (2.7)	2 (1.0)	3 (2.8)	14 (2.2)	
3	26 (7.8)	17 (8.2)	9 (8.3)	52 (8.0)	
4	36 (10.8)	18 (8.7)	15 (13.9)	69 (10.6)	
5	23 (6.9)	13 (6.3)	5 (4.6)	41 (6.3)	
6	5 (1.5)	4 (1.9)	5 (4.6)	14 (7.0)	
7 or over	4 (1.2)	2 (1.0)	2 (1.8)	8 (4.0)	

Captions: ^aMW: minimum wage; ^b vulnerable: person who needs constant care. ** Pearson's chi-square test; ***Fisher's exact test.



of first consultation was the public network office, representing 31.1% in the North and 34.6% in the Northwest Regions, while the private practice was the most frequent location of first medical consultation in the DR (32.4%). The medical specialist most frequently consulted at the first appointment was the pediatrician in the North Region (42.7%) and the clinic/general doctor in the Northwest Region and DR (40.4% and 33.3% respectively). In all Regions, a new consultation after the first visit was necessary (153 patients/37.2% of the total), while in the DR there was a need for over four consultations in 28.2% of patients (Table 2). The main reasons for new visits were patients not getting better (241/37.1%), getting worse, or developing new symptoms (141/27.1%), and lack of confidence in the medical diagnosis (104/16%). Families reported difficulties in getting to the HCIJB in 30.4% of cases (197 patients), with families more frequently coming from the DR (47/43.5%) and less frequently from the North Region (86/25.8%). The greatest difficulty found in all Regions was related to issues in the healthcare system (109/16.8%), described as problems in communication between healthcare network services, delays in procedures or transfer to oncology referral center.

The difficulty related to the healthcare system occurred more frequently with patients from the DR (30/27.8%) and less frequently with patients from the North Region (45/13.5%). In addition, issues with financial resources to afford commuting to the referral center and remaining there represented a significant difficulty to families. From the total of families, 11.4% reported facing financial issues, more frequently those from the DR

Table 2. Type, location and medical expertise of the first consultation, before accessing the Barretos Children's Cancer Hospital, by Regions of the State of São Paulo

	North	Northwest	Distant	Total	р*
			n (%)		
Type of first consultation n: 515					0.444
Public/SUS	159 (59.8)	94 (56.3)	41 (50.0)	294 (57.1)	
Private	107 (40.2)	73 (43.7)	41 (50.0)	221 (42.9)	
Place of the first consultation n: 647					0.277
Public network office	103 (31.1)	72 (34.6)	24 (22.2)	199 (30.8)	
Emergency service	89 (26.9)	40 (19.2)	33 (30.6)	162 (25.0)	
Hospital	41 (12.4)	31 (14.9)	15 (13.9)	87 (13.4)	
Private practice	92 (27.8)	62 (29.8)	35 (32.4)	189 (29.2)	
Others	6 (1.8)	3 (1.4)	1 (0.9)	10 (10.5)	
First consultation with specialist n:199					0.098
Pediatrician	44 (42.7)	18 (31.6)	12 (30.8)	74 (37.2)	
Clinic/General doctor	31 (30.1)	23 (40.4)	13 (33.3)	67 (33.7)	
Orthopedist	10 (9.7)	10 (17.5)	6 (15.4)	26 (13.1)	
Neurologist	5 (4.9)	2 (3.5)	0	7 (3.5)	
Ophthalmologist	3 (2.9)	0	3 (7.7)	6 (3.0)	
Oncologist	0	2 (3.5)	0	2 (1.0)	
Surgeon	1 (1.0)	1 (1.8)	0	2 (1.0)	
Others	9 (8.7)	1 (1.8)	5 (12.8)	15 (7.5)	
Number of medical professionals					0 429
seen after first consultation n: 411					0.020
1	76 (36.7)	56 (42.1)	21 (29.6)	153 (37.2)	
2	58 (28.0)	30 (22.6)	19 (26.8)	107 (26.0)	
3	30 (14.5)	19 (14.3)	11 (15.5)	60 (14.6)	
4 or over	43 (20.8)	28 (21.1)	20 (28.2)	91 (22.1)	

Caption: SUS: National Health System.

Rev. Bras. Cancerol. 2024; 70(4): e-164988

* Pearson's Chi-square test.



(20/18.5%), while 9.1% (19) of families in the Northwest Region reported this issue. Issues with transportation to the HCIJB were mentioned by 8.2% of all families, being significantly greater in residents from the DR (15/13.9%), while families in the Northwest Region had less transportation difficulties (11/5.3%). Issues related to distance from the family's residence to the HCIJB were reported by 5.4% of families, with a significant difference between Regions, with minor difficulties in patients from the Northwest Region (8/3.8%) and greater difficulties in families from the DR (14/13%). Financial resources from the own family were the most used to getting to the first consultation at the HCIJB (325/50.2%), ranging from 56.6% (189 families) in the North Region to 41.2% (45 families) in the DR (Table 3).

The DR (88/82.2%) presented a greater frequency of malign neoplasms as final diagnosis and the group of hematological neoplasms was the most frequent in every Region (60/35.5% in the Northwest Region and 28/31.8% in the DR). The malign neoplasms varied significantly between Regions. Tumors in the Central nervous system (CNS) were more frequent in the North and Northwest Regions (48/19.1% and 31/18.3%, respectively), followed by acute lymphoblastic leukemia (ALL) in both Regions (38/15.1% and 24/14.2% respectively). In the DR, there was a greater frequency of tumors in the CNS (20/22.7%), followed by osteosarcoma (13/14.8%) (Table 4).

The GeoSES socioeconomic index did not vary significantly between the patients' original municipalities regarding exams and referral to other doctors, place of first consultation, number and expertise of consulted professionals after the first appointment. There was also no significant variation regarding medical treatments or use of alternative treatments before accessing the oncology referral center.

DISCUSSION

In this study, patients living in regions far from Barretos more frequently had their first consultation in the private health network, needed four or more medical consultations in more than 25% of cases and faced greater obstacles in obtaining care at a pediatric

	North	Northwest	Distant	Total	p*
			n (%)		
Family found difficulties reaching the oncology treatment referral center n:649					0.020
No	247 (74.2)	144 (69.2)	61 (56.5)	452 (69.6)	
Yes	86 (25.8)	64 (30.8)	47 (43.5)	197 (30.4)	
Issues with financial resources	35 (10.5)	19 (9.1)	20 (18.5)	74 (11.4)	0.034
Issues with family responsibilities (caring for other family members)	15 (4.5)	11 (5.3)	7 (6.5)	33 (5.1)	0.705
Child's guardian was sick	3 (0.9)	2 (1.0)	0	5 (0.8)	0.855
Issues with the healthcare system					
(communication between services, delays in	45 (13.5)	34 (16.3)	30 (27.8)	109 (16.8)	0.002
procedures and delays in transfers)					
Issues with transportation	27 (8.1)	11 (5.3)	15 (13.9)	53 (8.2)	0.03
Issues with misinformation	18 (5.4)	11 (5.3)	10 (9.3)	39 (6.0)	0.295
Issues with distance	13 (3.9)	8 (3.8)	14 (13.0)	35 (5.4)	0.001
Others	4 (1.2)	1 (0.5)	4 (3.7)	9 (1.4)	0.061
Financial resources for first consultation at					0.015
HCIJB* n:647					0.015
Private	189 (56.6)	91 (44.2)	45 (41.2)	325 (50.2)	
Public	109 (32.6)	81 (39.3)	43 (40.2)	233 (36.0)	
Both	36 (10.8)	34 (16.5)	19 (17.8)	89 (13.8)	

Table 3. Difficulties reported by families in reaching the Barretos Children's Cancer Hospital and financial resources used in the first consultation, by Regions of the State of São Paulo

Captions: HCIJB = Barretos Children's Cancer Hospital;* Pearson's chi-square test.



Table 4. Benign and malign neoplasms, grouped and individually, of patients cared in the Barretos Children's Cancer Hospital (HCIJB), by Regions of the State of São Paulo

	North	Northwest	Distant	Total	р*
	n (%)				
Neoplasms					0.223
Malign	251 (76.5)	169 (82.0)	88 (82.2)	508 (79.3)	
Benign	77 (23.5)	37 (18.0)	19 (17.8)	133 (20.7)	
Group of Malign Neoplasm					0.656
Hematological	83 (33.1)	60 (35.5)	28 (31.8)	171 (33.7)	
CNS	48 (19.1)	31 (18.3)	20 (22.7)	99 (19.5)	
Bone	41 (16.3)	29 (17.2)	20 (22.7)	90 (17.7)	
Others	79 (31.5)	49 (29.0)	20 (22.7)	148 (29.1)	
Malign Neoplasm					0.027
ALL	38 (15.1)	24 (14.2)	9 (10.2)	71 (14.0)	
HL	24 (9.6)	18 (10.7)	7 (8.0)	49 (9.6)	
NHL	10 (4.0)	9 (5.3)	2 (2.3)	21 (4.1)	
AML	8 (3.2)	5 (3.0)	1 (1.1)	14 (2.8)	
CML	2 (0.8)	3 (1.8)	2 (2.3)	7 (1.4)	
MDS	1 (0.4)	0	5 (5.7)	6 (1.2)	
JML	0	1 (0.6)	2 (2.3)	3 (0.6)	
CNS tumors	48 (19.1)	31 (18.3)	20 (22.7)	99 (19.5)	
Osteosarcoma	24 (9.6)	18 (10.7)	13 (14.8)	55 (10.8)	
Ewing tumor	17 (6.8)	11 (6.5)	7 (8.0)	35 (6.9)	
Soft tissue sarcoma	15 (6.0)	16 (9.5)	6 (6.8)	37 (7.3)	
GCT/gonadal	18 (7.2)	10 (5.9)	3 (3.4)	31 (6.1)	
Neuroblastoma	12 (4.8)	4 (2.4)	2 (2.3)	18 (3.5)	
Wilms tumor	9 (3.6)	5 (3.0)	2 (2.3)	16 (3.1)	
Retinoblastoma	3 (1.2)	2 (1.2)	0	5 (1.0)	
Rare tumors	22 (8.8)	12 (7.1)	5 (5.7)	39 (7.7)	
Others	0	0	2 (2.3)	2 (0.4)	

Captions: ALL: acute lymphoblastic leukemia; HL: Hodgkin lymphoma; NHL: non-Hodgkin lymphoma; AML: acute myeloid leukemia; CML: chronic myeloid leukemia; MDS: myelodysplastic syndrome; JML: juvenile myelomonocytic leukemia; CNS: central nervous system; GCT: germ cell tumors; *Pearson's Chi-square test.

oncology reference center. In addition, patients' struggles were related to the healthcare network, slowness in communication between health services, delays in procedures and transfers, that suggest inequity of access to healthcare related to sociodemographic and economic factors of the population.

By identifying the sociodemographic characteristics of the population served at HCIJB and barriers encountered on their path to care at a pediatric oncology reference center, we seek to contribute to a better understanding of problems in the most populous state in Brazil and provide government spheres with relevant information that can assist in the development of public policies aimed at reducing health inequities, not only in the State of São Paulo, but also in other locations in the country.

The fact that most patients were male, and white is in line with the findings from literature around the world, though there are regional differences²⁰. Families frequently composed of 4 people, with medium family income, parents with low education level and living in urban areas may reflect more frequent characteristics of the Brazilian Southeast Region or specifically the population of the State of São Paulo²¹, or even that patients with higher income families had more opportunities to reach a referral center²².



Considering that the population coverage of public primary care in the SSP in the North Region is 62.0% and 65.9% in the DR²³ and that in this Region there are three large referral centers in pediatric oncology of the SUS that, together with the HCIJB, are responsible for 50% of all hospital records of cancer in children and adolescents²⁴, it can be suggested that patients with better financial conditions were able to carry out more first private consultations and subsequently travel to the HCIJB, even outside their Region of residence, seeking access to oncological diagnosis and treatment, pointing to an inequality in health in favor of families with better financial gains^{25,26}.

As reported by Forgie et al.²⁷, diseases that are more frequent in childhood, such as infectious diseases, may have unspecific symptoms that mimic the ones found in patients with neoplasms, making it harder to diagnose. In the present study, most patients sought other consultations after the first appointment, indicating lack of diagnosis in the first assessment and that, in the SSP, with more common non-oncological childhood diseases, an initial equivocated diagnostic hypothesis may occur, as reported in another study²⁸. However, it was found that the need for just one extra consultation after the first visit to the health system was more frequent (37.2%), while Grynszpancholc et al.²⁹, studying childhood neoplasms in Argentina, and Yk et al.³⁰, studying osteosarcomas in China, verified the need for two more consultations, and Ramesh et al.²² in India, studying hematological neoplasms, and Herber et al.³¹, with adolescents in England, verified that three or more consultations after the first visit were more frequent, suggesting that care within the Brazilian São Paulo healthcare system has shown a better performance when compared to other low and medium income countries and one high income country. Still, seeking to improve diagnostic challenges after the first appointment, a proposal in line with the world literature is expanding the training of health students and professionals so they are able to recognize early signs and symptoms of childhood cancer¹².

In this study, over 25% of patients from the DR needed four consultations after the first visit to seek diagnosis, and 16.6% of all patients came from Regions far from the HCIJB. There was a trip to a specialized pediatric oncology center far from home, as cited by Grabois et al.³², who reported 10% to 20% of consultations out of the regional hierarchical healthcare flux. Patients from Regions farther away from the HCIJB reported more difficulties in accessing the hospital, the main one being related to issues in the healthcare system, financial resources and transportation issues, when compared to patients from the North and Northwest Regions, suggesting that Outof-Home Treatment (OHT) showed little articulation in the health network, since apparently it was not capable of providing financial aid for patients' displacement so they could have equal and universal access to health, as advocated by the SUS³³. Results show the need for functional regionalization of oncology care and suggest that accessibility is influenced by geographic distribution of healthcare services and that socioeconomic differences perform a decisive role in the patients' journey, since those that have more resources usually have the means to travel in search of a diagnosis³⁴.

Difficulties accessing the healthcare system were reported by 30.4% of families, differing from the South-American literature, which pointed obstacles in 63.5% of times, and reconciling with them by showing that issues in the healthcare system are the most frequent, suggesting a compromise in the fundamental principles of health, which in Brazil are guaranteed by law, in addition to indicating that the quality of care for the population remains a challenge²⁹. Considering the obstacles, there is a need for improving the quality of the patient care network by speeding up referral to reference centers, in line with several authors³⁵.

Considering grouped malign neoplasms, hematological neoplasms were the most frequent in the studied Regions, in line with the world literature^{36,37}. The second more frequent group was CNS tumors, in line with the work developed by IARC with 153 records of cancer in the world³⁸. In absolute numbers, the most frequent malign neoplasms were CNS, followed by ALL and osteosarcomas, distinctly from other literature studies^{37,39}. There are regional variations in the world, with lymphomas being frequent tumors in African countries associated with greater rates of viral infection (Epstein Barr or human immunodeficiency virus)38 or high occurrence of germ cell tumors (GCT) in Japan when compared to England⁴⁰. Moreover, it is worth highlighting that HCIJB is a referral center in performing imaging tests such as computed tomography and magnetic resonance imaging for diagnosis encompassing the whole SSP through the Central Regulatory Authority for the Offering of Health Services (CROSS, in the Portuguese abbreviation), which aims to provide access for patients who require investigation at hierarchically higher levels of healthcare, which often ends up translating into more diagnoses and more patients enrolled for treatment at HCIJB.

This study presents limitations, including being conducted in a single oncology referral center in the SSP, having relied on non-randomized participant selection and, due to its ambispective nature, having relied on data



collected prior to the introduction of some questions in the guiding survey, which resulted in some topics not reaching a total of 650 answers. In addition, it relied on the family members' memories regarding the start of symptoms and their journey to reach the HCIJB, which may have favored a memory bias, even though a cancer diagnosis is striking to families, leading to precise answers even after a long time has passed.

This study brings sociodemographic and healthcare system accessibility information, detailing the main obstacles that influence early diagnosis. This panorama of childhood cancer epidemiology in the most populous Brazilian State helps filling an important gap in the existing information.

CONCLUSION

Epidemiological characteristics of children/adolescents and their families on their journey to reach an oncological diagnosis may reflect obstacles to universal healthcare access. After the first consultation, other assessments were needed, suggesting little suspicion by the health team in all the studied Regions, however, in the most distant Region from the assessed oncology center, four or more visits were required in over 25% of times, suggesting a worse performance of municipalities farther away from the HCIJB, even with the presence of three great pediatric oncology referral centers in the Region. The journey to seek the right to healthcare may reflect inequalities of access to consultations, tests, and referral to higher healthcare levels, with more obstacles associated with the healthcare system, though considering the same group of neoplasms. The need for further education of professionals and the population regarding childhood cancer was shown, as well as incentives to improve the service flows within the healthcare systems in Brazil's most populous State.

CONTRIBUTIONS

All the authors have contributed to the study design, acquisition, analysis and data interpretation, wording, and critical review. They approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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10

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