






Exploiting the Impact of Sociodemographics in the Diagnosis of Central Nervous System Tumors in Childhood

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Abstract

Introduction Central nervous system (CNS) tumors are the most common solid tumors in childhood, comprising 20% of all neoplasms in that age. Besides, they constitute the biggest cause of morbidity and mortality among childhood tumors, and about two thirds of the surviving patients have sequelae. The build-up of sequelae due to neoplastic growth is directly related with the time until diagnosis. Therefore, late diagnosis has a negative influence on the prognosis.

Objective To analyze the journey of the pediatric patients with CNS tumors and their families to the reference center.

Materials and Methods The present is a retrospective, prospective cohort study based on chart analyses and questionnaire application.

Results The mean age of the patients was 8.39 years, most were male (58%), white (56%), and originated from the Southeast of Brazil (56%). A total of 83% of the patients were accompanied by their mothers, and the family income obtained was below 3 minimum wages (20%). The average time until perception of the first signs or symptoms was 48 days, the mean time from symptom perception until the first medical appointment was 30 days, and the mean time between the first medical appointment and referral to Hospital de Amor Infantojuvenil de Barretos was 315 days. The most frequently present signs and symptoms were neurological manifestations (72%), such as headaches (14.8%) and projectile vomiting (6.5%). There was an association between the medical service (public or private service) where the first medical appointment took place and the first medical specialty consulted, although it did not relate to a shorter time until diagnosis.

Conclusion The difficulties in the journey of CNS tumor pediatric patients occurred mainly due to health system flaws and medical professionals' hardships. Thus, it is essential to reinforce the importance of continued medical education and to encourage new studies that may reveal precisely where these system flaws are taking place.

Keywords

- ▶ early diagnosis
- ▶ pediatrics
- ▶ central nervous system neoplasms

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Introduction

Central nervous system (CNS) tumors are neoplasms that primarily target the encephalus and spinal cord. They compose the most frequent group of solid tumors in childhood, corresponding to 20% of this age's neoplasms.¹ In Brazil, the incidence is about 1,500 to 2,000 new cases/year (Instituto Nacional de Câncer, 2016). The most common tumor types are the pilocytic astrocytoma, medulloblastoma, and ependymoma.

Central nervous system tumors constitute the biggest cause of morbi-mortality among childhood tumors, with a 5-year survival net of approximately 28.9% for Brazilian patients younger than 15 years old.² Besides, about two thirds of the surviving patients develop important sequelae,³ such as neurocognitive damage, among which damage to intelligence, information processing velocity, and executive function are the main ones, followed by memory and attention deficiency.⁴ These consequences are due as much to tumor growth as to treatment aggressiveness.

The build-up of sequelae caused by tumor growth is directly associated with the time until diagnosis, which is still a challenge to health care professionals due to the irregularity and diversity of the symptoms according to tumor type and localization. In addition, another predictive factor of early diagnosis is the ease and speed with which patients can access the health system and how that system receives them, this being immensely related to the demographic conditions that the family is inserted into.

Therefore, the present study aims to investigate the peregrination of pediatric patients with CNS tumors and their families to Hospital de Amor Infantojuvenil de Barretos and the main contributing factors to the delayed diagnosis.

Materials and Methods

Study Design

This is a retrospective and prospective cohort study. Data were collected at Hospital de Amor Infantojuvenil de Barretos, using a data collection form and analysis of medical records. The retrospective data was obtained between 2015 and 2022 from interviews with all patients' legal guardians or parents, in which they answered a questionnaire applied by either a nurse, medical doctor or medical student appropriately trained and belonging to the research team. The variables used were: age; gender, ethnicity; state of origin; guardian's schooling; guardian's civil status; number of siblings; number of people in need of caretaking in the residence; family income in minimum wages; basic domicile items; time until the perception of the first sign or symptom; time between the perception of the first sign or symptom and the first assistance; time between the first assistance and referral to the reference center; first sign or symptom that led to seeking medical attention; service of the first medical appointment; local of the first medical appointment; specialty of the first doctor. After the interview, members of the team did the medical records analysis for all the patients

included. The present study is part of a larger scientific project entitled "Late diagnosis in pediatric oncology".

Study Population

The present study brings together data from 215 patients selected for convenience. All patients between 0 and 17 years and 11 months diagnosed with CNS tumors, treated at Hospital de Amor Infantojuvenil de Barretos, were included. The exclusion criteria were being over 18 years of age at diagnosis and foreign nationality.

Statistical Analysis

Initially, a descriptive analysis of the data was carried out, with the quantitative variables summarized through the mean, median, standard deviation, and quartiles. Qualitative variables were summarized through absolute and/or relative frequency. In order to verify the association between the time (days) between the appearance of the first signs and symptoms until the diagnosis of the neoplasm with the socioeconomic factors, T-tests (or Man-Whitney) were used in order to compare the mean time between the different categories of these factors. If the factor had more than two categories, we used the analysis of variance (ANOVA) in order to carry out the same verification and, when such a difference between some of these categories was identified, we used the Bonferroni correction to make multiple comparisons between them. In order to verify the influence of clinical and sociodemographic factors as well as the times covered (dichotomized after searching the literature), we used the Log-rank test. To carry out the aforementioned tests, we used a significance level of 5%, and the analyses were performed using the IBM SPSS Statistics for Windows, version 21.0 (IBM Corp., Armonk, NY, USA) software.

Ethical Aspects

The present study was approved and conducted according to the local ethics committee's directives. Its ethics committee approval number is 38702114.6.1001.5437. There is no conflict of interests present.

Results

A total of 215 pediatric patients with CNS tumors treated at Hospital de Amor Infantojuvenil de Barretos were included in the present study. The mean age of patients was 8.39 years and most of them were male (58%), white (56%) and originated from the Southeast of Brazil (56%).

Regarding patients' parents or guardians, most patients (83%) were accompanied by their mothers. A large part of these women had high school degree (37%) and many of them did not have a formal job when their children's symptoms began, as 43.3% were either unemployed, housewives, or had informal jobs. Furthermore, guardians were preponderantly married, with a mean age of 36.95 years, and 20% of the families declared an income between one and three minimum wages. However, it is important to highlight a great missing in the income variable.

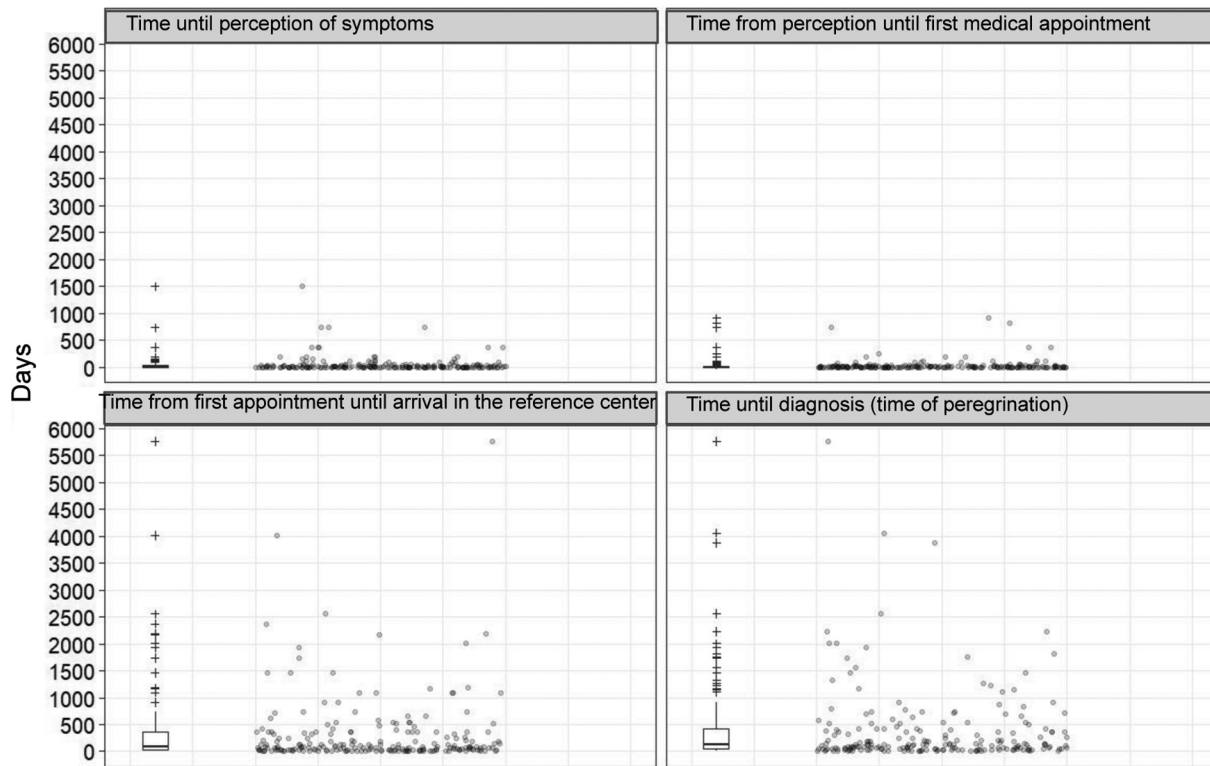


Fig. 1 Tables showing the distribution of patients within the time variables.

Regarding the time of peregrination, or time until diagnosis, – which contemplates the period between the onset of symptoms and the child’s referral to the reference center – it was subdivided in three variables: time until perception of symptoms; time between the perception of symptoms and the first medical appointment; time from the first medical appointment until referral to the reference center.

The average time until perception was 48 days, with a median of 3 days, minimum of 0 days and maximum of 1,500 days. The mean time from perception until first medical appointment was 30 days, with a median of 2 days, minimum of 0 days, and maximum of 910 days. Finally, the mean time between the first medical appointment and the referral to Hospital de Amor Infantojuvenil de Barretos was 315 days, with a median number of 90 days, a minimum of 1 day, and a maximum of 5,760 days. Therefore, the mean time of peregrination, considering the past 3, was 389 days, with a median of 120 days, a minimum of 4 days and a maximum

of 5,762 days. The time variables and tendency measures are shown in ►**Fig. 1** and ►**Table 1**.

The most frequently present signs and symptoms were neurological manifestations (72%), followed by pain (14.7%), and ocular alterations (10.1%). Among the neurological signs and symptoms mentioned, the most frequent were headache (14.8%) and projectile vomiting (6.5%). Nonetheless, neurological manifestations were generally associated with a longer time until diagnosis, with a mean time of 436.39 days.

Through associative analyses, it was observed that there is a statistically relevant relation between the medical service (public or private service) where the first medical appointment took place and the first medical specialty consulted. This can be seen in ►**Figs. 2** and **3**.

Nevertheless, that had no statistical difference in the early referral to the reference center, since there was no association between the service (public or private) of the first medical appointment and time until diagnosis.

Table 1 Time variables and tendency measures in days

Time variables/tendency measures (in days)	Minimum	Maximum	Mean	Median	SD
Time until perception of symptoms	0	1,500	48	3	147
Time from perception of symptoms until the first medical appointment	0	910	30	2	107
Time from the first medical appointment until referral to the reference center	1	5,760	315	90	648
Time until diagnosis	4	5,762	389	120	714

Abbreviation: SD, standard deviation.

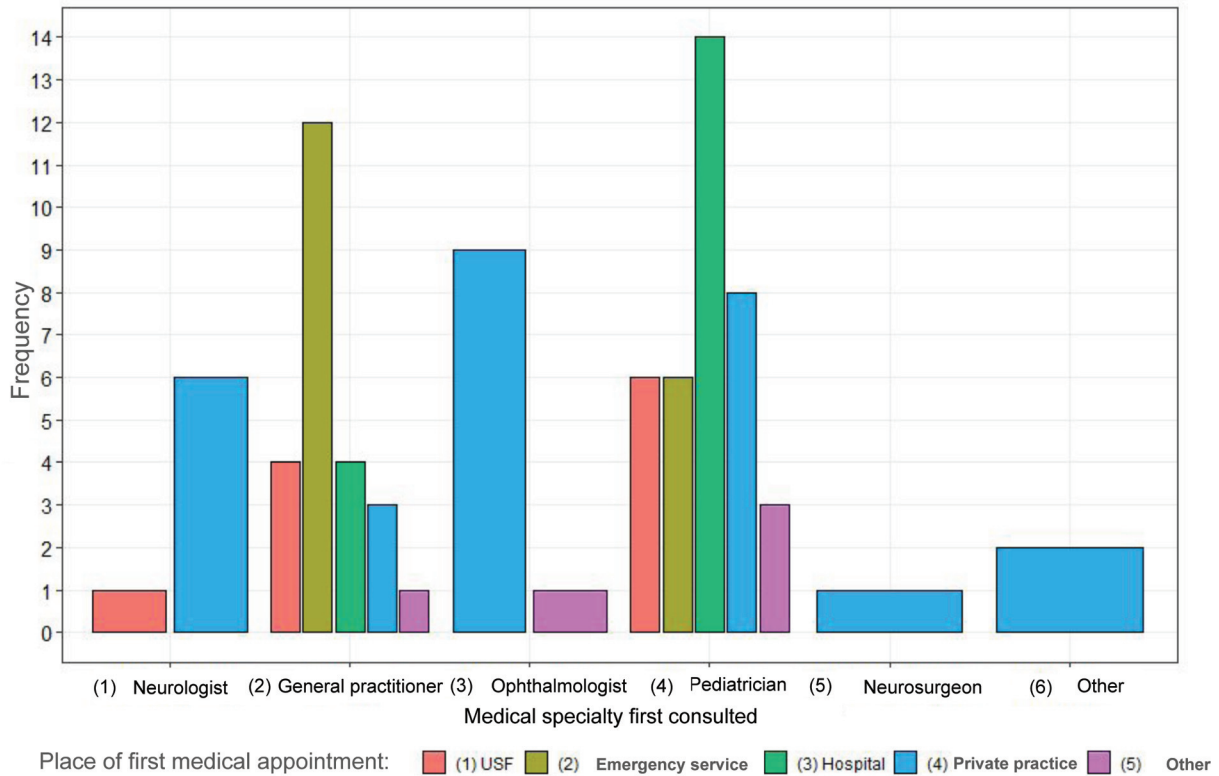


Fig. 2 Relation between medical specialty first consulted and where the first medical appointment took place. There was a statistical association between the variables. Abbreviation: USF, primary care unit from Brazil's public health system.

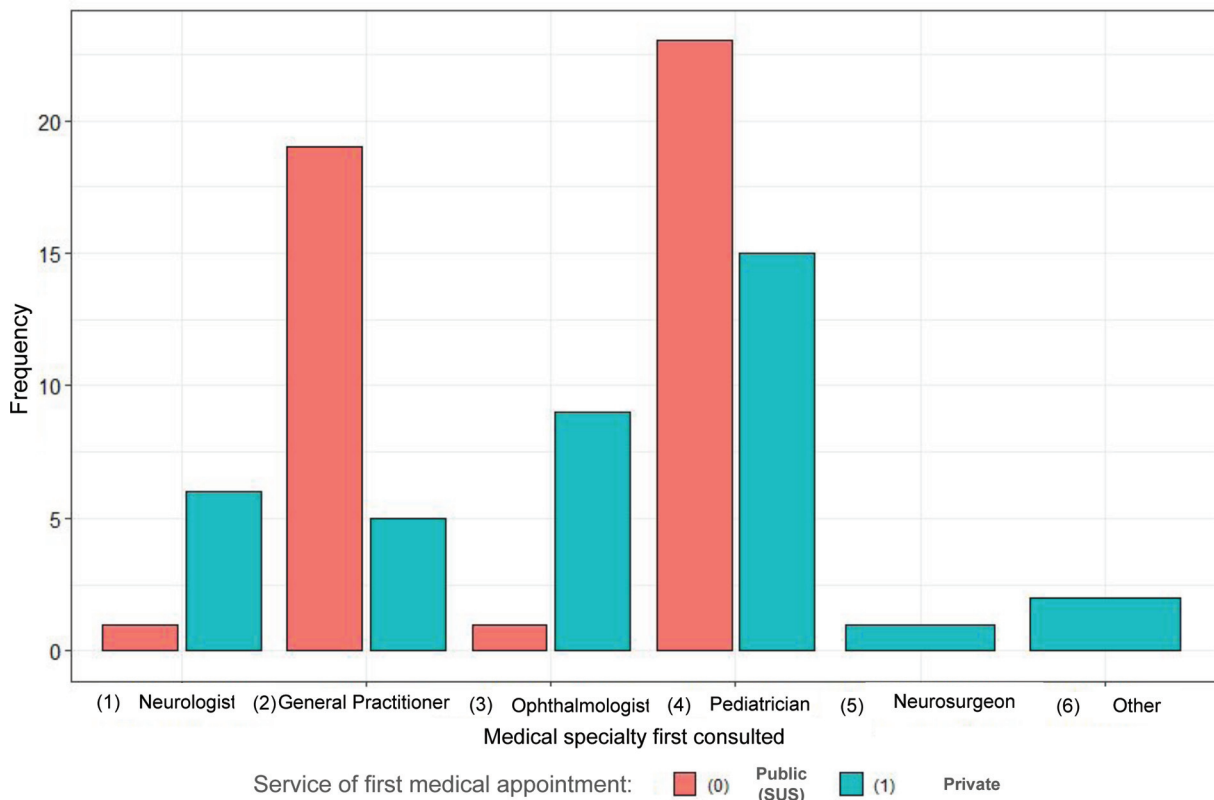


Fig. 3 Relation between the first medical specialty consulted and service (public or private) resorted to. There was a statistical association between the variables. Abbreviation: SUS, Unified Health System; public and universal health system from Brazil.

In addition, the medical specialty solely associated with the shortest time of peregrination was general medicine, with a mean 223.5 days and median of 109 days.

As revealed in ►Fig. 4, family income also had no association with the medical service utilized (public or private), although it reached a *p*-value close to statistical significance.

Besides, there was no statistical relation between self-designated ethnicity and time until diagnosis, neither between marital status of the parents or guardians and time of peregrination; finally, there was also no correlation linking the parents' schooling, state of origin, and time until diagnosis, which is shown in ►Fig. 5.

Discussion

Central nervous system tumors are the most frequent group of solid tumors in childhood and constitute the biggest cause of morbimortality among childhood tumors. Furthermore, tumor growth and treatment frequently cause sequelae such as neurocognitive damage, amongst others. That is why understanding this pathology and the pathway to a faster and more efficient diagnosis is so important.

Therefore, there are various studies that focus on the difficulties of obtaining an early diagnosis in childhood tumors, and one of them, the British article "Accelerating diagnosis for childhood brain tumors: an analysis of the Head-Smart UK population data"³, agreed with the present study.

Following this study's results, there are a few important subjects to address. First of all, while there was no association between ethnicity and time of peregrination. The study called "Population-based analysis of demographic and socioeconomic disparities in pediatric CNS cancer survival in the United States" suggests African American and Hispanic patients have an increased risk of death; however, the responsible factors to this correlation would be the differences in medical follow-up after diagnosis,⁵ which is not present in this study.

Regarding parents attributes, it is not surprising that the majority of patients were accompanied by their mothers in a country where 11 million single mothers raise their children alone (Getúlio Vargas Foundation - FGV), but it can also be explained by the oncologic patient's mother need of becoming a full-time parent and being always available to her child.⁶ Accordingly, a North American study demonstrated how oncologic pediatric patients' mothers are under a lot of stress, mainly in the beginning of their trajectory in pediatric oncology, and how overloaded they become from tending to an ill child as well as the rest of the family.⁷

Continuously, although the Unified Health System has as principles universality, integrality, and equity, more than 40% of patients resorted to private medical services for their first consultations. This, in a certain way, is in agreement with the findings of a British article that demonstrates the socioeconomic disparities in child cancer survival rates even in the presence of a universal access health system and

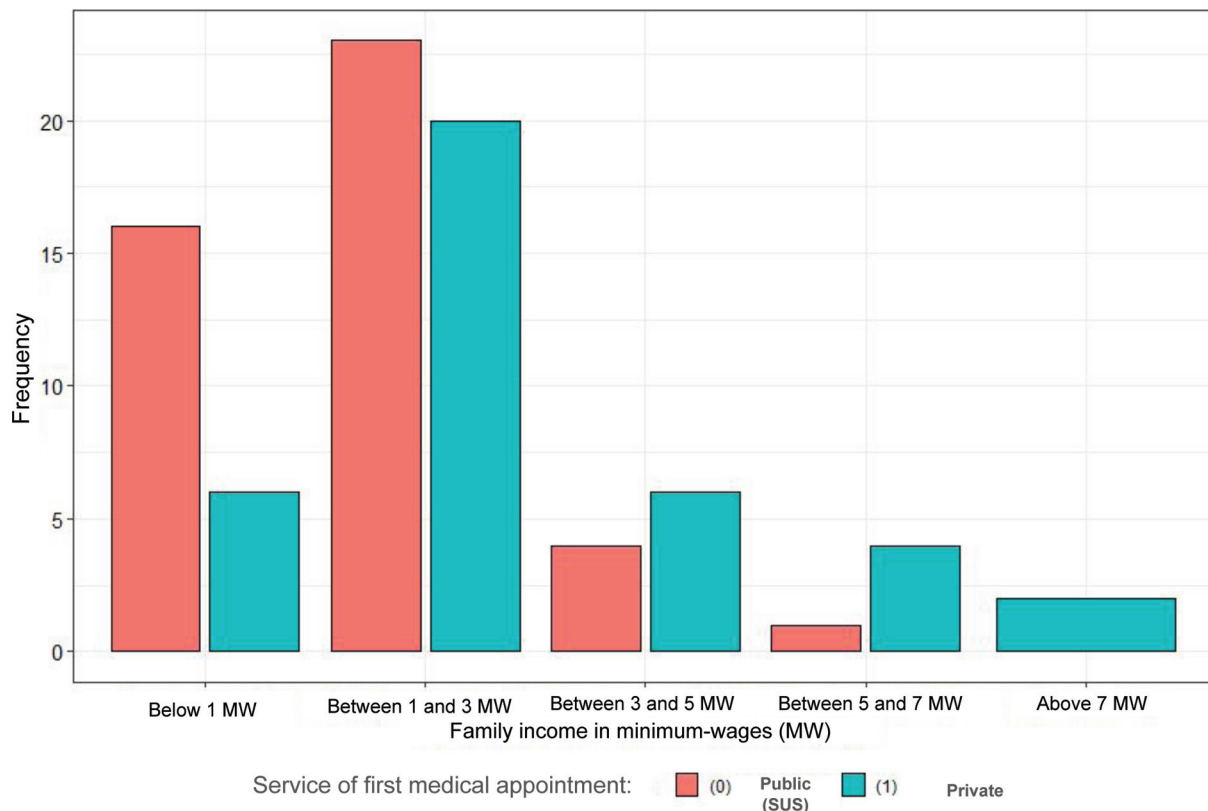


Fig. 4 Relation between family income in minimum wages and service (public or private) first resorted to. Abbreviation: SUS, Unified Health System; public and universal health system from Brazil. Note: Due to the small quantity of patients included in the above 5 minimum-wages category, there was no statistical association between the variables.

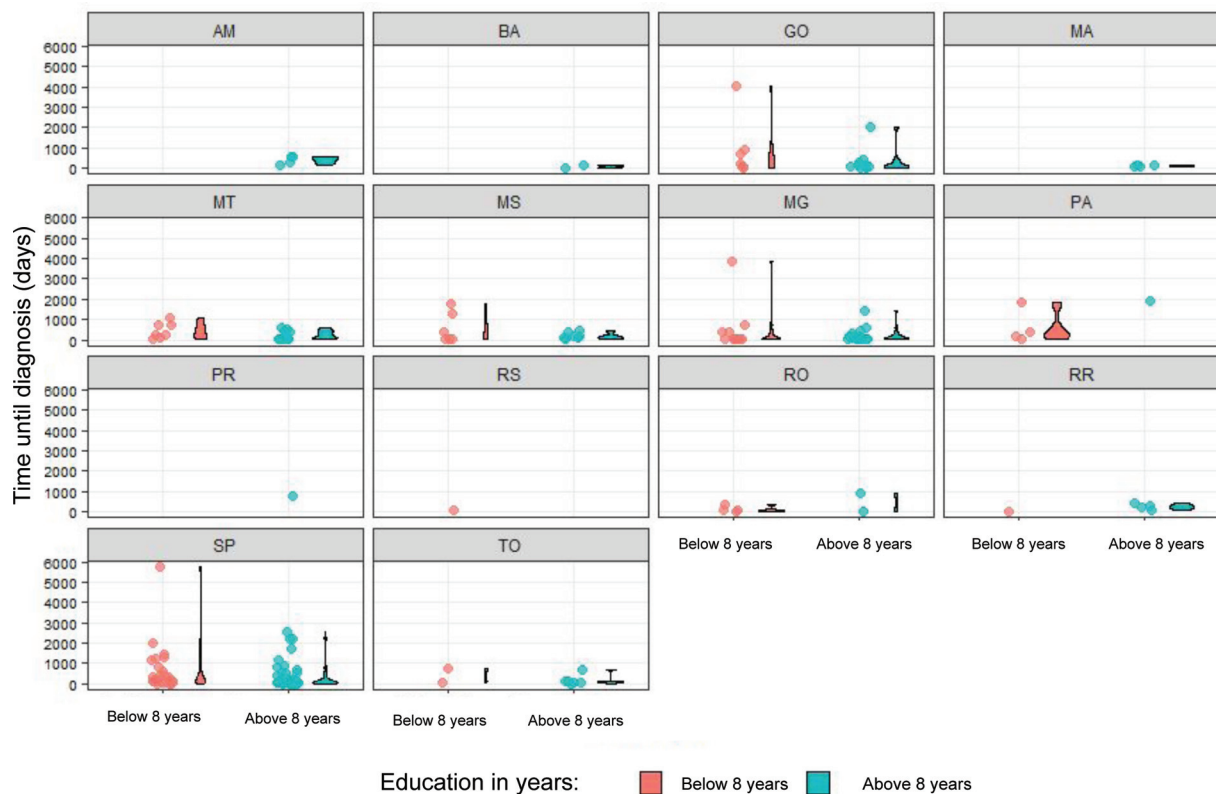


Fig. 5 Relation between parents' schooling, state of origin, and time until diagnosis. There was no statistical association between the variables.

expresses its consequences with difference in mortality rates due to CNS tumors.⁸

In that matter, patients who turned to the private medical service had access to secondary or tertiary level health professionals from the beginning of their peregrination, but had no difference in time until diagnosis, except for the sole patient who primarily consulted with a neurosurgeon.

This data exposes the problematic lack of knowledge of specialized medical doctors about CNS tumor symptomatology, and, sometimes, their naivety in discarding a CNS tumor diagnosis because of its rarity. Correspondingly, even patients with neurological manifestations were not rapidly diagnosed, reinforcing the medical unpreparedness against this pathology's clinical presentation.

Although there was no statistical connection between family income and the utilization of public or private health systems, the authors infer this is due to the lower percentage of patients originating from higher income families; had the study population been evenly distributed in terms of income, it is assumed there would be an association between family income and the chosen medical service.

Finally, the present study uses the same parameters as the British article "Accelerating diagnosis for childhood brain tumors: an analysis of the HeadSmart UK population data", and, as the previous one, separates the time variables (time for perception of symptoms, time from perception until the first medical appointment, and time between the first medical appointment and referral to the reference center) into patient interval (the first two) and system interval (the latest) and attributes to the system interval the main culpability for the

delayed diagnosis.³ This imputation repeated itself in the present study, since the mean time for perception of symptoms was 48 days, and until the first consultation it was 30 days, while the mean time between the first medical appointment and referral to the reference center was 315 days.

It is a fact that multiple social variables influence the journey of CNS tumor pediatric patients; however, the system interval corresponded to 80% of the time until diagnosis.

This indicates the presence of obstacles within the health system itself, and once again reveals the medical professional's hardships in diagnosing this pathology, or at least knowing when to refer the patients to a more specialized care center.

Study Limitations

The present study was partially performed during the coronavirus disease 2019 (COVID-19) pandemic, which influenced the extent of the study's population. Furthermore, the present study does not encompass the patients' treatment or overall survival rate after diagnosis, which would be an interesting analysis. In addition, the signs and symptoms were not individually associated with the time of peregrination, only subdivided in groups. The authors recognize the individual analysis could bring important information about CNS tumor presentation.

Conclusion

Even though the main cause of the delayed diagnosis of this study's patients can be attributed to the health system, it is possible to observe the existence of socioeconomic factors

that directly influence these patients' peregrination. Furthermore, it is necessary to investigate these referred factors and the importance of other ethnical aspects in the patient's trajectory after the diagnosis.

Despite the fact that CNS tumors are a highly valued pathology, the recurrence of some signs and symptoms, the variability of its clinical presentation, and its rarity still complicate the diagnosis hypothesis from the medical doctor's perspective.

Lastly, the difficulties in the journey of CNS tumor pediatric patients occurred mainly due to health system flaws and medical professionals' hardships. Thus, it is essential to reinforce the importance of continued medical education and to encourage new studies that may reveal precisely where these system flaws are taking place.

Authors' Contributions

MYL: collection and assembly of data, conception and design, data analysis and interpretation, and writing of the manuscript; LFL: final approval of the manuscript; RFF: collection and assembly of data, and data analysis and interpretation; TMVF: collection and assembly of data and data analysis and interpretation; DLQP: collection and assembly of data; WYH: conception and design and data analysis and interpretation; BMM: collection and assembly of data, conception and design, data analysis and interpretation, final approval of manuscript, and writing of the manuscript.

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Conflict of Interests

The authors have no conflict of interests to declare.

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