Sociodemographic, clinical, epidemiological and care aspects of children and adolescents treated for retinoblastoma in Brazil: a cross-sectional study

Aspectos sociodemográficos, clínicos, epidemiológicos e assistenciais de crianças e adolescentes atendidos por retinoblastoma no Brasil: estudo transversal

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ABSTRACT

Introduction: Retinoblastoma greatly impacts the affected children and adolescents and their families. Epidemiological approaches to this form of cancer in Brazil are scarce, and this gap motivated this study. **Objectives:** This study aimed to describe the sociodemographic, clinical, epidemiological, and care characteristics of children and adolescents treated for retinoblastoma in Brazil and analyze whether there is any association between them. **Methods:** It is a cross-sectional, descriptive-analytical study, carried out with accompanying family members of children and adolescents treated for retinoblastoma in Brazil, sampled by snowball sampling, via a web survey, based on a semi-structured questionnaire elaborated by the authors, shared on social media. **Results:** The children and adolescents were represented by 129 accompanying family members from the five largest regions of Brazil. Low education level, housewifery, and low family income were associated with exclusive care provided by the Unified Health System, while low family income was associated with the use of ocular prosthesis post retinoblastoma. **Conclusion:** The identified odds ratio indicated the importance of family members' sociodemographic aspects for the clinical, epidemiological and care outcomes of the children and adolescents treated. Public healthcare services were the most used for oncology care, which endorses the relevance of the Unified Health System for children, adolescents, and their family members who have been impacted by retinoblastoma in the country.

Keywords: Retinoblastoma, Child, Adolescent, Family, Eye neoplasms.

RESUMO

Introdução: O retinoblastoma impacta sobremaneira as crianças, adolescentes e familiares acometidos. Abordagens epidemiológicas sobre tal câncer no Brasil são escassas, lacuna esta que motivou este trabalho. **Objetivos:** Os objetivos desse estudo foram descrever as características sociodemográficas, clínicas, epidemiológicas e assistenciais de crianças e adolescentes atendidos por retinoblastoma no Brasil e analisar se existe associação entre tais características. **Métodos:** Tratou-se de um estudo transversal, descritivo-analítico, realizado com acompanhantes familiares de crianças e adolescentes atendidos por retinoblastoma no Brasil, amostrados por *snowball sampling*, via *web survey*, a partir de um roteiro autoral semiestruturado, compartilhado em mídias sociais. Os dados foram analisados por meio de estatística descritiva e inferencial, com o auxílio do *software Statistical Package for the Social Sciences*. **Resultados:** As crianças e os adolescentes foram retratados por 129 acompanhantes familiares das cinco grandes regiões brasileiras. A escolaridade baixa, a ocupação do lar e a baixa renda familiar dos respondentes associaram-se ao atendimento exclusivo pelo Sistema Único de Saúde, sendo que a baixa renda familiar também associou-se ao uso de prótese ocular pós retinoblastoma. **Conclusões:** As razões de chances identificadas sinalizaram para a importância dos aspectos sociodemográficos dos familiares para os desfechos clínicos-epidemiológicos-assistenciais das crianças e dos adolescentes atendidos. Os serviços públicos foram os mais utilizados para a assistência oncológica, o que endossa a relevância do Sistema Único de Saúde para as crianças, adolescentes e familiares impactados pelo retinoblastoma no país.

Palavras-Chave: Retinoblastoma, Criança, Adolescente, Família, Neoplasias oculares.

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https://doi.org/10.11606/issn.2176-7262.rmrp.2022.185512

INTRODUCTION

Retinoblastoma is the most common primary malignant intraocular eye tumor[1] and the most frequent in childhood[2,3]. With its rising incidence[4], this type of retinal cancer has affected developed countries and especially developing countries[5]. The cure and survival rates for such tumors still differ between countries of low, middle, and high income, and such inequalities have been attributed to factors such as access to treatment, delayed diagnosis, and socioeconomic and educational aspects[6,7].

The effects of retinoblastoma in the lives of affected children and adolescents go beyond the individual sphere, for it also affects their families and social circle. Psychosocial consequences emerge from the experience of this health-disease process[8], such as the insecurity one feels when faced with the risk of having an eyeball removed, of losing eyesight, as well as other complications inherent to cancer and to oncologic treatments in themselves[9,10].

Thus, despite the scientific advances and achievements in the field of oncology dedicated to children and adolescents[2] that, along with early diagnosis, make retinoblastoma one of the most curable types of cancer[1,11], the health-disease process of this disease still has a great impact on affected children and adolescents, as well as on their families, in terms of social, financial, and emotional aspects[8,12].

Therefore, if the objective is to trigger actions for prevention, early diagnosis, and treatment of cancer, or even to promote a cure, extend survival, and provide a better quality of life for people affected by the disease, understanding the population and care profiles related to retinoblastoma, along with access to information, guidelines, health education strategies, and public policies in the field of oncology are all important measures with the potential to minimize the negative consequences of this disease[12].

However, the sociodemographic, clinical, epidemiological, and care aspects of children and adolescents treated for retinoblastoma in Brazil have not been sufficiently addressed by the literature, nor do they constitute a picture that is fully known by healthcare providers and cancer researchers, a gap that justified and motivated the development of this study. For this reason, this study aimed to identify the sociodemographic, clinical, epidemiological, and care characteristics of children and adolescents treated for retinoblastoma in Brazil and to analyze whether there is an association between these characteristics.

METHOD

This was a cross-sectional, descriptive-analytical study, carried out via web survey, using social media, which approached relatives/followers of children and adolescents treated for retinoblastoma, from the five main regions of Brazil.

The inclusion criteria were as follows: to be 18 or older, and to have been a family member responsible for a child/adolescent diagnosed with or with a history of retinoblastoma. Given the rarity of this type of cancer, the sample was of the convenience or accessibility type, the reason why there was no sample size determination, and it was supported by the *snowball sampling* technique[13].

The semi-structured script used for data collection was developed and refined with the assistance of three experts in the following fields: cornea, anterior segment of the eye, and imaging exams in ophthalmology; head and neck cancer, rehabilitation of surgical and oncologic patients; and cancer epidemiology. The pilot study was composed of 15 initial respondents, who remained as participants.

Google Forms[14] was used to prepare the semi-structured data collection script. The script sections included the Informed Consent Form - ICF, eligibility criteria, sociodemographic characteristics of the accompanying family members, as well as questions regarding: disease characteristics, assistance received, and use of ocular prosthesis by children and adolescents.

The data collection was carried out between March and May 2020, including the initial 20 days of the pilot study. This step was performed by sending a link with a semi-structured script prepared by the authors via *Google Forms*[14], with response/self-completion by the study participants. The environment for access and invitation to participants consisted of support groups, associations, and virtual communities, existing in social networks, as well as by *WhatsApp* groups/communities.

Once the possibility of selection bias due to convenience sampling and *snowball sampling* was recognized, as well as the possibility of information bias due to the web survey strategy, the possible control measure for the researchers was to ensure due attention to the external validity of the results. The data returned were automatically stored in a spreadsheet linked to the collection script, and the double-entry process was replaced by database normalization.

Then, a descriptive analysis of the variables was performed, and the results were presented and discussed based on frequency distribution and measures of central tendency that had been observed. In preparation for the inferential approach, the independent/dependent qualitative polytomous nominal and ordinal variables were dichotomized according to the groupings of interest.

Due to the lack of specific reference in the literature on the cutoff points for the dependent variables of interest, it is hereby clarified that the choice for the new clusters was performed arbitrarily, according to the researchers' empirical knowledge. However, the process of recoding into new dichotomous categories was based on biostatistical principles.

Thus, the independent variable "education (of the accompanying family member)" was re-encoded as "has one to nine complete years of education" (yes or no); the independent variable "occupation/profession (of the accompanying family member)" was re-encoded as "family member without a job" (yes or no), "self-employed family member" (yes or no), "family member whose occupation is that of being a housewife" (yes or no); and the independent variable "family income (of the accompanying family member)" was re-encoded as "income of up to the basic wage" and "income of up to three times the current basic wage" (yes or no).

The dependent variable "type of healthcare service used" was re-encoded as "exclusive use of public services provided by *the Unified Health System (SUS)*" (yes or no). The other dependent variable "treatments received" was re-encoded as "enucleation as the only treatment received" (yes or no). And the third dependent variable "use and side of the ocular prosthesis" was re-encoded as "use of ocular prosthesis by the children and adolescents" (yes or no).

The verification of normality for numerical variables was performed using the *Shapiro-Wilk* test. The associations were analyzed using *Pearson's chi-squared* test or *Fisher's exact* test, estimating the crude Odds Ratio (OR). All tests were performed using a 5% significance level and the *Statistical Package for the Social Sciences (SPSS)* software.

The project was approved by the Research Ethics Committee of the proposing institution, according to legal opinion CAAE No. 24821819.3.0000.5142 and legal opinion No. 3,698,834 dated November 12, 2019.

RESULTS

The study consisted of 129 relatives/accompanying family members of children and adolescents diagnosed or with a history of retinoblastoma. Regarding the distribution of participants by Brazilian regions, we obtained more responses from people in the Southeastern region (n=51, 39.53%), followed by the Southern (n=29; 22.48%), Northeastern (n=28; 21.70%), Midwestern (n=15; 11.63%) and Northern (n=6; 4.65%) regions.

The spatial distribution according to county residence of the relatives (A) and of treatment (B) of the children and adolescents can be viewed on the map presented in Image 1.

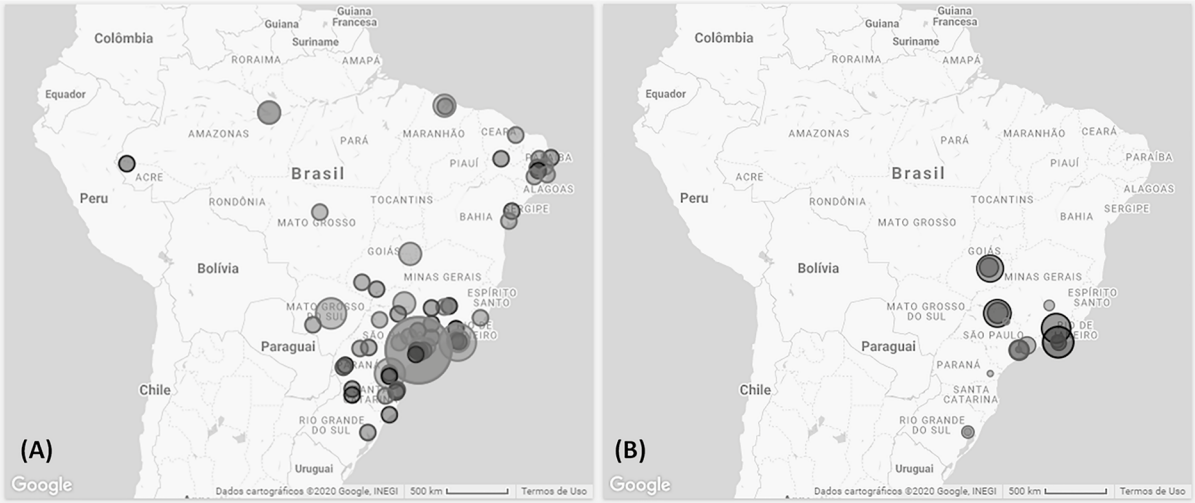

Image 1. Distribution of family members' county of residence (A) and treatment (B) of the 129 children and adolescents with history/diagnosis of retinoblastoma portrayed between March and May 2020, Brazil.
Source: Developed by the authors, 2021.

Regarding the family members' sociodemographic aspects, it was found that the average age of the companions was 34.61 years. Among the participants, 121 family members were female (93.80%) and eight were male (6.20%). Regarding the type of kinship, 121 were mothers (93.80%), 7 were fathers (5.43%), and 1 was an uncle (0.78%). Regarding the accompanying family members' education level, 83 participants had completed 11 years of schooling (64.34%) and two of them (1.55%) had completed less than one year of fundamental education. Regarding their profession/occupation, the responses housewife/housekeeper (29 participants; 22.48%) and self-employed (12 family members; 9.30%) stood out. Regarding family income, people who earned up to the current basic wage (33 respondents; 25.58%) predominated.

Regarding the profile of the 129 retinoblastoma patients, 74 (57.36%) were female and 55 (42.64%) were male. The mean age was 63.74 months (5.31 years). The children and adolescents were aged from 03 to 07 years (n = 62; 48.06%), 00 to 02 years (n = 42; 32.56%), 08 to 14 years (n = 20;15.50%), 15 years (n = 2; 1.55%), 16 years (n = 2; 1.55%), and 17 years (n = 1; 0.78%).

Regarding the detection age of retinoblastoma, an average of 11.20 months of life was noted. The average time to start the treatment for retinoblastoma was of 24.32 days from diagnosis. The detailed distribution of signs/symptoms and of the clinical-epidemiological and care variables of children and adolescents affected by retinoblastoma can be viewed in Table 1.

More often, children and adolescents presented the condition "cured and followed-up" (n=83; 64.34%), as well as the situation "in treatment" (n=33; 25.58%). In a smaller proportion, while situations of cure and hospital discharge (n=5; 3.88%), no treatment or waiting for assistance (n=2; 1.55%), without treatment with a reason for not treating (n=1; 0.78%), leading to death (n=1; 0.78%) or another situation (n=2; 1.55%) were noted.

Table 1. Clinical-epidemiological and care characteristics of the children and adolescents (129 = 100%)

Clinical-epidemiological and care characteristics of the children and adolescents affected by retinoblastoma		**Frequency**	
		N	**%**
Signs and symptoms mentioned (202 citations = 100%)	Leukocoria	95	47.03
	Strabismus	55	27.23
	Visual difficulty	20	9.9
	Photophobia	17	8.42
	Proptosis	4	1.98
	Other	11	5.45
Type of retinoblastoma	Unilateral or unifocal	70	54.26
	Bilateral or multifocal	56	43.41
	Trilateral	2	1.55
	Other	1	0.78
Form of genetic alteration / retinoblastoma classification	Sporadic alteration (random errors) / Non-congenital retinoblastoma (not hereditary)	56	43.41
	I do not know the form or classification	53	41.09
	Congenital alteration (germline mutation) / Congenital (hereditary) retinoblastoma	17	13.18
	Other	3	2.33
Treatments received (294 citations = 100%)	Enucleation surgery	67	22.79
	Laser therapy	58	19.73
	Intravenous (systemic) chemotherapy	55	18.71
	Intra-arterial chemotherapy	45	15.31
	Cryotherapy	31	10.54
	Intravitreal chemotherapy	21	7.14
	Radiotherapy	10	3.40
	Autologous bone marrow transplantation	3	1.02
	I do not know	3	1.02
	Other	1	0.34
Use and side of the prosthetic eye	Does not use a prosthesis	66	51.16
	1 prosthesis on the left side	28	21.71
	1 prosthesis on the right side	28	21.71
	2 prostheses	7	5.43
Type of healthcare service	Only Public Services of the Unified Health System (SUS)	72	55.81
	Either Public Services (SUS), or Health Plans/Insurance (Providers), or even other Private Services (Paid)	28	21.71
	Both Public Services (SUS), and Health Plans/Insurance (Providers) Services	15	11.63
	Only Health Plans/Insurance (Providers) Services	11	8.53
	Only Private Services (other offices, laboratories, and fee-for-service clinics)	3	2,33

Source: Developed by the authors, 2021.

Two accompanying family members were unable to respond to what the current situation of the child or adolescent was.

Regarding the existence/strength of associations among sociodemographic aspects of the accompanying family members, clinical-epidemiological and care characteristics of the children and adolescents with diagnosis or history of retinoblastoma, there were associations between:

- Family members' education level - from one to nine complete years of education - and the exclusive use of SUS public healthcare services (p = 0.028; OR: 3.487; 95%CI: 1.088 - 11.174);
- Accompanying family member's occupation/profession as being a housewifery and the exclusive use of SUS public healthcare services (p = 0.041; OR: 2.522; 95%CI: 1.022 - 6.227);
- Family income not exceeding the current basic wage value and exclusive use of SUS public healthcare services (p = 0.023; OR: 2.667; 95%CI: 1.124 - 6.329);
- Family income not exceeding three times the current basic wage and exclusive use of SUS public healthcare services (p = 0.001; OR: 3.478; 95% CI: 1.678 - 7.209).
- Family income not exceeding three times the current basic wage and the use of ocular prosthesis by children and adolescents (p = 0.010; OR: 2.512; 95% CI: 1.235 - 5.109).

In summary, it was found that accompanying family members with one to nine years of completed education, housewifery, and low family income were more likely to use SUS public healthcare services; and children and adolescents from low-income families were more likely to use ocular prostheses.

DISCUSSION

Sociodemographic aspects

A significant proportion of the accompanying family members were composed of mothers. Another important study carried out with oncological children patients portrayed a similar panorama, where 72.5% of the companions were mothers. This predominance of mothers as companions is explained by the cultural issue in which care is predominantly under maternal responsibility and by the historical/social perspective that mothers must sacrifice themselves for their children. Thus, the fact that the majority of the companions were female converges with the high number of mothers who accompany their children during the health-disease-care processes[15,16].

Regarding the companions' education level, 85.27% of them had completed more than nine years of schooling. A research carried out by the *Universidade Tuiuti do Paraná* (Tuiuti University of Paraná) also presented a similar result, where more than half of the accompanying family members had completed high school or college. The information regarding patient care needs to be shared with the accompanying family members considering their level of education when providing this information to them. The low education levels hinder the accomplishment of the companions' qualifications to train them to perform the continuity of the patient's care at home. When a low education level is identified, the healthcare providers must try to instruct the family member on how to care for the patient, using accessible methods, employing resources that facilitate the teaching-learning process[17,18].

Regarding their occupation/profession, 29 companions (22.48%) reported being housewifery, which stood out due to the increased frequency in relation to the other occupations. Among the companions studied by Essuman and collaborators[10], occupations with the highest frequency were merchants and craftspeople. In that study, the frequency of unemployment was 12.5%, while in the present study it was 3.10%. Housewifery and unemployed occupations allow the family members to dedicate themselves to a closer follow-up of the children and adolescents being treated for retinoblastoma. During the treatment the child or adolescent needs daily care and monitoring, making it difficult for the accompanying person to carry on with their routine activities, such as work. The daily stay of companions in the hospital can result in their involvement in care and it provides opportunities to detect signs of alterations in the physical and emotional state of their family members[18].

A significant portion of the companions was in the lower family income ranges. More than 37% of them had a monthly income of up to 1.5 times the current basic wage. It is believed that low income can be related to unemployment. One of the situations that most affects the family living with the process of the disease affecting one of their loved ones is financial difficulty.

This is due to the fact that, besides the significant budgetary damage, the disease within the family can also imply work-related losses, especially when it is necessary to consider who will take on the role of the patient's caregiver in the hospital environment, requiring him/her to take time off work[18,19].

Clinical, epidemiological, and care aspects

Regarding clinical, epidemiological, and care aspects of children and adolescents affected by retinoblastoma, it was possible to find in this study a slightly larger distribution of children and adolescents from the female patients (57.36%), compared to male ones (42.64%). Although there is no evidence of a relationship between gender and the clinical characteristics of retinoblastoma, some studies point to a slight predominance of male children and adolescents[20-24].

Regarding age, approximately 30% of the children and adolescents were aged between 0 and 2 years, and approximately 50% were aged between 3 and 7 years. Other studies on children and adolescents affected by retinoblastoma also had participants in these age ranges[21,25]. Therefore, this emphasizes that retinoblastoma is a disease that affects children in their first years of life.

Regarding the Brazilian federative units, the respondents from the state of São Paulo stood out, with 69.75% of the records. The attention to the spatial distribution of the municipalities of family origin, as well as the municipalities accessed for oncologic assistance, allows inferring that the demand for treatment of children and adolescents with retinoblastoma in Brazil generates an important flow of people at intrastate and interstate levels. This remark is important since the place of residence of the children or adolescents has a direct impact on issues such as promptness of diagnosis and adherence to treatment. Treatment for this type of cancer is centered in specialized centers, which may be distant from the countryside population or less accessible for socioeconomic reasons[26].

Considering that the southeastern region concentrates most of the human, technological and therapeutic resources of high complexity oncology in the country[19], the findings of this study converge with the known installed capacity of the state of São Paulo, for instance, to treat rare types of cancer[27], such as retinoblastoma. However, despite the alignment between the increased frequency of retinoblastoma records portrayed here and the geographic regions historically known for the higher incidence of this type of cancer in Brazil, it should be clarified that the higher density of participants in certain locations is also due to the result of sampling through the snowball technique, which differs from the methodological point of view of the findings in population-based surveys that aim to assess the incidence of cancer across the country[27].

The average age for detecting retinoblastoma was 11.20 months. In the state of Rio Grande do Sul, Brazil, this same measurement was 23.5 months. In other studies, the age of diagnosis ranged from 13 to 30 months[3,20,22-24,28,29]. The age of diagnosis varies according to the type of retinoblastoma to be identified, and unilateral retinoblastoma takes longer to be detected. Another factor that impacts the diagnosis of the disease is the level of development of the country in question. In Latin America, where there are many developing countries, the mean age of retinoblastoma detection is between 21.6 and 29.8 months of life[3]. The delay in diagnosis in these developing countries is related to the efficiency of healthcare systems, proximity to specialized treatment centers, the promptness with which healthcare providers can diagnose retinoblastoma, the referral time to other treatment centers, and the promptness with which parents and guardians identify symptoms[3,28,29].

Among the most frequent signs and symptoms mentioned by the accompanying family members were Leukocoria (47.03%) and Strabismus (27.23%). These manifestations are also widely described in the literature, which can guide educational measures that aim to promote early detection of retinoblastoma[3,20,23,24,28]. The companions, healthcare providers, parents, and close family members, when aware of the classic manifestations of the disease, such as the white reflex in the pupil, for instance, may seek medical help more promptly and contribute to a more favorable prognosis.

The average time span between the diagnosis of retinoblastoma and the beginning of its treatment was 24 days. This value converges to the period stipulated under Brazilian Federal Law nº 12732, which determines that patients with malignant neoplasms have the right to undergo their first treatment by the Unified Health System (SUS) in 60 days or less from the time of diagnosis[30]. The study by Lukamba and colleagues identified a similar average of 31 days[31].

In the study of patients with retinoblastoma classified as Group D and E, the average time between diagnosis and enucleation was around 3 days in Group D and 0 days in Group E11. According to Xiao and collaborators, the period between diagnosis and the beginning of treatment for retinoblastoma impacts the histopathological results of eyes submitted the most, especially, for enucleation[2], and it is also influenced by the low family income of the patient with retinoblastoma. Another possible relation with the delay in starting treatment is the parents' refusal to adhere to enucleation, due to fear, aesthetic non-acceptance of the surgery results, and the treatment costs[32].

The most frequent type of retinoblastoma was unilateral or unifocal retinoblastoma (54.26%), followed by bilateral or multifocal (43.41%) retinoblastoma. Only two patients were diagnosed with trilateral retinoblastoma (1.55%). These data differ slightly from other findings in the literature that indicate a prevalence of unilateral retinoblastoma between 63% and 71% cases and bilateral retinoblastoma between 23.7% and 33% cases. Studies point out that there is no major difference in the distribution of impairment of the right or left eye[20-24,28,29].

The most often form of genetic alteration was the sporadic alteration or random error (43.41%), associated with the classification of non-congenital retinoblastoma. This low frequency of congenital, or hereditary retinoblastoma and the high frequency of non-congenital, or sporadic retinoblastoma converges with the data presented in the literature[3,20,22-24,28]. Therefore, since part of the etiology of retinoblastoma may include genetic alterations, those who accompany children and adolescents with a family history of the disease should be even more attentive to the manifestations of typical symptoms, such as leukocoria and strabismus, for instance[3].

Regarding treatment, it was possible to note that approximately 23% of the citations corresponded to enucleation, associated or not with other therapeutic procedures. The choice of enucleation as a treatment for retinoblastoma presents diversified rates in the literature, varying with the type of retinoblastoma, with frequencies of 50% to 100% in cases of unilateral retinoblastoma[25,33,34]. In another study, in which epidemiological aspects of retinoblastoma in Latin America were analyzed, the prevalence of enucleation was over 60%[3]. The frequency of children submitted to enucleation is higher in developing countries that present, especially, low educational levels and high levels of poverty and demographic density[35].

On the other hand, the conservative treatments most often mentioned in this study were laser therapy (19.73%), intravenous chemotherapy (18.71%), intra-arterial chemotherapy (15.31%), and cryotherapy (10.54%). The choice for conservative treatments in the literature also exhibited similar frequency, varying according to the type of retinoblastoma[25,33,36].

Approximately 60% of the children and adolescents represented were cured or undergoing follow-up procedures, 25.58% were in the process of treatment, and one patient died. High survival rates are also described in the literature, with values above 80%. In cases of cure, total remission of the disease is frequently observed. Death is mainly related to the development of metastases and trilateral impairment[20-23].

A total of 63 children and adolescents (48.84%) used ocular prostheses after the enucleation of one or both eyes. Considering that there were 67 citations of this surgical procedure, associated or not with other treatments that had been provided to patients, it can be noted that 94.02% of the enucleated patients had access to ocular prostheses. There was no difference in the frequency of prosthesis use between the left and the right eyes, with 21.71% use on each side. It was noted that the frequency of prostheses use in one eye was higher than the use on both sides (21.71% versus 5.43%), which corroborates the data of greater unilateral impairment of the tumor.

In contrast, a study in sub-Saharan Africa demonstrated a lower frequency of use of ocular prostheses, where 76% of patients with unilateral retinoblastoma used this resource after receiving enucleation as a treatment[25]. It is believed that the disparity between these findings is related to possible differences between countries, related to early diagnosis, access to healthcare services, the type of treatment offered, and the prognosis of patients.

These findings highlight that accesses to healthcare services is, in fact, one of the essential elements in cancer care. The high frequency of use of public healthcare services of the Unified Health System (SUS) identified in this study highlights the relevant contribution of these healthcare points for the management and response to retinoblastoma in the country.

The relationship between the sociodemographic, clinical, epidemiological, and care aspects

Regarding education, family members with one to nine complete years of schooling were 3.4 times more likely to use public healthcare services compared to the likelihood of exclusive use of the SUS by family members with higher education. A similar finding was identified in the literature, where Ribeiro and colleagues[37] demonstrated that the relationship between the education level and use of the SUS was inversely proportional, i.e., care provided by the SUS to individuals with 11 years of education or more was less frequent compared to care provided by the SUS to users with a lower level of education.

Regarding occupation, family members being housewifery were found to be 2.5 times more likely to use SUS public healthcare services exclusively compared to the likelihood of exclusive use of SUS by family members with other occupations. No data corroborating this association was found in the literature; however, it is believed that "housewifery or homemaker" occupation is related to the well-known exercise of unpaid activities, which demand dedication, energy, and time, without, however, implying financial reward for the performance of the function. Therefore, housewifery conditions would be related to an income inconsistent with the access to supplementary healthcare by the private sector, which is possibly more feasible for people with paid jobs.

Attention to family income provides endorsement of the hypothesis of a relationship between occupation, people's income, and the use of the SUS for oncologic care. It was noted that families with low income are more likely to use exclusively the SUS health services (not exceeding basic wage = 2.6 times more likely / not exceeding three times what basic wage currently is = 3.4 times more likely), compared to the likelihood of exclusive use of the SUS by families with higher incomes. A previous study indicated that the variables income and education are both determinants of the likelihood of receiving care provided by the SUS and that there is probably some collinearity between them[37]. Another evaluative research developed in an urban center also evidenced a low income, of approximately 784 BRL, among the users of ophthalmologic services provided by the SUS[38].

It was possible to identify a positive association between family income not exceeding three times the current basic wage and the use of ocular prostheses by patients; children and adolescents from families with low income were 2.5 times more likely to use ocular prostheses compared to the likelihood of patients whose family income was higher. It was not possible to identify studies in the literature that have associated these two variables; however, Mattosinho and colleagues[26] point out that maternal education is related to the outcome of the disease, to the advanced stage at diagnosis, enucleation, and patient survival.

When analyzed in their entirety, the relationships between the sociodemographic, clinical, epidemiological, and care aspects investigated here indicate the importance of recovering and applying references such as the social determinants of health and disease as possible explanatory models of retinoblastoma and its interfaces. There is much to be learned in the understanding of the social determinants/conditioners of this type of cancer, as well as in the holistic interpretation of all the multi factors involved in the process of family support for children and adolescents during the process of dealing with retinoblastoma. It is hoped that the results of this study will contribute with reflections that shed light on the theme and reduce the gaps in knowledge that currently exist.

The non-probability sample adopted and the fact that the accompanying family members were invited to participate only virtually, were shortcomings of the study. Despite their operational, temporal, and logistical advantages for data collection, it is recognized that the *snowball sampling* technique and the *web survey* strategy can provide a partial selection of the target audience. Thus, the heterogeneous return rate under the geographical perspective, combined with the lack of knowledge on the access of the population of interest to the social media used, are highlighted as uncontrolled factors that may interfere with the external validity of the research. However, the results presented here, although not applicable to Brazil as a whole, are an important representation of the children and adolescents treated for retinoblastoma in the country.

Although the type of study presented here does not allow determining or discussing causality, since in cross-sectional studies the criterion of temporality cannot be contemplated, it is believed that, given one of the methodological advantages of sectional approaches, this study contributed to the proposition of hypotheses that need investigation and clarification.

Namely: low education level, low family income, and housewifery occupation of family members are associated with exclusive access to SUS public healthcare services; low family income is associated with the use of ocular prostheses by children and adolescents with retinoblastoma. Therefore, it is suggested that further research be carried out in order to elucidate the hypotheses listed here.

CONCLUSION

Children and adolescents treated for retinoblastoma were portrayed based on their family members in terms of sociodemographic, clinical, epidemiological, and care characteristics of this oncologic health-disease process. Education levels ranging from one to nine years of completed schooling, housewifery condition, and low family income were associated with the exclusive use of SUS public healthcare services, and the low family income was associated with the use of ocular prostheses by patients.

Odds ratios identified by this study highlighted the importance of the sociodemographic aspects of family members for the clinical, epidemiological, and care outcomes for the treatment of children and adolescents with retinoblastoma in Brazil. The public healthcare services of the Unified Health System were indicated as the most used for diagnosis, treatment, and follow-up of children and adolescents, which emphasizes the relevance of this healthcare network for people and families impacted by retinoblastoma in the country.

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FUNDING

This study was self-funded and did not receive support from any funding agencies.

Individual contribution of the authors:

- Authors[5, 6 e 7]: study design and planning; data collection, data collection, analysis, and interpretation; writing and final approval of the published version.
- Authors[1, 2, 3 e 4]: data collection, analysis and interpretation; writing and final approval of the published version.

Funding Sources: The study has not received any funding for its development.

Acknowledgements: To the families of children and adolescents treated for retinoblastoma in Brazil and to the Federal University of Alfenas, UNIFAL-MG, that made this study possible.

Conflict of interest declaration: Nothing to declare. There are no conflicts of interest of any kind.

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Editor:
Prof. Dr. Felipe Villela Gomes

Received: may 07, 2021
Approved: sep 13, 2021
