REPRESENTATION OF MOTHERS ABOUT THE CONDITION OF HAVING A CHILD WITH CANCER

Representação de mães sobre a condição de ter um filho com câncer

Representación de las madres sobre la condición de tener un hijo con cáncer

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ABSTRACT

Objective: To understand the social representations of mothers about the condition of having a child with cancer. **Method:** qualitative research, based on the theory of Social Representations. Carried out in a Cancer Treatment Unit, with 19 mothers of children diagnosed with cancer, through the projective drawing-story technique with Tema and the semi-structured interview. **Results:** the following thematic categories emerged: Impact of childhood cancer; and the process of coping between mothers and children with cancer, the last category was divided into two subcategories: Spirituality in the process of coping with the disease; and Family and social support in the disease process. **Conclusion:** the social representations of mothers showed that coping with their children with cancer are influenced by their children's health-disease process, changes and coping that modify their conceptual universes and guide their conduct.

Descriptors: Representation, Family, Cancer, Mom, Kid.

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RESUMO

Objetivo: Apreender as representações sociais de mães sobre a condição de ter um filho com câncer. **Método:** pesquisa qualitativa, fundamentado na teoria das Representações Sociais. Realizada em uma Unidade de Tratamento Oncológico, com 19 mães de criança com diagnóstico de câncer, através da técnica projetiva desenho-estória com Tema e a entrevista semiestruturada. **Resultados:** emergiram as seguintes categorias temáticas: Impacto do câncer infantil; e processo de enfrentamentos de mães ao filho com câncer, a última categoria se desdobrou em duas subcategorias: A espiritualidade no processo de enfrentamento da doença; e Apoio familiar e social no processo da doença. **Conclusão:** as representações sociais das mães mostraram que o enfrentamento ao filho com câncer são influenciados pelo processo saúde-doença de seus filhos, mudanças e enfrentamentos que modificam seus universos conceituais e orientam quanto suas condutas.

Descritores: Representação, Família, Câncer, Mãe, Criança.

RESUMEN

Objetivo: Comprender las representaciones sociales de las madres sobre la condición de tener un hijo con cáncer. **Método:** investigación cualitativa, basada en la teoría de las representaciones sociales. Realizado en una Unidad de Tratamiento del Cáncer, con 19 madres de niños diagnosticados con cáncer, a través de la técnica de dibujo de cuento proyectivo con Tema y la entrevista semiestructurada. **Resultados:** surgieron las siguientes categorías temáticas: Impacto del cáncer infantil; y el proceso de afrontamiento entre madres y niños con cáncer, la última categoría se dividió en dos subcategorías: espiritualidad en el proceso de afrontamiento de la enfermedad; y Apoyo familiar y social en el proceso de la enfermedad. **Conclusión:** las representaciones sociales de las madres mostraron que el hecho de que sus hijos sufran cáncer están influenciados por el proceso de salud-enfermedad de sus hijos, los cambios y el afrontamiento que modifican sus universos conceptuales y guían su conducta.

Descritores: Representación, Família, Câncer, Madre, Niño.

INTRODUCTION

Study on the social representations of mothers about the condition of having a child with cancer, which describes the changes and the confrontations of personal and family coexistence in the social reality of the mother facing the diagnosis of cancer.

Cancer (CA) is considered a public health problem worldwide, being responsible for 13% of all causes of death in the world. It is estimated that by the year 2020 there will be 15 million new cases. The mortality rate caused by cancer in Brazil is 13.7%, second only to circulatory system diseases, whose percentage reached 27.9%.[1]

Childhood CA is considered rare when compared to other tumors in the adult phase, corresponding to 2% and 3% of all malignant tumors. In addition, the most frequent neoplasms in childhood are leukemias, central nervous system tumors, and lymphomas. Despite the increasing incidence rates of childhood tumors, cures can be as high as 70%, depending on diagnosis and treatment. [2]

The disease in childhood results in implications for the child's development, collaborating to modification of the family group. A study[3] points out that receiving a diagnosis of CA causes several feelings, such as fear, doubts, anguish, worries, and concerns, precisely because the future becomes uncertain, often without prospects.

CA is a very stigmatized disease that generates uncertainty and suffering. Besides having a negative impact on people's lives, not only because of the social and economic repercussions of the disease, but also because of the suffering that the patient and the family begin to experience. [4]

With the impact and the difficulties imposed by the disease, the mother becomes the direct caregiver of her child. Therefore, being the mother of a child with cancer is to experience the construction of new roles, permeated by the duty and meaning attributed to cancer. [5]

The Theory of Social Representations is a socially elaborated and shared modality of knowledge, with a practical purpose that contributes to the construction of a common reality for a social group. Common sense representation, with which the individual constructs social representations in a shared way and in a rule of communication. [6-7]

Thus, knowing how mothers of children with CA share the same social reality becomes pertinent, so that interventions can be directed to the reality of this social group. Therefore, the objective of this study was to understand the Social Representations of mothers about the condition of having a child with cancer.

METHODS

A descriptive study of qualitative approach, based on the theoretical framework of social representations. The study was developed in the Support Group for Children with Cancer (GACC) in the municipality of Itabuna, Bahia, and data collection took place between January and March 2016. The research participants were 19 mothers of children with CA, meeting the following inclusion criteria: being 18 years old or older; being the mother of children aged between 1 and 10 years old diagnosed with CA, being treated at the institution mentioned in the study.

Data collection consisted of the following instruments: 1) Drawing-and-Story Projective Technique with Theme[8] (DET) and 2) semi-structured interview - both carried out with all participants and guided by a script to reach the objective. The script of the semi-structured interview was composed of a first block focused on the social identification of the group studied (mother and child); the second block of the script included the following triggering question: What changes have occurred in relation to caring for your child with cancer?

In the Projective Drawing-story with theme technique the three requests recommended in the application were made.[9] It was then requested: Draw a picture that represents the meaning of having a child with Cancer; Now, tell a story about your drawing, with a beginning, middle, and end; Finally, give a title to this story.

For the treatment of the data collected we used thematic content analysis[10] in the interviews and stories. A thematic modality that aims to discover the nuclei of meaning and provide meaningful communication to reach the proposed objectives, following three stages, starting with the pre-analysis, consisting of a floating reading of the empirical material. Successive readings of the interviews' content allowed the codification of the data from the cut of the text to identify the registration units. Then, the data were classified and aggregated into themes, categories, and subcategories, both of the contents of the stories and drawings, and of the interviews.

Initially, a systematic observation of the drawings and themes was made; then, the drawings were selected by graphic similarity and/or approximation of the themes. Triangulation[11] of the data produced was carried out, through the interlocution of the techniques used in data collection and analysis.

Thus, seeking to preserve anonymity, the participants were identified with a mother's name, followed by a number according to the order in which the interview was carried out. The research was submitted and approved by the Research Ethics Committee (CEP) of the UESB through opinion no. 1.356.685 /2016, having thus complied with Resolution No. 466/2012 of the National Health Council, which regulates research involving human beings.

RESULTS AND DISCUSSION

Characterization of the research subjects

Of the 19 participating mothers, 52.8% (n=10) were over 30 years old; regarding marital status, 63.2% (n=12) had partners; regarding religious affiliation, 78.9% (n=15) said they belonged to the Catholic religion; as for the level of education, 47.4% (n=9) reported having attended elementary school. Regarding occupation, 78.9% (n=15) said they were housewives; about their place of residence, 73.7% (n=14) said they lived in urban areas; all the participants lived outside the area covered by the municipality; Regarding family income, 89.5% (n=17) corresponded to a minimum wage (R$ 880.00); regarding the number of children per mother, it was evident that 52.8% (n=10) had 2 children, 36.8% (n=07) had more than 3 children, and 10.4% (2) had only 1 child.

After analysis of the data from the interviews and the technique of DET, the following thematic categories emerged: Impact of childhood cancer; and coping process of mothers to the child with cancer, and the latter category unfolded into two subcategories: Spirituality in the process of coping with the disease; and Family and social support in the disease process.

Impact of childhood cancer

In the first category, it was evidenced that mothers are the first, as a family member, to receive the diagnosis of CA of their children, constituting a devastating event, both in the lives of mothers and their families, causing feelings, initially inexplicable and characterized by shock, despair, fear. As can be observed in the following statements.

"[...] At the beginning it was very hard for me, not only for me, but for the whole family. And, as soon as I received the diagnosis, it shook the whole family, his grandmother started to feel sick as soon as she found out, I tried to hold on for a few days, but it didn't work, it was very difficult...". (Mother 3 - Fragment of semi-structured interview).

"[...] I was sad, I cried a lot, and I couldn't do anything else..." (Mother 4- Fragment of Semi-structured Interview).

"[...] I was scared, no one ever imagined, it never crossed my mind that my son would go through this, it was very difficult..." (Mother 6 - Fragment of Semi-structured Interview).

"[...] I despaired because my family never had this..." (Mother 11 - Fragment of Semi-structured Interview).

"[...] once upon a time, there was a very happy family, but one day they received very sad news, because their only daughter had a very serious illness. At that moment of the news, it seemed that the world was ending for that family..." (Mother 16 - Fragment of the story).

From the statements mentioned above, one can see the impact caused by the revelation of the disease, representing suffering, not only for the mothers, but also for the family. Upon discovering that they are the mother of a child with cancer, they experience feelings of sadness through the revelation of the unexpected news, besides facing the fragility of their child's life due to the disease. These participants' confrontations arise from the impact of the diagnosis of the disease, which causes family disruption, due to the need to leave home in search of treatment for the child affected by the disease, thus changing the environment and distancing the family. In spite of this, the involvement of the disease in the family group indicates a hard and complex experience, with uncertainties, several feelings, physical and psychological restrictions.[4]
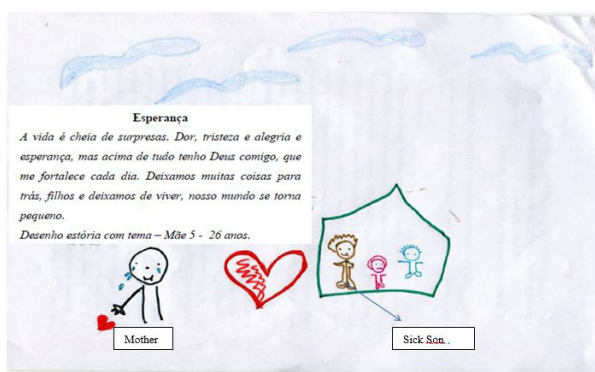
In this context, the social group under study expresses through their personal realities and shared experiences, several representations in common, such as shared feelings: the feeling of helplessness about the revelation of the disease and the fear of death, thus projecting the process of empathy.

Thus, SRs emerge as complex phenomena, always active and acting in social life, in the wealth of diverse elements, informative, cognitive, ideological, normative, beliefs, values, attitudes, opinions, image, among others.[6] Emphasizing the diagnosis, prognosis, and care of a child

with cancer, the conceptual universe, with its signs and symbols, is being formed and interacting with those that are already part of individuals.[12]

A scholar[13] states that social representations are immersed in daily communications, circulating in the statements, ideas, and images, materializando-se nas condutas, como pode ser evidenciado no grafismo (**Figura 1**).

Figure 1: Story drawing with theme. *Esperança. Itabuna- BA,* 2016.

By observing Figure 1, the graphic elaboration of the story drawing with theme, of the mother 5 reveals the terrifying representation before the diagnosis of cancer. The maternal figure is without hair, because a study[14] aborts that hair can be associated with the vital force of the woman. The impact of receiving the diagnosis of the disease is represented by the abandonment of vanity and, consequently, the maternal identification process of wanting to be in the place of the sick child, represented by the lack of hair on her, when it should be on the child affected by cancer, and also by placing herself outside the house in a vulnerable situation. Everything that is naturally the child's suffering, but that the mother unconsciously brings upon herself.

The mother figure allows herself to be without hair, but does not allow herself to see her son in the same condition. Perhaps in the mother's unconscious, the representation of being inside the house is to have protection, and outside the house to the vulnerability imposed by the disease. In a probable process of rationalization, the mother thus denies the illness condition of her son.[15]

Thus, the RS of this mother about her son with cancer is expressed in a drawing of herself, showing insignificance in the face of the disease, isolation from family and social life, evidenced by the graphic image with the absence of parts of her own body and a facial expression marked by sadness and pain.

Social representations seek in the symbolic elements that the individuals of a social group express their thoughts and conceptions, their opinions about a certain object that is relevant to this group. In this context, the social representations of these participants are immersed in everyday communications, circulating in discourses, ideas,

and images, materializing in the behaviors.[7]

Mothers' coping process for their child with câncer

In this category, it is evidenced the forms of coping that the participants take on the condition of being with a child affected by cancer, because they face difficulties related to the illness of the child, the fear itself for the loss of the child and the suffering of family estrangement. The participants develop coping mechanisms related to spirituality and family support. This coping process demonstrates that the phenomena permeate the strategies used by the participants in their daily lives with their children. Thus, it was possible to divide them into two (2) subcategories: Spirituality in the process of coping with the disease; and Family and social support in the disease process.

Spirituality in the process of coping with illness

In this first subcategory, it can be noticed that among the strategies of mothers with children with CA is the one of using spirituality as a way to face daily situations and continue taking care of their children. A strategy that arises in the face of great emotional destabilization, it appears as a resource that maintains the hope of the one who is suffering.16 In this way, it can be noted in the statements of this social group, mentioned below.

"[...] and I delivered into God's hands and my daughter is healed. I trust God a lot..." (Mother 11 - Fragment of Semi-structured Interview).

"[...] I ended up discovering that I have a faithful God, I also discovered that I have so much faith in God...Put God in front of everything in your life and you will see how He will put you above any obstacle. Faith, Family, Overcoming, sums up the moment I am going through..." (Mother 7 - Story Fragment).
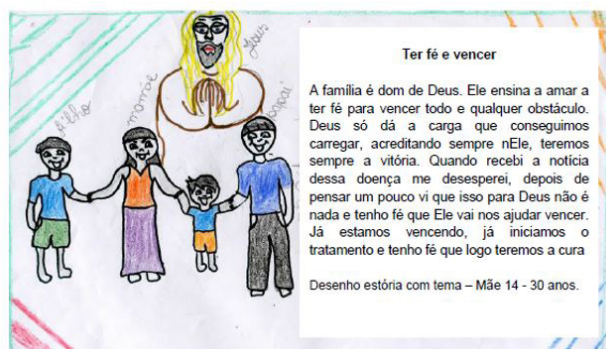
"[...] So I thank God and at no time was I afraid. The healing of my daughter, which is practically already near, com fé em Deus..."(Mãe 18 - Fragmento de Entrevista semiestruturada).

Through the statements of the participants, one can see that religiosity, faith in God is the way in which the social group uses to strengthen and assist in coping with the disease. The religious phenomenon plays the role of facilitating people's understanding of the inexplicable and the acceptance of what had never been imagined, in the case of limiting situations, as we can see in the case of cancer.[17]

Thus, the impact of having a child with cancer makes mothers create means of coping with the disease, and faith and hope in God influence the way the participants react and adapt to the new situation.[18] Spirituality emerges in the representations that this group carries about their children with CA, serving as an indispensable mechanism in the fight and coping with the disease.

In this sense, religious coping is defined when a subject turns as a way to deal with stress, different situations from their daily lives, the hopelessness generated by the diagnosis of the disease, the distance from their families, that is, these participants use the use of religious beliefs and behaviors to facilitate the resolution of problems and prevent or reduce negative emotional consequences,[19] as can be evidenced in the graphics of Figure 2, from the story drawing with the following theme.

Figure 2: Story drawing with theme. Have faith and win. Itabuna- BA, 2016.

In the graphic elaboration of figure 2 reveals a very religious imagery production, being represented by the protection of the figure of a superior being - Jesus Christ. The need to cling to spirituality arises with the purpose of obtaining strength to overcome obstacles, as the same refers in the story. The graphics show interconnected human figures, which suggests a connection between the characters, through the holding hands and smiling family members. And the affection constituted by linked hands: representing love. [20] Care is represented by acquiring responsibility and protection.

In this sense, the process of spirituality is based as an indispensable support for the construction of meanings in the lives of the participants and the family, such as hope, the healing of the child, and strength to bear the whole situation generated by the impact of the disease, as can be seen in the statements of the interviews below.

"[...] and I have a lot of faith in God that my son is going to be healed and we are going to win, the victory we are going to achieve..." (Mother 14 - Fragment of semi-structured interview).

"[...]God will give strength for my son's cure...". (Mother 15 - Fragment of semi-structured interview).

Family and social support in the disease process Family support is essential for mothers to find strength and help to face the disease. The SR of the mothers from the communicative elements allow the exchange of meanings about the family and the network of social support. This

support shows to be important for the coping of several situations experienced and family restructuring caused by the impact of the disease, as can be seen in the following statements.

"[...] I also thank my family who gave me support..." (Mother 2 -Fragment of semi-structured interview).

"[...] I have a united family that helps me in all the difficult moments and good moments...". (Mother 6 - Story Fragment).

"[...] My family helped me when I most needed it, during the difficulties I went through with my daughter. I only have to thank them for giving me a lot of strength and support...". (Mother 12 - Fragment of the story).

Through the testimonies of mothers 2, 6 and 12, the importance of family can be seen, which is fundamental for overcoming and coping with the disease, the support in the maintenance during treatment, and the well-being of the family group. The family appears as the main source of support and strength to face the disease. A study[21] emphasizes that the family plays the role of providing physical and emotional resources to maintain health and an indispensable support system at this time. Thus, the family is a social institution, which exerts great influence on the processes of SR formation that an individual carries, giving them their own cultural values to which they are inserted. [22]

Facing the disease, the participants talk to other mothers who share the same reality of having a child diagnosed and treated for cancer, leaving them more comforted and stronger to deal with the therapeutic process, as can be seen in the following statements.

"[...] and having people giving us strength is the best thing that can happen..." (Mother 3-Fragment of Semi-Structured Interview).

"[...] but I was strengthened by the stories of other mothers...". (Mother 15 - Fragment of semi-structured interview).

Therefore, the testimonies show the importance of social support, especially in the phase of the diagnosis of the disease, when mothers and family members are distressed. The communication established among this social group somehow represents a comfort and helps in the process of care and coexistence, forming a network of social support.[24] In this sense, the social support contributes to help these mothers to face the new context established, thus performing the identity function of social representations. This identity allows protection, safeguarding the positive image of these mothers, [25] which is necessary to face the process of the child's illness.

In this context, it is understood that in these daily relationships and family interactions, the conceptual universes, particular to the social reality that are being formed and gaining consistency, become part of these subjects, in common sense theory, guiding the individual's conduct in the social world, their values, and social aspirations. [26]

Thus, the family represents one of the main institutions that help in the process of coping with the disease, which is part of a core called social support. [19]

CONCLUSIONS

It was evidenced how these mothers deal with the confrontations of the routine of caring for these children. From this perspective, in an attempt to adapt to the new social reality imposed by the discovery of the disease, the social group under study faces a new routine, with changes in their relationships. The confrontations experienced by these participants go through cognitive and behavioral modifications, such as: spirituality and family and social support, among others, which were reported by the participants.

It is concluded that the Social Representations of this social group in facing the child with cancer are influenced by the presence of the health and disease process of their children and by the changes and confrontations that modify their conceptual universes and guide their behaviors, within the family context in the care of their children. It is worth highlighting the changes that are provided to these participants, experiences and communicative interactions, to which new concepts and meanings are incorporated into the daily life of these individuals, guiding their practices in the family group through the care of the child with cancer.

In this context, the present study signals the importance of new studies, with the purpose of favoring a reflection about the confrontations and experiences from a look directed to these caregivers, in order to provide them with better conditions to deal with the problems and confrontations arising from this social reality.

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