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SOCIAL REPRESENTATIONS OF CHILDREN AND ADOLESCENTS' CAREGIVERS ON CHILDHOOD CANCER

Representações sociais de cuidadores de crianças e adolescentes sobre o câncer infantojuvenil

Representaciones sociales de los cuidadores de niños y adolescentes sobre el cáncer infantil

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ABSTRACT

Objective: to apprehend the social representations of caregivers of children and adolescents about cancer in children and adolescents. **Method:** qualitative, exploratory, descriptive research, based on the structural approach of the Theory of Social Representations, based on the Theory of the Central Nucleus. The Free Word Association Technique and the semi-structured interview were used for data collection. Participants were 34 family caregivers, in the city of Itabuna, Bahia. The data from the Free Word Association Technique were processed by the EVOC software. **Results:** from the analysis of the data, the following thematic categories emerged: Impact and feelings that permeate the daily life of the caregiver, and confrontations encountered by the caregivers to overcome childhood cancer. **Conclusion:** it was evidenced that the social group has representational elements in the evoked terms "God" and "suffering", pointing out that the diagnosis of the disease causes suffering for caregivers, children and adolescents. Demonstrating that caregivers share their everyday experiences about coping with the disease.

DESCRIPTORS: Cancer; Child; Adolescent; caregivers; Social Representation;

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RESUMO

Objetivo: apreender as representações sociais de cuidadores de crianças e adolescentes sobre o câncer infantojuvenil. **Método:** pesquisa qualitativa, exploratória, descritiva, fundamentada na abordagem estrutural da Teoria das Representações Sociais, baseada na Teoria do Núcleo Central. Foram utilizados para coleta dos dados a Técnica de Associação Livre de Palavras e a entrevista semiestruturada. Participaram 34 cuidadores familiares, na cidade de Itabuna, Bahia. Os dados oriundos da Técnica de Associação Livre de Palavras foram processados pelo software EVOC. **Resultados:** a partir da análise dos dados, emergiram as seguintes categorias temáticas: Impacto e sentimentos que permeiam o cotidiano do cuidador, e enfrentamentos encontrados pelos cuidadores para vencer o câncer Infantojuvenil. **Conclusão:** evidenciou-se que o grupo social possui elementos representacionais nos termos evocados “Deus” e “sofrimento”, apontando que o diagnóstico da doença acarreta sofrimento para os cuidadores, crianças e adolescentes.

DESCRITORES: Câncer; Criança; Adolescente; Cuidadores; Representação Social;

RESUMEN

Objetivos: aprehender las representaciones sociales de cuidadores de niños y adolescentes sobre el cáncer en niños y adolescentes. **Método:** investigación cualitativa, exploratoria, descriptiva, basada en el enfoque estructural de la Teoría de las Representaciones Sociales, fundamentada en la Teoría del Núcleo Central. Para la recolección de datos se utilizó la Técnica de Asociación Libre de Palabras y la entrevista semiestructurada. Los participantes fueron 34 cuidadores familiares, en la ciudad de Itabuna, Bahía. Los datos de la Técnica de Asociación Libre de Palabras fueron procesados por el software EVOC. **Resultados:** del análisis de los datos surgieron las siguientes categorías temáticas: Impacto y sentimientos que impregnan el cotidiano del cuidador, y enfrentamientos encontrados por los cuidadores para superar el cáncer infantil. **Conclusión:** se evidenció que el grupo social posee elementos representacionales en los términos evocados “Dios” y “sufrimiento”, apuntando que el diagnóstico de la enfermedad provoca sufrimiento a los cuidadores, niños y adolescentes. Demostrar que los cuidadores comparten sus experiencias cotidianas sobre cómo sobrellevar la enfermedad.

DESCRIPTORES: Cáncer; Niño; Adolescente; cuidadores; Representación Social.

INTRODUCTION

Cancer is considered a public health problem worldwide. In Brazil, cancer is the leading cause of death (8%) among children and adolescents aged 0-19 years.1 It is considered rare when compared to cancer in adults, accounting for between 1% and 3% of all malignant tumors. The National Cancer Institute (INCA) has estimated that there will be 8,460 new cases of cancer in Brazilian children and adolescents between 2020 and 2022, with an estimated risk of 138.44 of all new cases in the country.[1-3]

Cancer in children and adolescents is a group of numerous pathologies that have in common the uncontrolled multiplication of abnormal cells, invading tissues and organs, and can occur anywhere in the body. Although not very significant when compared to the disease in adults, cancer in children and adolescents is embryonic in nature and commonly affects cells in the blood system and supporting tissues.[4]

Significant progress has been made in the treatment of cancer in children. Currently, it is estimated that 80% of children and adolescents affected by the disease can be cured if diagnosed early and in specialized centers. They therefore have a better chance of developing a good quality of life after appropriate treatment.[4-5]

Despite the progress and favorable prognosis that the disease has achieved, cancer still causes many changes in the lives of individuals and their families, such as making decisions and taking on responsibilities that previously didn't even exist and which are now imposed in order to care for the person affected by the serious and difficult-to-control disease. This permeates the life of the family caregiver with feelings of fear, uncertainty, impotence and incapacity that affect the family's routine.[6-8]

Thus, from the perspective of the Theory of Social Representations (TSR), caregivers of children and adolescents with cancer rethink and resignify their representations, enabling new knowledge and social practices, favoring the construction of new social knowledge that is produced on a daily basis.[9]

In this sense, Joselet[10] states that Social Representation (SR) is a "modality of knowledge, socially elaborated and shared, with a practical objective, and which contributes to the construction of a reality common to a social group". In this process, caregivers are a social group that generates SR about the disease, trying to make it familiar in its many aspects and developments. For this reason, Moscovici[11] emphasizes that "the purpose of all social representations is to make something unfamiliar and familiar".

The aim of this study is to understand the social representations of caregivers of children and adolescents about childhood cancer.

METHOD

This is a quantitative-qualitative, exploratory, descriptive study based on the structural approach of TSR, based on the Central Nucleus Theory (CNT). CNT proposes that every representation is constructed by a set of information, beliefs and opinions of a social group. The structural approach is organized by the central core, made up of elements that occupy a prominent position in this structure, related to meaning and its internal organization; and a peripheral core, which would provide integration to the common core with everyday experiences.[12]

The research site was the Support Group for Children with Cancer (GACC), located in the municipality of Itabuna, Bahia/Brazil, during the second half of 2021. Thirty-four caregivers of children and adolescents with cancer participated in the study, selected according to the following inclusion criteria: age 18 or over; being a companion of a child or adolescent with cancer undergoing treatment at the GACC; and having participated in the educational activities carried out at the institution.

Due to the social isolation caused by the Covid-19 pandemic, the interviews were conducted via the Google Meet platform and WhatsApp application, which were recorded in the second half of 2020. Data collection took place after all participants had read, understood and signed the Informed Consent Form (ICF). For data collection, a form was used containing general data and questions aimed at identifying the social group. By scheduling pre-established days and times with the participants, data was collected using the google meet digital platform and/or the whatsapp application. Thus, video calls were made with each participant in the study to collect information, and the Free Word Association Technique (FWAT) was initially applied, followed by the semi-structured interview. In this context, the FWAT, widely used in the field of SR, consists of asking the participant to verbalize up to 5 words that come to mind from an inducing term, which in this study was "Cancer". The participants were then asked to list the evocations in order of importance.

The semi-structured interview followed a previously prepared script, allowing us to delve deeper into situations presented in everyday life and record the experiences of caregivers of children and adolescents with childhood cancer.

To analyze the FWAT data, the evocations were submitted to the EVOC software (Ensemble de Programmes Permettant I'analyse des Evocations) - version 2005, which made it possible to identify the central core and the peripheral elements that make up the social representations. The interview data was analyzed and categorized using thematic content analysis according to Bardin13 and based on the structural approach of TSR, based on CNT. Triangulation[14] was then carried out on the data produced, through the interlocution of the techniques used to collect and analyze the data.

The research was submitted to and approved by UESB's Research Ethics Committee (CEP) under Opinion No. 4.173.310/2020 and CAAE: 34673620.5.0000.0055, thus complying with Resolution No. 466/2012 and CNS Resolution 510/16 of the National Health Council, which regulates research involving human beings. In order to preserve the anonymity of the participants, a capital letter "C" was used to identify the caregivers, followed by Arabic numerals.

RESULTS

After processing the data, it was found that the inducing term "cancer" produced 150 evoked words among the 34 caregivers, 21 of which were different.

To compile the values related to the composition of the central core and peripheral elements, the Rangmot report issued by the EVOC 2005 software was generated, with minimum frequency = 6, average frequency = 12 and order of evocations (rang) = 3.2. The following illustrates the organization of the elements from the evocations by drawing up the four-box table.

Chart 1 - Table of Four Houses for the inductive term "cancer" of caregivers of children with cancer. Jequié/BA/BR, 2021.

CORE ELEMENTS			ELEMENTS OF THE 1ST PERIPHERY		
Frequency ≥ 12 / Rang < 3,2			Frequency ≥ 12 / Rang ≥ 3,2		
Freq		Rang	Freq		Rang
God	19	1,737	Fear	16	3,313
Suffering	26	3,154	Death	18	3,278
CONTRAST ELEMENTS			ELEMENTS OF THE 2ND PERIPHERY		

Frequency < 7 / Rang < 3			Frequency < 7 / Rang ≥ 3		
Freq		Rang	Freq		Rang
Care	6	3,167	Medication	8	4,625
Healing	10	2,500	Health	8	4,000
Victory	10	2,900			

Table 1 shows that the upper left quadrant contains the elements considered to make up the probable central core of the social representation drawn up by the caregivers, the most frequent being "God" and "Suffering", which also appear with high frequency in the social group's evocations. In the upper right quadrant, called the 1st periphery, there are also very strong elements such as the words "Fear" and "Death". However, their appearance in the top evocation positions was not significant.

In the lower left quadrant, the words and expressions that stand out are: "Care", "Healing" and "Victory", which are also elements pertinent to the peripheral system, of the so-called zone of contrasting elements and, therefore, with low frequency and average order of appearance in the first positions. In the lower right quadrant, there are elements from the second periphery, such as "Medication" and "Health", with a high average order of appearance and organized around the central core, related to the social practices of caring for children and adolescents with cancer.

The analysis of the semi-structured interviews led to the identification of two thematic categories: the impact of the diagnosis and the feelings that permeate the caregiver's daily life; and the caregivers' coping with childhood cancer.

Category 1: Impact of the diagnosis and feelings that permeate the caregiver's daily life

In the first category, it was clear that the SRs apprehended from the caregivers' statements go through a process of resignification after the diagnosis of the disease. The emergence of feelings of fear, loss, sadness, among others, makes these caregivers go through difficult situations, representing something frightening and desperate in the face of this new social reality, as can be seen in the following statements:

> *When I arrived here at the health unit and we were diagnosed with the disease, it was initially complicated, because I didn't really understand what she* (daughter) *had, I'd only heard about it on television. But when we arrived for treatment, and I saw the other children without hair, I felt quite sad and down, it was a very difficult time* (C1).
>
> [...] *I felt sad, bitter, the feeling was that the world had collapsed on me, I just cried, cried and was very afraid of losing my daughter* (C2). The first day I received the diagnosis I was desperate, fear and anguish took over me. I kept questioning myself and wondering how such a disease could appear in my family (C5).
>
> *We felt despair, fear, fear that our little girl would die* (C10).
>
> *I felt that at any moment she* (the teenager) was going to die from this disease (C25).

Category 2: Coping with childhood cancer encountered by caregivers

In the second category, representations emerged which show that after the diagnosis, caregivers use coping strategies to deal with the disease in the face of the new scenario imposed on the social group. The caregiver establishes coping strategies to help them experience the new social reality, such as support in faith, support in spiritual forces, because belief in God brings them comfort, in the social support network, in building resilience to improve the clinical condition of their children and adolescents in the search for a cure, according to the following statements:

> [...] *with faith in God, my baby will be cured and this problem won't come back, because Jesus won't let it* (C 03).
>
> *I just think positively, God willing, everything will work out and she'll be cured* (C 08).
>
> [...] *I have a lot of faith in God and that everything will work out and we'll overcome all this* (C10).
>
> [...] *I have a lot of hope that he will be cured and I will go back to work, with a lot of faith in God* (C1).
>
> *Thank God, whenever I feel alone, I feel that God comforts me and he sends people to comfort us and give us support to get through this phase* (C11).
>
> *At these times, family is fundamental as a support to help us face this illness and reach a cure* (C6).

DISCUSSION

The SRs about cancer, revealed by the study through the social group, present constructions that caregivers face in the health context, making it possible to understand and externalize emotions through the process of constructing SRs and giving them a specific meaning.[15] The structural approach to SR implies recognizing the different social factors in the thought processes that influence living with a child or adolescent with cancer, taking into account the importance that the subjects involved attribute to dealing with the health of this specific clientele.[12]

The structural analysis of the evocations based on the inductive term cancer (chart 1) showed that, for the participants, the objectification of cancer is anchored in suffering. In this sense, a similar study with adolescents mentions that the social representation of cancer is strongly anchored in the social stigma[16] that the disease still carries. Suffering can be seen in the first category through the testimonies, when the social group reports feelings of powerlessness, fear and dread of death, expressed through their personal realities.

Thus, the term "suffering" makes up the central core of the representation of cancer for the caregivers and, like a similar study carried out with mothers of children with cancer, expresses an unpleasant emotional experience[17] and is evoked 26 times, along with the term "God", which appears 19 times. The experience of suffering caused by the diagnosis and painful treatment caused by the disease triggers countless reactions in caregivers in the face of the disease[18] such as fear, insecurity, situations that can be evidenced through the central nucleus of the four-house framework and verified through the statements of the semi-structured interviews, in the first category entitled, "Impact and feelings that permeate the caregiver's daily life".

The second term to stand out in the central core area was "God". Despite the negative representations, the evocations were also positive, expressed by the term "God", located in the central core. The caregivers anchor their representations in the faith of divine power, supported by spirituality as a resource for coping with childhood cancer, placing their hope in a cure, as can be reinforced by the statements of the social group, evidenced in the second category generated from the statements of the semi-structured interviews, "Caregivers' coping with childhood cancer". Studies on Social Representations add that these representations[11] are combined with values, knowledge and practices that lead social relations and are evidenced through speeches, expressions, actions and feelings.

Corroborating our study, Sanches et al.[19] point out that in order to cope with the disease and the fear of death, it is essential that the caregiver and the family have a lot of faith and support in religious beliefs, as a way of supporting and accepting death.

In the structural analysis of the first periphery of the representation, the term "death" appeared as the third most evoked element. It is central to and organizes the representation of cancer and is associated with the fear of death, as mentioned by the social group about the impact when they are diagnosed with the disease. Thus, the diagnosis of cancer alludes to the awareness of death, carrying feelings such as anguish and fear of the treatment itself.[20] These representations are ratified in the statements of caregivers 5, 10 and 25 in the first category.

Cancer is a disease with a lot of representation, it has a big impact on people's individual and social lives and is seen as synonymous with death.[21] As for the practical elements of social representation, these are evidenced by the terms "medication" and "health", elements that in social representation are equivalent to objectifying the practical commitment that the social group assumes in relation to daily care for children and adolescents with cancer. Coping with the diagnosis and treatment of cancer in children and adolescents is related to daily care practices that prevent the child and/or adolescent from getting worse, such as drug therapy.

From the participants' statements, it can be seen that the caregivers' representations revolve around the health education that the social group receives at the institution where the child or adolescent is being treated for the disease. Health education includes guidance on the emergency signs to look out for in the event of any alterations, care regarding drug therapy and precautions related to the environment and food.[17,22]

In this sense, maintaining the health care of their loved ones provides comfort and security to the social group[17] Thus, TSR permeates all care and is immersed in everyday communications, circulating in statements, ideas and images, materializing in conduct.[11] Therefore, understanding the practices and dynamics of the social group allows us to understand how its representations work. Thus, studying SR is fundamental to understanding the dynamics of social interactions and explaining the determinants of the practices in which these individuals are inserted.[12]

The elements considered to be constituent, located in the contrast zone, "care", "cure" and "victory", through the evocations represent different variations, marked by positive discourses and attitudes in coping with cancer. They thus reinforce the idea that if the social group carries out the care according to the guidelines they received at the institution, they can achieve the cure and, consequently, the victory that everyone wants.

The process of coping with the disease is found in spirituality, in faith in a God who can do anything and in the support they receive from their family and from the people in their circle of contact[17]. This is corroborated in the speeches in the second category, the search for faith and belief as a strategy for relieving suffering and seeking a cure.

Thus, the SRs of caregivers based on communicative elements allow for the exchange of meanings[23] about the strategies for care that are used for the progression of the disease and the social support network that are fundamental to the construction of representations.

In this context, understanding the representation of the thought structure of the social group under study means unveiling a meaning, sometimes unconscious and subjective, which permeates through the individual's cognitive system, associated with values, experiences, according to social context[24, 25].

FINAL CONSIDERATIONS

By understanding the Social Representations of caregivers of children and adolescents with cancer about coping with the disease, the social thinking of this social group was revealed. It became clear that the representational elements imply the contents of the descriptive conceptions that the caregivers have in relation to cancer and the impacts that the disease has on coping with the health situation.

The probable centrality of the terms "God" and "Suffering" was evident, representing the structural analysis of the central nucleus. The findings show that the diagnosis of the disease causes a great deal of suffering for the caregivers and the whole family, bringing the possibility of fear of death that it can bring to children and adolescents. It also demonstrates the conceptual dimension with knowledge about cancer based on the ideas, beliefs and experiences that are shared in everyday life.

It can be seen that when suffering, the social group seeks to anchor itself in the divine figure as a way of coping with cancer, in search of victory, represented by the cure. The peripheral systems contain terms that reveal the caregivers' way of coping with the disease, through medication and health care as a way of achieving a cure.

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