ORIGINAL ARTICLE

Social Representations of Retinoblastoma: Family Perspectives

Representações Sociais do Retinoblastoma: Perspectivas Familiares

Representaciones Sociales del Retinoblastoma: Perspectivas Familiares

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ABSTRACT

Introduction: Retinoblastoma, a primary intraocular malignancy predominant in childhood, profoundly impacts the lives of children and their families. Understanding the perceptions and feelings of family members facing this challenge is crucial for optimizing psychosocial well-being and healthcare quality. **Objective:** To understand the social representations attributed to retinoblastoma, as expressed by family members accompanying children affected by cancer. **Method:** A social representation research was conducted, involving 114 relatives of Brazilian children with retinoblastoma. The study project received prior approval from the Research Ethics Committee of the proposing institution in Brazil, with reference to CAAE No. 24821819.3.0000.5142 and Opinion No. 3,698,834 dated November 12, 2019. The study employed a qualitative approach anchored in the Collective Subject Discourse. The qualitative approach anchored in the Subject Collective Discourse was employed. A structured digital form was used to collect sociodemographic data of the children and their families, as well as to record perceptions of retinoblastoma. The participants' characterization data were presented through descriptive statistical analysis, while the discursive responses that constituted the qualitative data were analyzed using the Collective Subject Discourse method. **Results:** The study involved 114 family members of children diagnosed with retinoblastoma. Most were adult female family members, primarily mothers aged 30 to 39, with over 11 years of education. The affected children were mostly female, aged between 25 to 62 months. Predominantly, cases were non-hereditary and were treated through public health services in São Paulo. Emerging social representations of retinoblastoma among family members included: "Ocular cancer / tumor in the retina", "Curable disease when treated early, despite severity", "Rare tumor / cancer with possible genetic / hereditary origin", "Silent, serious, difficult, aggressive disease causing fear and affecting the family", "Cancer / tumor afflicting infants and children", "Phase, coping, change, and new life", "Unknown, underpublicized disease with limited information, yet frequent", and "Other meanings". **Conclusion:** Family members demonstrated diverse meanings, perceptions, and knowledge regarding retinoblastoma, addressing not only the nature of the disease but also the complexity of the experience of caring for an affected child. These representations underscore the need for a biopsychosocial care approach, emphasizing

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family perspectives, to enhance multiprofessional care and the therapeutic journey of children with retinoblastoma.

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

RESUMO

Introdução: O retinoblastoma, um tumor maligno intraocular predominante na infância, impacta profundamente a vida das crianças e suas famílias. Compreender as percepções e sentimentos dos familiares diante desse desafio é crucial para otimizar o bem-estar psicossocial e a qualidade da assistência médica. **Objetivo:** Compreender as representações sociais atribuídas ao retinoblastoma, conforme expressas pelos membros da família que acompanham crianças afetadas pelo câncer. **Método:** Realizou-se uma pesquisa de representação social, abordando 114 familiares de crianças brasileiras com retinoblastoma. O projeto do estudo recebeu aprovação prévia do Comitê de Ética em Pesquisa da instituição proponente no Brasil, com referência ao CAAE No. 24821819.3.0000.5142 e à Opinião No. 3,698,834 datada de 12 de novembro de 2019. Utilizou-se a abordagem qualitativa ancorada no Discurso do Sujeito Coletivo. Um formulário digital estruturado foi usado para coletar dados sociodemográficos das crianças e de suas famílias, bem como registrar as percepções sobre o retinoblastoma. Os dados de caracterização dos participantes foram apresentados por meio de análise estatística descritiva, enquanto as respostas discursivas que compuseram os dados qualitativos foram analisadas por meio do método do Discurso do Sujeito Coletivo. **Resultados:** O estudo envolveu 114 membros da família de crianças diagnosticadas com retinoblastoma. A maioria era composta por membros adultos do sexo feminino, principalmente mães com idades entre 30 e 39 anos, com mais de 11 anos de educação. As crianças afetadas eram principalmente do sexo feminino, com idades entre 25 e 62 meses. Predominantemente, os casos não eram hereditários e foram tratados por meio de serviços públicos de saúde em São Paulo. As representações sociais emergentes dos familiares sobre o retinoblastoma foram: “Câncer ocular / tumor na retina”; “Doença que tem cura se tratada precocemente, apesar de grave”; “Tumor / câncer raro que pode ter origem genética / hereditária”; “Doença silenciosa, séria, difícil, agressiva, que gera medo e mexe com a família”; “Câncer / tumor que acomete bebês e crianças”; “Fase, enfrentamento, mudanças e nova vida”; “Doença desconhecida, pouco divulgada, sem informações, mas frequente” e “Outros significados”. **Conclusão:** Os familiares revelaram significados, percepções e conhecimentos heterogêneos sobre o retinoblastoma, abordando não apenas a natureza da doença, mas também a complexidade da experiência de acompanhar uma criança afetada. Essas representações ressaltam a necessidade de uma abordagem de cuidado biopsicossocial, com ênfase nas perspectivas familiares, para enriquecer a assistência multiprofissional e a jornada terapêutica das crianças com retinoblastoma.

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

RESUMEN

Introducción: El retinoblastoma, un tumor maligno intraocular predominante en la infancia, impacta profundamente en la vida de los niños y sus familias. Comprender las percepciones y sentimientos de los familiares ante este desafío es crucial para optimizar el bienestar psicosocial y la calidad de la atención médica. **Objetivo:** Comprender las representaciones sociales atribui-

das al retinoblastoma, tal como son expresadas por los miembros de la familia que acompañan a niños afectados por el cáncer. **Método:** Se realizó una investigación de representación social, involucrando a 114 familiares de niños brasileños con retinoblastoma. Se obtuvo la aprobación previa del Comité de Ética en Investigación en Brasil (CAAE No. 24821819.3.0000.5142 y la Opinión No. 3,698,834 de 2019). Se empleó el enfoque cualitativo anclado en el Discurso del Sujeto Colectivo. Se utilizó un formulario digital estructurado para recopilar datos sociodemográficos de los niños y sus familias, además de registrar las percepciones sobre el retinoblastoma. Los datos de caracterización de los participantes se presentaron mediante análisis estadístico descriptivo, mientras que las respuestas discursivas que constituyeron los datos cualitativos fueron analizadas utilizando el método del Discurso del Sujeto Colectivo. **Resultados:** El estudio involucró a 114 miembros de la familia de niños diagnosticados con retinoblastoma. La mayoría eran miembros adultos de la familia, principalmente madres de entre 30 y 39 años, con más de 11 años de educación. Los niños afectados eran en su mayoría del sexo femenino, con edades comprendidas entre los 25 y 62 meses. Predominantemente, los casos no eran hereditarios y se trataron a través de servicios de salud pública en São Paulo. Las representaciones sociales emergentes del retinoblastoma entre los familiares incluyeron: “Cáncer ocular / tumor en la retina”, “Enfermedad curable cuando se trata tempranamente, a pesar de su gravedad”, “Tumor / cáncer raro con posible origen genético / hereditario”, “Enfermedad silenciosa, seria, difícil, agresiva que genera miedo y afecta a la familia”, “Cáncer / tumor que afecta a bebés y niños”, “Fase, afrontamiento, cambio y nueva vida”, “Enfermedad desconocida, poco difundida, con información limitada, pero frecuente” y “Otros significados”. **Conclusión:** Los familiares demostraron significados, percepciones y conocimientos diversos con respecto al retinoblastoma, abordando no solo la naturaleza de la enfermedad sino también la complejidad de la experiencia de cuidar a un niño afectado. Estas representaciones destacan la necesidad de un enfoque de atención biopsicosocial, enfatizando las perspectivas familiares, para mejorar la atención multiprofesional y el viaje terapéutico de los niños con retinoblastoma.

Palabras-clave: Retinoblastoma, Familia, Niño, Neoplasias del Ojo, Enfermería.

INTRODUCTION

Retinoblastoma, characterized as the prevailing primary malignant intraocular tumor[1] and primarily prevalent during childhood[2,3], stands as a subject of persistent concern within the domain of pediatric oncology. Notwithstanding the remarkable strides and accomplishments achieved in this realm[2], where early detection has rendered retinoblastoma one of the most amenable cancers for treatment[1], its pertinence continues to cast significant biopsychosocial repercussions upon afflicted children and their families [4,5].

The diagnosis of cancer in children can have a significant impact on the physical and psychological well-being of both the child and their family. This elicits a broad spectrum of physical symptoms and emotional responses, including shock, stress, insecurity, anxiety, depression, and a sense of loss of control on the part of parents and the family[6–7]. As a result, affected children and their families often require additional emotional, social, and financial support to cope with the challenges posed by the health-disease process of retinoblastoma and its treatment[7,8.]

In this context, the role of healthcare professionals as a cornerstone of support for families with pediatric cancer patients assumes paramount importance, contributing to favorable outcomes in the face of adversity. This, in turn, underscores the necessity of a holistic approach to retinoblastoma care, one that should encompass programs addressing the biopsychosocial needs of caregivers in dealing with the multifaceted challenges inherent to the disease, its treatment, and their child's survival[9,11].

In light of the aforementioned, the exploration of the social representations held by family members pertaining to this malady emerges as an initial juncture in the provision of holistic and superior oncological care. The synergistic endeavors of a multidisciplinary team, with nursing taking a prominent role, remain integral in catering to the exigencies of both the pediatric patients and their families. Against this backdrop, the principal objective of this study resides in the comprehension of the social representations attributed to retinoblastoma as articulated by family members accompanying children affected by the scourge of cancer.

METHOD

Ethical aspects

The work was approved by the Research Ethics Committee of the proposing institution in Brazil, according to CAAE No. 24821819.3.0000.5142 and Opinion No. 3,698,834 of November 12, 2019. Each accompanying family member electronically recorded their agreement to participate in the study, via the Informed Consent Form, digitally marked.

Research Team and Reflexivity

The eight authors conducted data collection by sharing invitations with an electronic form through social media and WhatsApp groups. JLLM, female (specialist, master's student, nurse), was a postgraduate student, had no experience with qualitative research, had no relationship with the participants, and did not establish any relationship before the study. Participants were unaware of the researcher. RSL, JVS, MCN, males, SMCLF, NOS, LLCB, females, (specialists, PhDs, and nurses), were postgraduate professors with experience in qualitative research, had no relationship with the participants, and did not establish any relationship with them before the study. Participants were unaware of any characteristics of the researchers. FLO, female (specialist, PhD, biologist), was an undergraduate professor, had no experience with qualitative research, had a connection with participants through a WhatsApp group containing families of children with retinoblastoma from Brazil, and established a virtual relationship before the study. As a result, the majority of participants were aware of the researcher's personal and professional interest in the topic.

Study concept

Type, data source and study environment

This is a qualitative research of social representation, based on social media. For conducting the research and writing the manuscript, the COREQ - Consolidated criteria for reporting qualitative research - criteria were observed[12].

The data collection occurred between March and May 2020 and was conducted by sending a link with structured questions prepared by the authors via Google Forms[13], 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 groups of contacts from the WhatsApp application.

In order to identify potential participants, researchers conducted searches on Facebook for Brazilian pages related to the topic of retinoblastoma. They initiated contact with the individuals responsible for creating and managing these social media platforms to request authorization to engage with these virtual communities. The aim was to explain the research proposal and share invitations for participation in the study.

For instance, “Retinoblastoma Brasil” is a non-profit organization established by a group of parents with children who have experienced retinoblastoma. This association can be located through the Retinoblastoma Brasil channel: https://www.facebook.com/retinoblastomabrasil/. Similarly, the Retinoblastoma Community aims to disseminate information from a mother who enjoys studying, researching, and receiving news pertaining to the disease, patients, and their families, as described on their homepage: https://www.facebook.com/retinoblastomas/.

As for the “Mães e Pais Retino” (Mothers and Fathers of Retino) WhatsApp group, it was designed for the sharing of news, personal experiences related to retinoblastoma patients, as well as providing a platform for mutual support among families grappling with the issue. Access to individuals in this group via telephone was facilitated through a personal connection that the author, FLO, had with a mother of a child with retinoblastoma who was also a member of the group.

Research participants and the inclusion criteria

The research participants were accompanying family members of Brazilian children with retinoblastoma. The inclusion criteria were: being 18 years of age or older; and having been a family member responsible for a child diagnosed with retinoblastoma.

As a substantial majority of the Facebook profile administrators and WhatsApp group members were individuals with direct experience in caring for a child with a history of or ongoing treatment for retinoblastoma, these individuals were initially approached and identified as the initial study participants.

This initial participant selection was, thus, achieved through non-probabilistic sampling, specifically accessibility or convenience sampling. Subsequently, by authorizing researchers to engage with other individuals collectively through social media, allowing the collective sharing of invitations, endorsing the study’s significance, and even inviting/referring new candidates, these initial participants contributed to the expansion of the sample through the snowball sampling technique. This technique facilitated the definition of the final sample by reference.

Study organization

For data collection, the authors prepared a structured questionnaire using the Google Forms platform[13], which included socio-demographic data of the children, their accompanying family members, and the question: "What does retinoblastoma mean to you?" This instrument was submitted to the evaluation of three experts in: cornea, anterior segment of the eye and imaging exams in ophthalmology; head and neck cancer, rehabilitation of the surgical and oncologic patient; and cancer epidemiology. It was unanimously observed that the script was adequate to the object of study.

Regarding the use of Google Forms to operationalize data collection, the sections included the Free and Informed Consent Term, eligibility criteria, participant characteristics, and the open-ended question, along with instructions for participants to provide as complete and detailed responses as possible.

As participants accessed the electronic form, completed, and submitted their responses online, the content was automatically recorded in an electronic spreadsheet through the Google Forms platform. Due to the dynamic nature of this data collection process, there was no need for audio recording or transcription of responses. Regarding the variables used for characterization, the common practice of double verification during data tabulation was omitted in favor of normalizing the variables in an Excel software format spreadsheet. After completing the questionnaire, participants also received a digital copy of their submitted responses via email, along with a copy of the informed consent form.

There were no incomplete answers or blank records that needed to be excluded. However, 15 responses from relatives of teenagers affected by retinoblastoma (who were not part of the target population) were recorded in the electronic spreadsheet. As a result, after excluding these ineligible individuals from the 129 respondents, the final number of participants considered was 114 family members.

In this work we did not adopt saturation criteria, since this procedure is not used in the Collective Subject Discourse (DSC) technique. For the DSC it is necessary to consider the totality of the answers, from all participants, for the analysis of the speeches, since this technique has as its object "the thought of collectivities that allows the illumination of the social field researched, retrieving in it the universe of differences and similarities between the visions of the social actors"[14].

Thus, the returned textual data were then stored in full automatically in an electronic spreadsheet. As soon as the participant answered the questionnaire, he received a digital copy of his own answers by e-mail. The double-typing process was replaced by normalizing the database and checking the answers for comprehensibility. In DSC, data collection and normalization occur in a previous stage, completely unlinked to the subsequent stage of analysis, an additional characteristic that naturally makes the use of data saturation, present in other qualitative research frameworks, unfeasible.

Analysis and Results

Theoretical and methodological framework, and data analysis

The participants' characterization data were presented through descriptive statistical analysis, while the discursive responses that constituted the qualitative data were analyzed using the Collective Subject Discourse (DSC) method[14], based on the theoretical and methodological framework of the Social Representations Theory – SR[15]. The analysis was performed by the main author and the research supervisor, with the collaboration and review of the other authors, and was started by vertical and horizontal in-depth readings of the answers to the question about the meaning of retinoblastoma.

The DSC step-by-step consisted in identifying key expressions (EC) and central ideas (IC), which were grouped into identical, similar, and complementary ideas. From these groupings came the construction of the DSC itself[14]. The Collective Subject Discourses were opportunities for the "collective self", consisting of family members of children affected by the disease, to manifest and exemplify what such cancer represents to them. Thus, the meanings that emerged from the groupings of central ideas, detailed in the DSC panel, corresponded to the participants' social representations on the topic of interest.

RESULTS

Sociodemographic and clinical characteristics

The study included 114 companions family members of children diagnosed or with a history of retinoblastoma. The most frequent participants were adult female family members, mothers, aged 30 to 39 years, with more than 11 years of schooling, occupation/homeworker, family income of up to one minimum wage, and living predominantly in the state of São Paulo.

The children affected by the disease were mostly female, aged 25 to 36 months (three years) and 50 to 62 months (five years). According to information provided by accompanying family members, there was a predominance of unilateral (unifocal) retinoblastoma, a tumor resulting from a sporadic alteration (random error), configuring a non-congenital retinoblastoma (not hereditary), treated exclusively in public services of the Unified Health System (UHS), mainly in the state of São Paulo.

Meanings of retinoblastoma

The clusters of central ideas corresponding to the meanings of retinoblastoma are presented, along with the codes and the quantification of participants who contributed to each meaning, as shown in Table 1.

Table 1. Meanings of retinoblastoma, according to emerged central ideas, family member codes, and frequency of participants contributing to each Central Idea.

Meanings	Participants	n	%
A – Ocular cancer / retinal tumor	F1, F2, F4, F7, F9, F12, F17, F19,F23, F24, F26, F30, F31, F34, F36, F38, F40, F41, F42, F44, F45, F46, F48, F51, F53, F54, F56, F57, F59, F64, F66, F69, F70, F75, F78, F81, F84, F85, F88, F89, F90, F94, F95, F96, F98, F100, F101, F105, F106 e F112	50	34,72%
B – Curable disease if treated early, despite being serious	F3, F5, F9, F16, F18, F19, F21, F22, F29, F32, F37, F43, F45, F47, F58, F61, F64, F72, F79, F82, F93, F107, F111 e F113	24	16,67%
C – Rare tumor / cancer that may have a genetic / hereditary origin	F6, F16, F19, F45 e F76	5	3,47%
D – Silent, serious, difficult, aggressive disease that generates fear and impacts the family	F8, F13, F15, F18, F27, F33, F37, F50, F52, F60, F67, F68, F69, F83, F91, F107 e F108	17	11,81%
E – Cancer / tumor that affects babies and children	F10, F19, F20, F25, F37, F55, F62, F65, F69, F71, F73, F74, F76, F77, F80, F85, F87, F98, F101, F103, F104, F109, F110, F111 e F114	25	17,36%
F – Phase, coping, changes, and new life	F11, F14, F28, F39, F49, F86, F99 e F102	8	5,56%
G – Unknown, poorly publicized disease, lacking information, but frequent	F15, F21, F32, F35, F47, F58, F63, F93 e F103	9	6,25%
H – Other meanings	F5, F15, F49, F50, F92 e F97	6	4,17%
Total number of participations		**144**	**100%**

Note: Code F and the sequential number refer to the participating family member and the chronological order of the corresponding response.

Next, the panel presents the Discourses of the Collective Subject (DCS) related to each of the eight emerged meanings from the researched collective. It is the moment of the "collective self," constituted by the accompanying family members of the affected children, representing "what retinoblastoma means to them."

A – Ocular cancer / retinal tumor

Retinoblastoma is a rare ocular cancer located in the retina, where cancerous cells proliferate and affect the cornea, potentially spreading and being classified from A to E. It can manifest unilaterally, bilaterally, or trilaterally, even reaching the brain in severe cases. It is a malignant tumor that impairs vision and can lead to the loss of the eye, appearing as a cat-eye-like spot, visible under light or flash. Detection is challenging, often revealing itself in advanced stages. In summary, it is an ocular cancer in the retina.

B – Curable disease if treated early, despite being serious

Retinoblastoma, a severe eye disease, is curable despite its impact on ocular health. This swiftly progressing tumor requires early diagnosis for ocular preservation and patient survival. Timely discovery renders it treatable with over 85% cure rates. Treatment is prolonged, with few specialists in our country. It's a malicious ailment with variable outcomes based on detection timing, possibly subject to divine intervention. Retinoblastoma initially threatened our peace like a monster, yet with faith and persistence, we conquered it using abundant curative resources.

C – Rare tumor / cancer that may have a genetic / hereditary origin

It is a tumor that, in our case, has been passed from parent to child. Thus, there are cases of retinoblastoma related to genetics, due to a RB1 gene mutation. In other words, it is a rare cancer that can be hereditary or not.

D – Silent, serious, difficult, aggressive disease that generates fear and impacts the family

It's a silent disease, fatal when diagnosed late. Even early discovery is terrifying, especially fearing my daughter might lose her eye. Retinoblastoma is aggressive, persistent, and silent; many parents can't perceive symptoms. It's serious, grave, and treacherous; it almost took my daughter. This disease disrupts the family intensely, leaving us shaken and scared. It's devastating, affecting psychological well-being. With God and healthcare professionals' support, we find strength to overcome.

E – Cancer / tumor that affects babies and children

Retinoblastoma is a rare type of childhood cancer that affects very young children, typically occurring until the age of five. In most cases, it emerges in very young children, even babies up to 2 years old. This malignant cancer impacts the most innocent beings on our planet, our children, and if not swiftly diagnosed, it can lead to death.

F – Phase, coping, changes, and new life

To me, retinoblastoma is a life-altering malignancy, prompting a battle against death for survival. It disrupted our family's routine, introducing a new life perspective. I found solace and meaning through a change in religion. Presently, retinoblastoma is a temporary obstacle for our family, a challenge we will conquer.

G – Unknown, poorly publicized disease, lacking information, but frequent

Retinoblastoma, a severe ocular ailment, was previously unfamiliar to me and my relatives. While once rare, it has seen a noticeable surge in cases over the years, now appearing more common than anticipated, particularly evident in pediatric cancer hospitals. The issue lies in the lack of awareness among parents, with limited information available about Retinoblastoma in Brazil, as observed from my standpoint. Upon discovering our child's diagnosis, the novelty of the disease was astonishing and challenging to fathom.

H – Other meanings

Retinoblastoma appeared surreal to me. Its discovery triggered a cascade of emotions, an unformed cell, a disease laden with risks, and it felt like a verdict of death. Initially, I perceived it as destiny, unable to pinpoint its cause. However, my current understanding interprets it as more than mere chance.

The synthesis illustration of Figure 1 depicts the set of represented meanings.

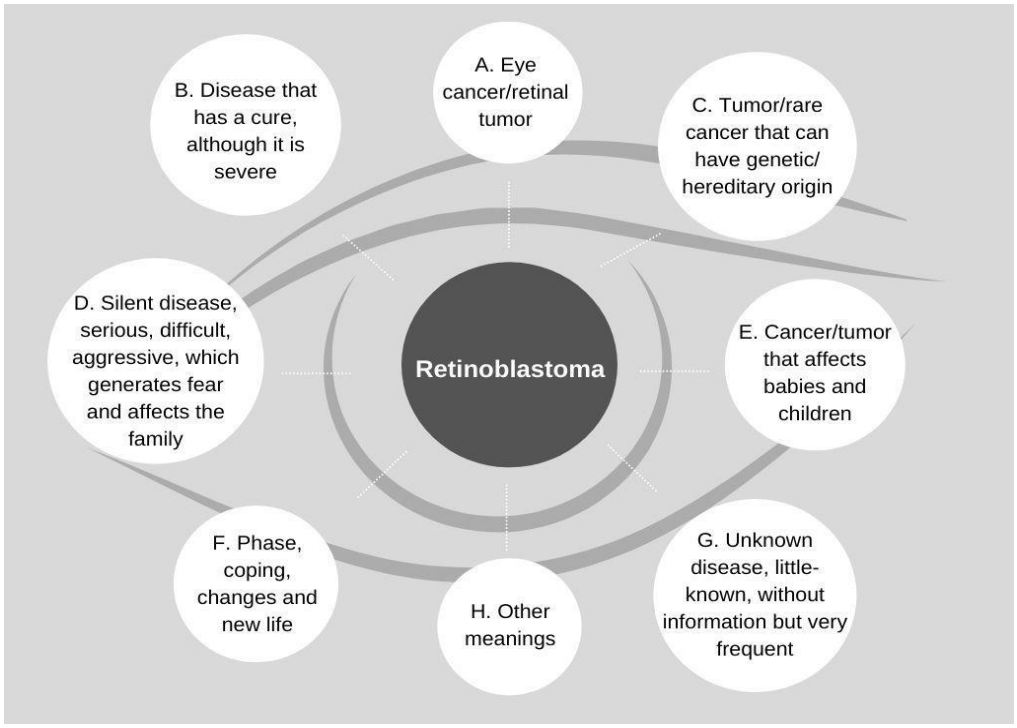

Figure 1. Model synthesis of the social representations about retinoblastoma by accompanying family members of children affected by cancer, Brazil, 2020.

The most significant meaning in relation to its degree of dissemination in the social field of study was the one that generated the Collective Subject Discourse (CSD) A: “Ocular cancer / retinal tumor.” This outcome suggests a comprehension among family members regarding the concepts, definitions, and technical as well as clinical characteristics of cancer. This discourse, along with the CSD “Silent, serious, difficult, aggressive disease, which generates fear and messes with the family,” exemplifying negative aspects within the familial context, will be further discussed.

DISCUSSION

Definitions and technical and clinical characteristics of cancer

The Collective Subject Discourse (DSC) concerning the meaning “Ocular cancer / retinal tumor” reveals social representations permeated by definitions, technical and clinical characteristics of cancer, referring to the origin, clinical forms and locations of the tumor. By expressing the tumor this way the children’s family companions demonstrate some knowledge learned from the diagnosis of the disease and the therapeutic itinerary.

In this context, family members reinforce in several expressions the words cancer and tumor, making the localizing, direct and objective reference to the eye, vision and retina. “[...] Retinoblastoma is a rare eye cancer located in the retina [...] a malignant tumor that compromises vision and even causes loss of the eye [...]”. This representation aligns with the clinical definition of retinoblastoma, the most common malignant intraocular tumor of childhood, with a global incidence in Brazil of 7.02 cases per million in the age group of 0-4 years, potentially yielding unfavorable outcomes[16-18.]

According to Amador et al.[19] the suffering caused by the diagnosis of retinoblastoma in the family and the uncertainty of what it represents drives relatives to search for information to understand all aspects of the disease. However, they do not always find the information they need to solve their doubts and may have difficulties understanding due to stress and fear. According to these authors, the family eagerly seeks to know what is happening to the child to decide on the best form of treatment, this is relevant since the understanding of parents about the disease is a key resource to achieve better treatment for children.

However, a study developed by Xiao et al[20] in an eye oncology unit of a tertiary eye center in southern China, showed that only one third of the parents adequately understood the basic and most important aspects of retinoblastoma, such as genetic and clinical screening, which denotes the need for more strategies for health education for parents of this group of children, without disregarding the sociocultural reality of the families.

In this study, one can discern a thorough understanding of retinoblastoma, which, according to the literature, is linked to a favorable prognosis when early diagnosis and treatment are achieved. It is increasingly recognized that early detection and treatment by a specialized multidisciplinary team maximize the chances of survival and ocular/vision preservation while minimizing treatment-related toxicity[16].

Genetic counseling about cancer predisposition in children is related to improved levels of knowledge and satisfaction. According to the authors, most participants improved their knowledge about the disease from this type of counseling, suggesting that information about genetics can bring benefits to families facing cancer. Facilitating the decision to perform genetic testing on their children; helping and empowering the family to assess the risks and benefits of early testing are exemplified as advantages in this context[21.]

Retinoblastoma is the only tumor of the central nervous system that can be easily observed without specialized equipment and is visible to the naked eye[22.] When a family member notices something different in the child’s eyes, for example, a white reflex (leukocoria), strabismus (squint), heterochromia (change in iris colour), nystagmus (constant eye movements), an unexplained painful/red eye or orbital cellulitis[23] they suffer, mainly because they don’t understand what is going on. The relatives start to seek information from specialists in order to understand what the retinoblastoma is about, however, they do not always find the information they need to solve their doubts. Sometimes, even with adequate information, it is difficult to understand the situation due to stress andfear[19].

Another study showed that the main source of information for family members about retinoblastoma was websites. In addition, family members reported high satisfaction with the information about the cancer received from health professionals. In this context, despite the risks of unreliable information that the internet may pose, this new scenario can alleviate the concerns of accompanying family members in their quest for knowledge about the disease[24].

Therefore, it is necessary to promote strategies that disseminate information about ocular cancer, in order to help families and promote the knowledge of the first signs and symptoms of the disease[25]. Health communication strategies, for example, can be employed when the family of a child with retinoblastoma is navigating a challenging and uncertain period during the illness. The multidisciplinary team must be attuned to the needs and provide support along with clear information about the disease. In this regard, it is crucial to assess the comprehension levels of families who may struggle to understand the information due to the stress of the situation, low educational attainment, or cognitive difficulties.

Concepts and negative biopsychosocial impact: Feelings, suffering, individual and family burden

In the DSC “Silent, serious, difficult, aggressive disease, which generates fear and messes with the family”, the family members materialize the feelings of difficulties such as fear, suffering, changes that occur in the family daily life before the diagnosis and the negative impacts. They reinforce the severity and aggressiveness of the disease, inferring that a delay in diagnosis can be fatal for the child, and they consider the disease treacherous, which presents itself in a very subtle way, due to the difficulty in perceiving its initial signs and symptoms.

Amador et al.[19] say that fear comes from the unknown, from the family’s lack of understanding about the disease and the reason for their child’s involvement. These feelings are combined with the despair of losing the child because the diagnosis of cancer is often associated with death, in the symbolic field.

The diagnosis of retinoblastoma causes great stress for family members, since it is a disease little known by society, generating fear of the unknown of the changes imposed by the treatment, such as possible loss of vision, the eyeball and the risk of death of the child.

A study that investigated symptoms of anxiety, stress and depression in parents of children with retinoblastoma found that most parents showed mild depression, anxiety and stress during the process of discovery and treatment of the disease. The authors also reported severe depression in separated parents and in parents of children with multifocal involvement[27].

The use of the word “terrible” in the discourse stands out, exemplifying the panic that arises at the time of diagnosis, profoundly altering the experience of the entire family involved in the process. It is imperative to consider that the tender age of affected children and their dependence on their parents significantly contribute to the elevated levels of stress at the time of diagnosis. This stress can further intensify during the oncological follow-up, as family members are called upon to actively participate in caregiving and decision-making

related to treatment.

In this context, it becomes evident that confronting retinoblastoma entails an exceptionally distressing period. However, a thorough understanding of the disease's natural history, derived from real-world evidence, should serve as a reminder to both healthcare professionals and parents of the potentially life-threatening nature of this cancer. This awareness underscores the importance of initiating prompt treatment from the moment of diagnosis[28].

In a study conducted to explore the experiences and perspectives of mothers with children diagnosed with retinoblastoma, mothers transitioned from a sense of unacceptance to embracing challenges and finding inner strength[29]. This outcome indicates psychological adaptation and the development of coping strategies among these mothers.

The literature suggests that family members employ diverse approaches to reinterpret the experience of accompanying a child with retinoblastoma. Some individuals seek restructuring and discover a new, positive meaning in the face of this challenging experience. Additionally, some studies indicate that accepting the circumstances imposed by the treatment can facilitate the implementation of medical interventions and aid in overcoming the associated difficulties[4-9,19].

In terms of practical implications, it is of utmost importance to routinely conduct assessments of maternal social support, traditional health beliefs, and spirituality. Furthermore, there is a strong emphasis on the need to guide parents, family members, caregivers, and companions in harnessing their inner strengths and for the development of intervention programs aimed at promoting psychological adjustment, all without causing treatment delays[29].

In this direction, the study conducted by Fathollah Zadeh et al.[30] on the hope of Iranian mothers of children with cancer, evidenced that the best psychosocial and spiritual support contributed to the highest level of hope. Dolan et al.[31] corroborate on the importance of religiosity and spirituality in the context of illness. When studying the association of psychological suffering and religious tendencies in coping with cancer of their children, the researchers concluded that religion and spirituality were important coping strategies with reduced psychological suffering during the treatment process. Such data reaffirm the importance of hope, religiosity, and spirituality, and indicate the need for psychosocial interventions based on these domains[5,8,29,32].

It is very important that the accompanying family members have the opportunity to talk and express their feelings when the disease is discovered. Many negative feelings can be alleviated with information about the disease, the possibility of treatment and, especially, the high probability of cure. Therefore, it is understood that a biopsychosocial approach, provided by a multiprofessional health team, in which nurses are supported by social representations about retinoblastoma to enrich their assistance to affected children and their relatives, is a valuable care strategy for the therapeutic itinerary in oncology.

Study limitations

The fact that the accompanying family members were invited to participate in an exclusively virtual way and self-recorded

their answers in typed form, instead of interviews recorded in transcribed audio, constituted weaknesses of the study. Despite their operational, temporal, and logistical advantages for data collection, it is recognized that snowball sampling and the web survey strategy may provide a partial selection of the target audience. Thus, heterogeneous return from a geographical perspective, coupled with lack of knowledge about 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 study.

In addition, the recording of responses by means of typing on cell phones, computers or other electronic devices does not seem to provide the same completeness and depth in the content of the statements, as historically observed in the data obtained through interviews. In the authors' perspective, although web surveys have emerged as a new possibility for data collection in qualitative research, the face-to-face recorded interview still remains one of the most privileged communication techniques. It was noticed that data from electronic forms seem to contribute with less discursive material, or less robust raw material, concerning the key expressions necessary for more abundant and richer Collective Subject Discourses (DSC). However, the results discussed here constitute an original and important portrait of the social representations of retinoblastoma by family members of children affected by cancer in the country.

Contributions

Considering the above, the adoption of a biopsychosocial approach through a multidisciplinary healthcare team is pivotal. In this context, nurses assimilate social representations related to retinoblastoma to enhance care for affected children and their families, proving to be a valuable strategy within oncological therapeutic trajectories.

It is therefore recommended to disseminate the findings of this study to healthcare professionals, especially nurses in maternity wards and Primary Healthcare Units. Beyond the importance of recalling and communicating disease indicators, an investment in early detection of retinoblastoma is necessary, facilitated by effective neonatal screening and ocular examinations up to the age of three, coupled with appropriate referrals to ocular investigation services. Genetic counseling is also paramount to identify siblings of affected children through molecular research, reproductive health guidance, and long-term survivor follow-up.

Thus, this study holds the potential to enrich nursing care provided to children and their families, who grapple with the social, economic, familial, cultural, and emotional impacts of the disease. The outcomes also shed light on the reality faced by vulnerable families in the cancer context, underlining the imperative for investments in pediatric oncological care to facilitate timely access and quality treatment through the Healthcare System and Oncology Care System.

CONCLUSION

The retinoblastoma was represented by characteristics of the disease, by clinical definitions of the cancer and by its genetic/hereditary origin. The emotional impact emerged materialized in anguish, caused by the uncertainty of prognosis and treatment. The speeches showed the unpredic-

tability of retinoblastoma, the knowledge about this cancer, and portrayed the fear generated by the disease, initially seen as a fatality.

Therefore, it is observed that family members address heterogeneously the different facets of retinoblastoma in their collective discourse, representing in an integrated and articulated way not only the meanings of the disease itself, but also expressing how they have experienced retinoblastoma in the family context.

Further studies are suggested to investigate educational strategies that can better contribute to improving the level of information of family members, the multi-professional team and, consequently, to a better coping with retinoblastoma, with active participation of oncology nursing in the care of children with ocular neoplasms.

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JLLM, NOS, FLO, MCN: study design and planning; data collection; data collection, analysis, and interpretation; writing and final approval of the published version.

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