Assistance to Children and Teenagers with Cancer in Minas Gerais: Portrait of a Decade

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Atendimentos a Crianças e Adolescentes com Câncer em Minas Gerais: Retrato de uma Década

Asistencia a Niños y Adolescentes con Cáncer en Minas Gerais: Retrato de una Década

Murilo César do Nascimento[1]

Abstract

Introduction: Cancer in children and teenagers has global epidemiological relevance. **Objective:** To know and describe the epidemiological, clinical and care settings of the children and teenagers with cancer treated in Minas Gerais from 2007 to 2016. **Method:** An exploratory, descriptive study with secondary data via IntegratorRHC about the records of care in the State of children and teenagers with cancer. **Results:** There were 4,953 visits to children and teenagers with cancer. Predominate: age range of 15 to 19 years; male subjects; and brown. The most frequent primary site of the tumor was the hematopoietic system. The primary basis for the diagnosis of the tumor that predominated was the histology of the primary tumor. The first treatment received at the hospital that predominated was chemotherapy; the reasons for not dealing more filled after the "not applicable", "other reasons" and "no information" options were "death" and "treatment carried out". "Stable disease" meaning "stable patient" was the disease state at the end of the first most observed treatment. The most frequent clinic at the beginning of the treatment was Oncology Clinic. The result "Precursor Cell Lymphoblastic Leukemia" was the most frequent among histological types identified. We found 36 institutions that make up the oncology network in 21 municipalities of the State. There was a reduction of records / services to children and teenagers with cancer. **Conclusion:** The proposed characterization and description were reached and portrayed the visits in Minas Gerais, to children and teenagers with cancer between 2007 and 2016.

Key words: Neoplasms; Child Health; Adolescent Health; Health Services Research; Cancer Care Facilities.

Resumo

Introdução: O câncer em crianças e adolescentes possui relevância epidemiológica em escala global. **Objetivo:** Conhecer e descrever a configuração epidemiológica, clínica e assistencial dos atendimentos a crianças e adolescentes com câncer tratados em Minas Gerais, de 2007 a 2016. **Método:** Estudo exploratório, descritivo, com dados secundários via IntegradorRHC, sobre os registros de atendimentos no Estado a crianças e adolescentes com câncer. **Resultados:** Houve 4.953 atendimentos a crianças e adolescentes com câncer. Predominaram a faixa etária de 15 a 19 anos; indivíduos do sexo masculino; e pardos. A localização primária do tumor mais frequentes foi o sistema hematopoiético. A base principal para o diagnóstico do tumor predominante foi a histologia do tumor primário. O primeiro tratamento recebido no hospital que prevaleceu foi a quimioterapia; as razões para não tratar mais preenchidas, depois das opções "não se aplica", "outras razões" e "sem informação", foram o "óbito" e o "tratamento realizado fora". "Doença estável" significando "paciente estável" foi o estado da doença ao final do primeiro tratamento mais observado. A clínica no início do tratamento mais frequente foi a oncologia clínica. O resultado "leucemia linfoblástica de células precursoras" foi o mais frequente entre os tipos histológicos identificados. Constataram-se 36 instituições que compõem a rede de oncologia em 21 municípios do Estado. Verificou-se aparente redução dos registros/atendimentos a crianças e adolescentes com câncer. **Conclusão:** A caracterização e a descrição propostas foram alcançadas e retrataram os atendimentos, em Minas Gerais, a crianças e adolescentes com câncer entre 2007 a 2016.

Palavras-chave: Neoplasias; Saúde da Criança; Saúde do Adolescente; Pesquisa sobre Serviços de Saúde; Institutos de Câncer.

Resumen

Introducción: El cáncer en niños y adolescentes tiene relevancia epidemiológica a escala global. **Objetivo:** Conocer y describir la configuración epidemiológica, clínica y asistencial de los atendimientos a niños y adolescentes con cáncer tratados en Minas Gerais, de 2007 a 2016. **Método:** Estudio exploratorio, descriptivo, con datos secundarios vía IntegradorRHC, sobre los registros de atendimientos en la Provincia a los niños y adolescentes con cáncer. **Resultados:** Hubo 4.953 atendimientos a niños y adolescentes con cáncer. Predominaron: grupo de edad de 15 a 19 años; individuos del sexo masculino; y pardos. Localización primaria del tumor más frecuente fue el sistema hematopoyético. La base principal para el diagnóstico del tumor que predominó fue la histología del tumor primario. El primer tratamiento recibido en el hospital que predominó fue la quimioterapia; las razones para no tratar más completadas después de las opciones "no se aplica", "otras razones" y "sin información" fueron el "óbito" y el "tratamiento realizado fuera". "Enfermedad estable" que significando "Paciente estable" fue el estado de la enfermedad al final del primer tratamiento más observado. La clínica al inicio del tratamiento más frecuente fue la oncología clínica. El resultado "Leucemia Linfoblástica de Células Precursoras" fue el más frecuente entre los tipos histológicos identificados. Se constataron 36 instituciones que componen la red de oncología en 21 municipios de la Provincia. Se verificó reducción de los registros / atendimientos a niños y adolescentes con cáncer. **Conclusión:** La caracterización y la descripción propuestas fueron alcanzadas y retrataron los atendimientos, en Minas Gerais, a los niños y adolescentes con cáncer entre 2007 a 2016.

Palabras clave: Neoplasias; Salud del Niño; Salud del Adolescente; Investigación en Servicios de Salud; Instituciones Oncológicas.

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INTRODUCTION

Cancer has become an important public health problem in all regions of the world[1]. On the global level, more than 150 thousand children are diagnosed with cancer every year[2]. In Brazil, as in developed countries, cancer is the leading cause of death from disease among children and adolescents[3]. The state of Minas Gerais accounts for approximately 24% of all Brazilian hospital cases recorded in high-complexity oncology in the year 2009. In this state of Brazil, a relevant share of cases were amenable to control and detection measures which, if implemented early, could contribute significantly to non-fatal evolution[4].

As if this epidemiological scenario were not worrisome in itself, estimates indicate that cancer incidence will increase even further in the future, with a major impact on the global burden of disease and quality of life of patients and jeopardizing the already limited resources for healthcare[5]. Considering that most children and adolescent survivors of cancer require close lifetime monitoring by specialists[6], detailed analysis of individual, clinical, and treatment data in pediatric oncology can help public health administrators to better meet the needs for chronic care in these children and adolescents[7].

In Brazil, the National Cancer Institute José Alencar Gomes da Silva (INCA) is the agency with direct administration under the Ministry of Health and with growing nationwide capillarity that has the mission of developing and coordinating integrated work in cancer prevention and control in the country. Activities by INCA include multidisciplinary patient care provided directly and free of cost by the Unified National Health System (SUS); work in such strategic areas as prevention and early detection; training specialized professionals in various areas of health; development of research; and production of epidemiological data[8].

Cancer registries are a crosscutting source of data for all these activities in cancer research and care, from the local and regional scale to the national level. They are the sites that operate the collection, storing, processing, and analysis of information on patients or persons with confirmed cancer diagnosis. The registries can be population-based (Population-Based Cancer Registries) or hospital-based (Hospital-Based Cancer Registries) and play a crucial role in epidemiological studies and detailed analysis of individual, clinical, and treatment characteristics in oncology in Brazil[9].

The Hospital-Based Cancer Registries are specifically aimed to help improve patient care and intra-institutional planning, to assist the organization of a Cancer Information System, and to promote continuing professional education in the collective health field. In addition, the information produced in hospital-based registries also reflect the clinical staff's performance in patient care[9].

Given the above and the magnitude of the current cancer problem, which includes not only patient care but also important social and economic facets[1,2,9], it is necessary to enhance scientific knowledge and health surveillance in the fight against cancer in children and adolescents.

The current study thus aimed to investigate the epidemiological, clinical, and patient care profile of children and adolescents with cancer treated in the state of Minas Gerais, Brazil, from 2007 to 2016. The study drew on a demographic and clinical characterization of children and adolescents who underwent cancer treatment, identifying the municipalities comprising the cancer care and hospital registry network in the state, and describing the temporal distribution of cancer care for children and adolescents.

METHOD

This was a descriptive exploratory study with open-access secondary data on high-complexity cancer care in the state of Minas Gerais. The study's target thus consisted of all hospital cancer records in the state of Minas Gerais with available databases for the period 2006 to 2017, referring to patients 0 to 19 years of age, since this was a cross-section in space, time, and age bracket.

The data for "analytical cases" and "non-analytical cases" were obtained equally via online consultation of the *IntegradorRHC* "Hospital Tabulator" of the Information System from the Hospital-Based Cancer Registry (SisRHC), based on selection of the Minas Gerais state database, which is available online (like other Brazilian state registries), with unrestricted access by users and the general public[10]. The current study's researcher used one of his institution's own notebook computers with internet access at his home university to conduct the data collection, tabulation, and analysis.

The individual target variables were sex, age bracket, and race/color. Concerning clinical and patient care characteristics, the study's variables were primary tumor location by group, the most important basis or test for diagnosis of the tumor, first treatment received at the hospital, main reason for not performing antineoplastic treatment at the hospital, disease status at the end of the first treatment in the hospital, clinical department at the start of treatment, and histological type of the primary tumor. As for time, the study recorded the year of the patient's first consultation, and place was the field on the tabulator for the municipality where the hospital unit is located.

The tables and cartographic data were organized and analyzed with the software packages *Stata 11.0, Epi Info 7, Excel 2013*, and *TabWin 4.1.5*. The variables were analyzed with descriptive statistics, and the nominal and categorical data were submitted to analysis and presentation of simple and relative frequencies, while the continuous data were analyzed and presented as measures of central tendency means, medians, and modes, as well as measures of dispersion, variance, and standard deviations.

According to Resolution no. 466 of December 12, 2012[11], and the method used in this study, namely the design, target public, and nature of the study, as well as the data's type, source, collection technique, and analysis, there was no need to submit the research project to the Institutional Review Board on Research in Human Subjects.

RESULTS

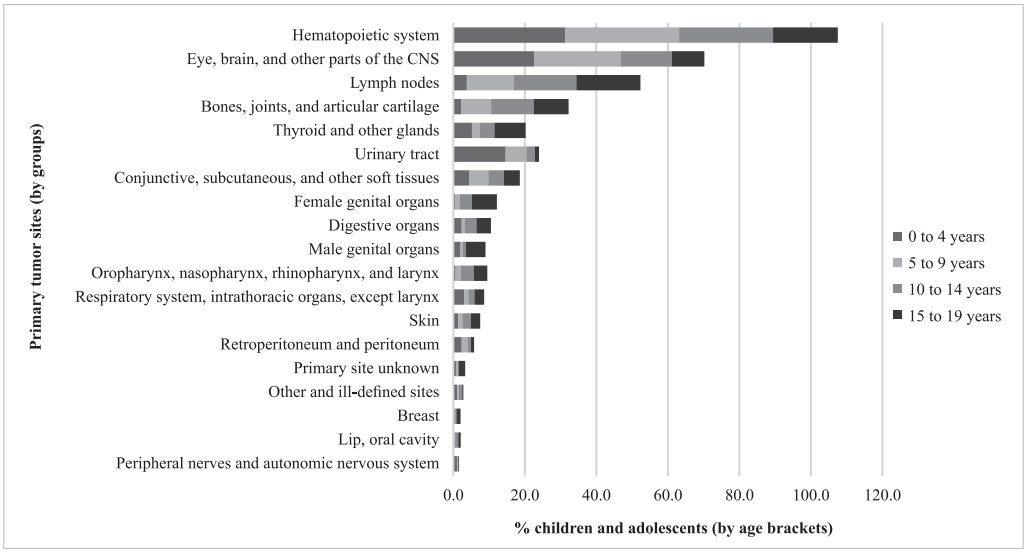
There were 4,953 records of care for children and adolescents in Minas Gerais from 2007 to 2016. As for the demographic characteristics of this patient population 0 to 19 years of age, the most frequent age subgroup was 15 to 19 years (1,744; 35.21%), followed by 0 to 4 years (1,244; 25.12%), 10 to 14 years (1,095; 22.11%), and 5 to 9 years, with 870 records, or 17.56% of the records. Mean age was 10.49 years, with a median and mode of 12 years, with variance of 37.93 and standard deviation ±6.15.

A total of 2,645 records were for male patients (53.40%) and 2,308 were for females (46.60%). Race/color showed the following distribution: 2,130 brown or mixed-race (43.00%), 1,792 white (36.18%), 409 black (8.26%), 19 Asian-descendant (0.38%), and 8 indigenous (0.16%); 595 of the records lacked information on race/color, corresponding to 12.01% of the records.

One of the most important clinical characteristics of children and adolescents with cancer is the primary tumor location. Importantly, hospital-based cancer registries use an adaptation of the International Classification of Diseases for Oncology, ICD-O[12], to code the tumors, classifying them by topography and histology. Graph 1 shows the distribution of tumor sites according to the groups and the relative frequency of children and age bracket percentages.

Table 1 shows the clinical and treatment characteristics based on details from the databases for tumor diagnosis, principal reasons for not treating at the hospital, first treatments received, and disease status at the end of the first treatment at the hospital.

The ten most frequent clinical departments at the start of cancer treatment were: Clinical Oncology (1,282 cases; 25.88%), Pediatric Oncology (730 cases; 14.74%), Clinical Hematology (698 cases; 14.09%), Radiotherapy (662 cases; 13.37%), Neurosurgery (212 cases; 4.28%), Surgical Oncology (186 cases; 3.76%), Pediatric Surgery (146 cases; 2.95%), Head and Neck (117 cases; 2.36%), General Surgery (88 cases; 1.78%), and Orthopedics (74 cases; 1.49%). Gynecology, Ophthalmology, Urology, Pediatrics, Nuclear Medicine, Plastic Surgery, Thoracic Surgery, Neurology, Dermatology, and Others totaled 6.10% of the cases, with 303 records. This information was missing on four records (0.08%), and in 451 records it was recorded as "not applicable" (9.11% of cases).



Graph 1. Percentage distribution of primary tumor location by ICD-O group, according to age bracket of children and adolescents with cancer in Minas Gerais, Brazil, from 2007 to 2016

The results for most frequent histological type in the pediatric population are shown according to race/color and the three primary tumor sites reported most often in the state: "Hematopoietic system", "Eye, brain, and other parts of the CNS", and "Lymph nodes", based on ICD-O. Due to the high number of histological classifications, the choice was made to present the three most frequent histological types for each of the principal primary tumor sites. Thus, Graph 2 shows the percentage distribution of the nine most frequent histological types according to race/color and the principal primary tumor sites (2a, 2b, and 2c). To facilitate visualization, the summary image did not include records that lacked information on race/color, referring to each histological type (4.97% of all the records).

The high-complexity cancer care network in Minas Gerais consists of 36 institutions that provide cancer care and have Reporting Units that feed the state's SisRHC database. These establishments are distributed across 21 municipalities (counties): Alfenas, Barbacena, Belo Horizonte, Betim, Cataguases, Curvelo, Divinópolis, Governador Valadares, Ipatinga, Juiz de Fora, Montes Claros, Muriaé, Passos, Poços de Caldas, Ponte Nova, Pouso Alegre, São João del Rei, Sete Lagoas, Uberaba, Uberlândia, and Varginha.

In the state capital, Belo Horizonte, there were 2,794 treatment records, or 56.41% of all the state's records. The municipalities of Montes Claros and Juiz de Fora ranked second and third with 391 records (7.89%) and 363 records (7.33%) in this age bracket. Figure 1 shows the spatial distribution of treatment records for children and adolescents with cancer in the municipalities of Minas Gerais during the target period.

Graph 3 shows the yearly distribution of children and adolescents with cancer treated in Minas Gerais from 2007 to 2016.

As for the ten-year historical series analyzed here, the records were most numerous in the years 2007 (589; 11.89%) and 2008 (563; 11.37%), with an apparent fluctuation over time, as seen in the total records for 2016, with 351 records (7.09%).

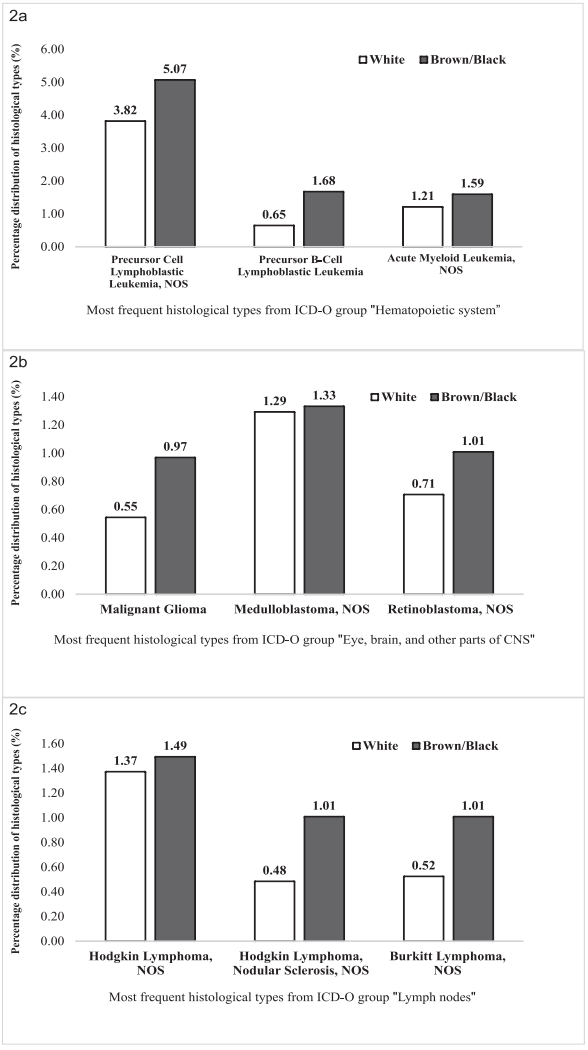
DISCUSSION

Childhood cancer in Brazil accounts for 3% of all cancer cases in the country, with approximately 12,500 new cases per year in children and adolescents (up to 19 years)[9]. Despite the growth in the number of accredited services in high-complexity oncology since the creation of the Unified National Health System, this cancer care

Table 1. Clinical and treatment characteristics of children and adolescents with cancer treated in Minas Gerais, Brazil, from 2007 to 2016

Variable	Domain	N	%
Most important basis for tumor diagnosis	Histology of primary tumor	3,517	71.01
	Imaging test	314	6.34
	Tumor markers	223	4.50
	Cytology	697	14.07
	Clinical diagnosis	97	1.96
	Histology of metastasis	41	0.83
	Clinical research	34	0.69
	No information	30	0.61
First treatment received at the hospital	Chemotherapy	2,108	42.56
	Surgery	657	13.26
	Radiotherapy	614	12.40
	None	499	10.07
	Less frequent treatments * and others	1,071	21.62
	No information	4	0.08
Disease status at the end of first treatment at the hospital	Stable disease (stable patient)	1,378	27.82
	No evidence of disease (complete remission)	572	11.55
	Not applicable	569	11.49
	Death	441	8.90
	Partial remission	385	7.77
	Disease in progression	332	6.70
	Oncology supportive care	30	0.61
	No information	1,246	25.16

Key: *Less frequent treatments (abbreviations): SX + CT; CT + RT; SX + CT + RT; SX + RT; Others + CT; HT + CT; HT; Others + CT + RT; CT + BMT; SX + Others; BMT; SX + Others + CT; SX + HT; HT + RT; SX + HT + CT; SX + Others + CT + RT; HT + Others + CT + RT.



Graph 2. Percentage distribution of the most frequent histological types according to the principal primary tumor sites (2a, 2b, and 2c) and most frequent race/color in children and adolescents treated for cancer in Minas Gerais State, Brazil, from 2007 to 2016
Source: INCA[10].

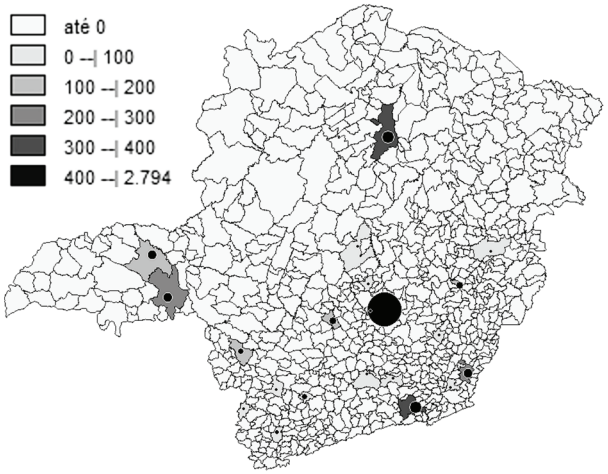
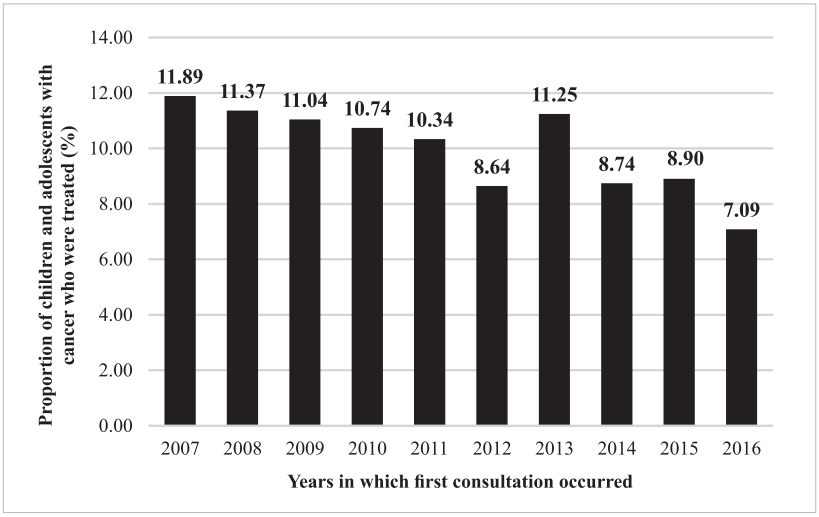


Figure 1. Spatial distribution of treatment records for children and adolescents with cancer in the state of Minas Gerais from municipalities with Hospital Reporting Units, from 2007 to 2016
Source: INCA[10].

network is still insufficient to meet the epidemiological demands[13]. In this scenario, not all patients who need care are able to access it at qualified services, and certain barriers to access can lead to diagnostic delay, exacerbation of the patient's health status, and even death in these children and adolescents[14]. This emphasizes the importance of knowing the profile of care for children and adolescents with cancer.

Many types of childhood cancer show differences in survival that can be attributed to underlying socioeconomic factors. The literature reports an association between race/ethnicity and survival in acute lymphoblastic leukemia, acute myelocytic leukemia, neuroblastoma, and non-Hodgkin lymphoma, for example[15]. The most common types of cancer in children and adolescents are leukemias,



Graph 3. Yearly distribution of children and adolescents with cancer treated in Minas Gerais State, Brazil, from 2007 to 2016
Source: INCA[10].

tumors of the central nervous system, and lymphomas[9]. Concerning primary tumor sites by groups of children and adolescents treated in Minas Gerais, the most frequent locations were "Hematopoietic system", "Eye, brain, and other parts of the CNS", and "Lymph nodes".

In a nationwide study by INCA on hospital morbidity in 2016, the highest rates were for carcinomas (except skin), accounting for 38.4% of cases, followed by lymphomas, with 18.3%, and leukemias, with 10.9%. These three neoplasms together accounted for 67.6% of all cancer cases in Brazilian adolescents and young adults[9].

Table 1 lists the most important tests or basis for tumor diagnosis, led by "histology of the primary tumor" with more than 70% of the records. This is important, since there are major differences between histological types that lead to differences in the epidemiological profile of incidence and peak ages[9].

Knowledge of the reasons for not treating at the reporting hospital, as well as disease status at the end of each treatment, is essential for understanding prognosis, as well as for assessing the effectiveness and type of treatment performed (or needed) for children and adolescents with cancer. Thus, the data produced by this study on the first treatments received, on the principal reasons for not treating at the hospital, and on disease status at the end of the first treatment at the hospital are relevant aspects for this patient population's follow-up over time.

The most frequent reasons for not treating at the hospital (after "not applicable", "other reasons", and "no information") were "death" and "treatment performed elsewhere". The most frequent reason for not treating, namely "not applicable", can be explained largely by the fact that most of the patients received treatment. In this context it was not a recording problem, but a positive aspect in the provision of care.

Although more than 80% of children diagnosed with cancer are cured of the illness, the growing numbers of childhood cancer survivors experience high rates of morbidity and mortality due to the "late effects" of treatment. International guidelines have thus been developed to standardize screening of survivors, addressing various models for survival care. According to these guidelines, the ideal model depends on various individual factors, including the person's needs and preferences, as well as local resources with a well-coordinated transition of care between services[6].

When identifying the municipalities comprising the cancer care and hospital registry network in the state of Minas Gerais, the study found that of the 21 municipalities, 15 are home to Regional Health Supervisory Divisions (SRS in Portuguese) or Regional Health Administrations (GRS). The other municipalities that are not hubs or headquarters for Health Micro- or Macro-Regions are representatives of their respective Health Regions[16], which is positive from the strategic point of view. This spatial distribution expresses an alignment between the level of healthcare required by high-complexity oncology and the operational principle of Brazil's Unified National Health System (SUS), namely regionalization, which corroborates the economy of scope and scale in health.

Finally, comparing the distribution over time in the ten years analyzed here, a fluctuation was observed in the number of records from the first to the last year in the historical series. Due to the study's descriptive nature, it was not possible to establish causal relations to explain the apparent decrease in the number of treatment records. However, the fact that there are Hospital Units with an important share of the records in the SisRHC registry that failed to report cases in 2015 and 2016 suggests that the simple absence of reporting may explain the apparent decrease in the number of patient care records. If this inference is true, it is an important signal of the importance of focusing on and investing in the appropriate flow and referral of records.

Another hypothesis is that more intensive use of technology in high-complexity oncology in Minas Gerais had a positive impact on the distribution of treatment records. This hypothesis is feasible, considering a resulting reduction in referrals between institutions for complementary treatments with different resources. If this hypothesis of improved therapeutic resources is correct, the apparent reduction in the number of cases makes sense. Patients who were previously recorded more than once (in more than one institution, and who now need no referral) would appear in the system with just a single record. Rather than the negative connotation of a possible drop in the number of treatments, the interpretation would have to do with the positive impact from better structuring of the services.

Since this study opted to work with data from both "analytical cases" and "non-analytical cases", some patients may have been recorded more than once in different institutions over the course of the study period. If the initial choice had been to work only with data from analytical cases, there would have been more clarity on the historical series of treatments for children and adolescents with cancer in the state. By acknowledging this limitation to the study, the suggestion is to develop other complementary studies in order to identify factors to explain the yearly variation in the distribution of treatment records.

The literature mentions the completeness and consistency of cancer records[17], pointing to the importance and need for improving medical records, structuring

mandatory reporting items and standardization of the patient chart system[18]. Thus, even while noting that the state of Minas Gerais displays good completeness in the variables related to clinical and epidemiological aspects, which is positive in the context of childhood cancer surveillance and control, the results emphasize the need to maintain and improve continuing, systematic, and high-quality data completion and data feeding into the SisRHC registry.

Although the data produced in the Hospital-Based Cancer Registries are not used to calculate incidence, since they portray the treatments provided by a given institution or set of establishments[3,10], the profile of patients and treatment records from 2007 to 2016 is believed to provide an important sign of the demand and flow in the high-complexity oncology network in cancer control in children and adolescents in the state of Minas Gerais.

CONCLUSION

This study allowed identifying and describing the epidemiological, clinical, and patient care profile of children and adolescents with cancer treated in the state of Minas Gerais, Brazil, from 2007 to 2016. Exploring the information from hospital cancer registries allowed performing a demographic and clinical characterization of the children and adolescents that underwent cancer care; identifying the municipalities comprising the network of hospitals with cancer registries; and describing the annual distribution of treatment in oncology for children and adolescents. It is hoped that the study's results will expand the scientific knowledge base on this theme, besides contributing useful epidemiological information for health surveillance and enhancing cancer control in children and adolescents in the state.

CONTRIBUTION

The author contributed to all stages of the study.

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CONFLICT OF INTEREST

None.

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None.

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