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Social support as a coping strategy for the family of children and adolescents with câncer

Suporte social como estratégia de enfrentamento da família de crianças e adolescentes com câncer

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ABSTRACT

To describe how social support networks help the family in coping with childhood cancer. A qualitative study, based on the Social conceptual framework, with family members of children and adolescents with cancer, treated at a pediatric oncology outpatient clinic of a public hospital in a municipality in the state of Mato Grosso do Sul. A semi-structured, audio-recorded interview with enhanced Content Analysis was conducted. The social support networks that help the family are characterized by the bonds created from the child's illness experience, evidenced by the interpersonal relationships between family members, the health team and other families living in similar situations; by spirituality and the information received. When identifying the importance of networks for families, it is highlighted the importance of strengthening care practices in which the family is the protagonist of care.

Keywords: Social Support. Pediatric Nursing. Nursing. Family. Medical Oncology.

RESUMO

Descrever como as redes de suporte social auxiliam a família no enfrentamento do câncer infantojuvenil. Estudo qualitativo, fundamentado no referencial conceitual Suporte Social, com familiares de crianças e adolescentes com câncer, atendidos em ambulatório de oncologia pediátrica de um hospital público em um município do Mato Grosso do Sul. Realizou-se entrevista semiestruturada, áudio-gravada, submetida à Análise de Conteúdo. As redes de suporte social que auxiliam a família são caracterizadas pelos vínculos criados a partir da experiência de adoecimento da criança, evidenciados pelo relacionamento interpessoal entre os membros da família, equipe de saúde e com outras famílias que vivem situações similares; pela espiritualidade e pelas informações recebidas. Ao identificar a importância das redes para as famílias evidencia-se a importância do fortalecimento de práticas de cuidado em que a família é protagonista do cuidado.

Palavras-chaves: Apoio social. Enfermagem pediátrica. Enfermagem. Família. Oncologia.

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INTRODUCTION

Cancer in children and adolescents has represented the leading cause of death from disease in children and adolescents aged 1 to 19 years. Estimates indicate that about 215,000 cases are diagnosed in children under 15 years of age.[1] In several countries around the world, including Brazil, there is progress in terms of therapy and early diagnosis, and much is discussed regarding the use of less aggressive and more effective treatments.

However, since the diagnosis, the family suffers emotional impacts on its structure and functionality. During treatment, the family seeks balance for decision-making and strategies that help them to cope with stressful situations and negative feelings. Therefore, families need to feel welcomed and strengthened.[2]

In this context, it is important to reinforce family relationships and social interactions, as they provide important support during times of crisis and to promote family resilience. Support can be composed of social networks - a set of significant systems and people - in which established relationships allow the emergence of supportive and support networks.[3]

The health professional has been appointed as a support reference for families, who experience special health conditions for their children, especially as informational, spiritual, emotional, material support, and for child care. They must ensure quality care with a patient- and family-centered approach, and seek to support them in the multiple situations triggered by the child's illness.[4]

Professional experience and readings on the subject refer to the challenges faced by the family of children and adolescents with cancer and the question about what are the social support networks accessed by the family during the treatment of cancer in children and adolescents? In this perspective, the present study aimed to describe how social support networks help the family in coping with cancer in children and adolescents.

METHODOLOGY

This was a descriptive, qualitative study, developed in accordance with the criteria established by the Consolidated Criteria for Reporting Qualitative Research (COREQ)[5] and approved by the Research Ethics Committee of the Federal University of Mato Grosso do Sul, under the opinion 2.038.691.

The study was carried out in a pediatric oncology outpatient clinic of a public teaching hospital in a municipality in the state of Mato Grosso do Sul. Participants were family members who met the inclusion criteria, which consisted of families of children/adolescents diagnosed with cancer undergoing chemotherapy, between August and September 2017. Regarding the exclusion criteria, participants who had no bond with the child/adolescent during treatment and family members whose children/adolescents were in critical clinical situations and/or at the end of life were excluded.

For this study, the classification of children and adolescents suggested by the Ministry of Health[5] was adopted, and family, the definition of "who its members say they are"[6].

Data were collected by semi-structured, individual interviews with a family member of the child or adolescent, by the main researcher, in a reserved room at previously agreed times. Upon acceptance, participants signed an Informed Consent in two copies: one copy owned by the researcher and another by the participant.

The script used consisted of building a genogram and ecomap of the family, in order to identify the family structure and the networks accessed by it. Then the guiding question was triggered: What do you believe has supported you during the treatment of (name of child/adolescent)? What do you consider to be essential at this point in the treatment of (name of child/adolescent)?

For data analysis, the interviews were transcribed in full, on the same day they were held. Each family member received the letter "E", followed by the natural number in the sequence of interviews, such as, for example, E1, to designate the interview. Subsequently, they were manually subjected to content analysis, going through the stages of pre-analysis, material exploration, treatment of results and interpretation.[7]

In the pre-analysis, the organization of data and readings of the interviews was carried out, identifying the units of meaning. For the exploration of the material, the grouping of codes was used, forming provisional categories. Thus, according to the similarities, categories and subcategories were formed, which passed to the stage of data processing and interpretation in light of the conceptual framework of social support.[7-8]

The conceptual framework of social support guided the data analysis. Social support is defined as the actions in which a person's social needs are met through their interaction with other instruments, as well as the social bonds individuals create with other individuals, groups, or communities.[8]

The social support framework promulgates four types of support: emotional support - represented by actions of care and empathy between people and by the network of friendships; information support - characterized by the existence of people and institutions providing clarification and information, as well as being sources of knowledge; material support - from the provision of financial resources, material and physical assistance; and evaluation support, which provides suggestions, praise and affirmations about the way the person is acting.[9-10] The choice of this reference allowed conducting the interpretation of the data related to the supports made available by society and accessed by the family to meet their demands, in the context of coping with childhood cancer.

RESULTS

Of the six family members of children and adolescents who are followed up by the pediatric oncology sector, five (82%) are mothers and one (18%) is a father. Of these, four are married or live in a stable relationship (66.6%) and two (33.3%) are divorced. The average age of participants was 37 years old, ranging from 31 to 46 years old. Five reported a family history of cancer (grandparents and uncles), and all cases evolved to death.

The average treatment time for children and/or adolescents was seven months, ranging from six months to three years. As for the medical diagnosis, three children/adolescents were diagnosed with a Central Nervous System tumor (Astrocytoma, Optic pathway gliomas, low-grade Medulloblastoma), one with Acute Lymphoid Leukemia (ALL), one with Willms Tumor and one with Osteosarcoma. The average age of the children was six years old, ranging from two to 13 years old.

Of the participants, three families live in the interior of the state of Mato Grosso do Sul and the others live in the capital; in addition to four living in their own house, one borrowed and one in a rented house. The city halls of municipalities far from the capital are responsible for the cost of transporting the child/adolescent and family member to the health institution, where the treatment is carried out.

Regarding the parents' employment, one is on sick leave, two are unemployed and three are housewives. The family income of the interviewees ranged between one thousand and seven thousand reais, with an average of R$1,766.00, and two (33.2%) did not know about it. As for the benefits, three (50%) receive a minimum wage for the treatment of the child, one (16.6%) receives a child benefit and income vouchers and one (16.6%) receives a school allowance, all of which come from the federal government.

Their respective genograms and ecomaps were constructed together with the participating family members, for a better interpretation of the family structure and visualization of their social support networks. On family composition: three families are made up of parents and siblings, one, of parents and an only child, and two of mothers and children. The number of children per family ranged from one to four, with an average of three children. As a family leisure activity, the participants cited: visits to family members; fishing, going to church, shopping and to parties promoted by the support center for children and adolescents with cancer and their families, and walking in the town squares where they live.

After constructing the genogram and ecomap, interviews were held, which lasted an average of 40 minutes. From the content analysis, four categories emerged: 1) Interpersonal relationship as a support for the treatment of the child/adolescent with cancer, composed of two subcategories: the hospital environment as support, and the family as the foundation of care; 2) Instrumental support as a facilitating mechanism in aiding the treatment of the disease, consisting of three subcategories: family support as an aid in times of fragility, social media for fundraising, and public policies for financial assistance; 3) Spirituality and religiosity as family strengthening factors; 4) Information as a foundation for coping with the disease by the family. 3) Spirituality and religiosity as family strengthening factors; 4) Information as a foundation for coping with the disease by the family.

CATEGORY I: INTERPERSONAL RELATIONSHIP AS A SUPPORT FOR THE TREATMENT OF THE CHILD WITH CANCER

In this category, topics related to the relationship of family members with the health team and their extended family are addressed. It portrays the means that family members have found to face the obstacles generated by the child's health condition. The interpersonal relationship is used as a social network to overcome the situation experienced and, consequently, interferes with the family's coping. In addition, it enables the sharing of information, doubts, anxieties, and afflictions among close people.

In the hospital environment, the interpersonal relationship is characterized by conversations with the health team and with families who experience similar situations, while in the family environment, it is characterized by the interaction between members.

The hospital environment as support

In this subcategory, the interpersonal relationship between parents of children/adolescents with cancer is evidenced, as a source of support for the treatment of the child. The relationship discussed was restricted to the hospital environment, characterized by the relationship between parents and the health team and other family members who experience similar situations.

The family members perceive that the health team provides support, through conversations about topics related to the health of the child/adolescent and the treatment of the disease, and they evaluate this attitude as beneficial, reporting that they are satisfied with the service provided, which can be exemplified by the speeches below:

> *They talk to me a lot, try to cheer me up and support me when I need it, I am satisfied with their work, for me, here today, I am well assisted.* (E1)
> *They* [nurses] *are a support. Because when we discover cancer in a child. You will feel it, we fall apart. In the old days, if you said you had cancer, you would die, right?! Nowadays, no [..] there is a psychologist either, she comes to talk to you in your room.* (E2)
> *The Nurse helps a lot. She talks to the parents, explains everything that will happen. It is all straightforward.* (E3)
> *Yes, it helps a lot. I understand everything.* (E5)

Regarding the diagnosis of the disease, family members claim that the health professional should be sincere and clear when informing about the disease.

> *There is no other way but to speak. It must be realistic. I prefer....* (E2)

The interaction between family members who experience a similar disease situation is an effective therapeutic measure, as families believe that there is an exchange of experiences in relation to the care of the child/adolescent and the possibility of addressing other issues that are not only related to the illness.

In addition, it was possible to show that conversation circles, created by the health team, have been a support tool for families, as it allows family members to know the situation of the other and develop their own coping mechanisms in the face of adversity.

> *The psychologist holds a conversation circle and there we see each other's situation and find the strength to continue....* (E1)
> *When there are a lot of people, time passes so quickly. We are talking and I do not even see it. We are talking about crochet.* (E2)

Family as the foundation of care

Each family organizes itself and adopts a flexible dynamics to handle and help in the care of the sick child/adolescent, so that the members establish certain roles. In the care trajectory, interactions can be strengthened or weakened according to the experience of each member. Some family members play an active role in providing help, while others have more difficulty in participating in the child's care.

> *Those who help me the most are my mother-in-law, my mother, and my brothers. My mother not so much. After my dad died, she*

> *got a little crazy. My father helped the most.* (E2)
> *My brothers are more attached to him* [child] *than to me. They help with everything.* (E3)
> *My Aunt* [is the one who helps]. *In fact, she is my adoptive mother, I did not live with my biological mother.* (E5)

The family relationship undergoes some changes after the cancer diagnosis, in which some bonds are intensified and others are weakened. In one of the cases, the marital relationship remained unshaken and the husband left his formal job to take care of the house and children. Often the mother prioritizes the child's well-being over her own.

> *My husband is very affectionate with the children, the family relationship is also very good, we are united... I have nothing to complain about. He is a very good person and very affectionate with his children. He is not an aggressive person. He is a good father; he pays attention to the children and to me. As a husband he is great.* (E3)

Family members try to be more present, for example, constantly calling in search of news about the sick child and, when necessary, protecting and calming. In addition, it was evident that the people who help may or may not be people close to the family. Even going through changes after the diagnosis of the disease, family members unite and strengthen themselves in the face of difficulties, showing affection with each other.

> *They are very concerned about her; they call constantly to find out what is going on with her. When I am anxious or stressed, they calm me down and say that in the end everything will work out... The people closest to my family are my mother, my brothers, sisters, the staff at the old restaurant where I worked.* (E1)
> *The relationship between family members changed a lot after the diagnosis of the disease, when he was good* [healthy] *people did not get involved, they did not get too attached, it changed a lot.* (E4)

CATEGORY II – INSTRUMENTAL SUPPORT AS A FACILITATING MECHANISM IN AIDING THE TREATMENT OF THE DISEASE

Instrumental support refers to material help from the extended family, external assistance, and fundraising via social media, which help the family during the treatment of the child/adolescent.

Family support as an aid in times of fragility

The help from family members is essential to face situations of social vulnerability experienced by these families, who experience concerns regarding the financial situation that is impacted by the care demands of the child/adolescent. In view of this, some family members assume financial responsibilities, which vary according to the need presented, such as, for example: purchasing clothes for the child/adolescent, transporting the family, preparing special meals, paying rent, purchasing medication, and buying food to the family.

> *The support we receive comes from our family, the income I have today is R$ 500.00 from the pension, my mother pays rent, food, and medication for her granddaughter*. (E1)
> *His grandfather helps a lot, he buys a lot of things for his grandchildren, like clothes and shoes. I do not even worry, because he always buys... even retired, he helps a lot. He works to bring things to the boys. It is great.* [...] *I have nothing to complain about my mother. I love her so much. She does everything, she cooks food for my children every day. She defends her children and grandchildren from everything.* (E3)
> *The help we receive is only from my family, who helps is my son, the baby's brother, he helps when he donates some things that the baby needs. L.* [brother], *when necessary, he calls the UBER to take us.* (E6)

Social media for fundraising

In the therapeutic trajectory, families recognize the influence of social media in helping to treat children/adolescents with cancer. In order to supplement the family's income and/or meet the needs presented, families use electronic media to publicize charitable events to raise monetary funds, which help them in the acquisition of medicines, examinations and/or acquisition of orthopedic materials.

However, these events often do not cover all expenses and the family is left with debts due to the treatment. The social media used are: television programs, radio programs, facebook, instagram and whatsapp. However, some families choose to preserve the image of the child/adolescent, using private electronic means; others fail to use specific media, due to negative experiences, and there are examples of parents who are not comfortable with the idea of exposing their child's case on social media.

> *My family organizes charity events and some charitable things to help, they use the internet, facebook, radio in the city to publicize it. We did an event in January; on this Saturday, there was a beans and pork, and in June, there was a bazaar in Maracaju, to help K.* [adolescent] *[...] the events do not give enough return, because the expenses are high, I already got into debt in the onset of the disease and depending on the bank so that he could perform all the examinations.* (E1)
> *We had a charity lunch for K.* [adolescent] a*nd then we shared it on facebook. Just once.* (E2)
> *My friends held an event for M.* [child], *it was publicized by the TV report. Some people helped with food. However, many people promised that they would help us with the construction of the house, but they did not help at all. They just promised, I will not advertise it on television anymore.* (E3)
> *No, I never disclosed my son on social media, only once did his mother post it on facebook and I*

> *got mad, because we do not need to expose the child like that to ask for help, today if someone puts him up, I'll sue.* (E4)
> *From a charity event, we already prepared a charity lunch, when we discovered the disease. But I only disclosed it on Whatsapp, I did not want to expose D.* [child]. *Then we got the money, I even used it in the MRI. It helped a lot.* (E5)

Public policies for financial assistance

The family seeks public policies that help supplement the family income and, consequently, obtain material for the treatment of the child/adolescent. Through the reports, situations of vulnerability caused by the insufficiency and/or absence of material resources are identified. As a result of bureaucratic obstacles, some aid intended for these families is barred and/or the waiting time is prolonged.

The aid mentioned by the interviewees is characterized by a financial transfer in the amount of the current wage, destined by the federal government to children/adolescents who are undergoing antineoplastic treatment. Some families receive the aid, others are with the process in progress and there are those who do not receive it, as they do not fit the requirements established by the government. Regarding the assistance offered by municipal bodies, the interviewees mention the support related to transportation and accommodation in the city where the child undergoes treatment.

> *We did not receive any aid, in this case, we applied for aid, but they denied it because of my per capita income, which was very high. So now that I entered again, and reformulated what I earned to be able to apply.* (E1)
> *Maracaju City Hall is responsible for paying for transportation and a support house to stay in Campo Grande.* (E2)
> *Yes, I receive help, help during K.'s treatment, but when the treatment is over, they cut it, this help is a minimum wage.* (E4)
> *We have not received any aid yet; my daughter's retirement is about to come out.* (E6)

CATEGORY III – *SPIRITUALITY AND RELIGIOSITY AS FAMILY STRENGTHENING FACTORS*

Religion and spirituality are important foundations in moments of fragility. Faith is considered a source of hope and support for the families of children/adolescents with cancer. Through the reports, it appears that church members support families through home visits, conversations, and prayers. In addition, all respondents reported attending church, some daily, others sporadically.

> *I attend church rarely, once a month or so.* (E1)
> *I go to the church for support and my family to each other.* (E2)
> *Yes, I go to church, they visit D.* [child], *they go to talk, say a prayer, a rosary.* (E5)
> *Yes, I do go to church, my daughter encourages me to go.* (E6)
> *I go to church; I go every day.* (E4)

Respondents mention fear of God and believe that faith acts as a refuge and basis for overcoming the difficulties experienced.

> *I have the fear of God in my life.* (E1)
> *God, who gives me strength and helps me to overcome difficulties.* (E1)
> *Faith belongs to us. People must overcome. If we get discouraged, it discourages the patient who has cancer even more. It is God.* (E2)

CATEGORY IV- INFORMATION AS A FOUNDATION FOR COPING WITH THE DISEASE BY THE FAMILY

Families access information through social media, health institutions and through sharing information between parents who experience the same situation. Parents also use electronic media as a source of research, to find out about the disease and the treatment of the child/adolescent.

> *Yes, I use the internet a lot. I research a lot about the disease.* (E2)
> *L. and C.* [children] *have internet and they research things when they need to, about the baby's illness.* (E6)
> *Yes, I use the internet, I read the news to stay informed about the disease* (E5).

Family members also seek information from the health team and other parents. They realize that the information acquired in the hospital environment helps in coping with the situation and managing the care of the child/adolescent. For respondents, it is important when the team talks to family members and provides information regarding the disease and treatment.

> *They explain everything right* [about the disease] (E2).
> *The nurse helps a lot. She talks to the parents, explains everything that will happen. It is all right... I do not like to ask the health team for anything, I am very reserved. I think they help me a lot* (E3).

The hospital's nursing staff, in partnership with university professors and students, carries out projects in the pediatric oncology sector, which aim to provide care to families who experience situations of chronic illness, mainly related to childhood cancer. The project's activities help families in coping with, through conversation circles and explanations about the child/adolescent's illness.

> *The project nurse helps by talking and explaining everything about the child's illness.* (E5)

DISCUSSION

In this study, the families' narratives allowed to identify the social, emotional, informative, and instrumental support accessed by them to copy with the disease. According to the literature, emotional support is related to feelings of love, affection, empathy, and respect;

information, suggestions, information, advice, and opinions received; the instrumental, financial support, time dedicated to the child's therapy, the provision of resources, goods and services during therapy. There is also spiritual and psychosocial support, which can be offered to sick children/adolescents and their families.[11-12]

The literature points out that the social network helps families in coping with adversities that arise during the chronic illness, favoring the family's adaptation to the new reality, making it less traumatic.[8] The disease can weaken previously established family bonds[7], which contradicts the results found in this study, in which families reported strengthening bonds.

Instrumental support refers to financial aid and all practical help or assistance coming from external sources.[11] As in this study, other findings in the literature also reflect the difficulties of family members in carrying out their work activities and providing care to the sick child/adolescent, with the need to leave work to accompany the child.[8-12]

As cancer has a long-lasting treatment, with side effects and recurrent hospitalizations, availability of resources is required, which burden the family budget. Results described in a literature review corroborate this finding by emphasizing how the impact of treatment is related to increased expenses with the disease; they are exhausting, mainly those caused by commuting to the hospital and the impossibility of carrying out work activities.[13]

In this research, it was evidenced that part of the family members interviewed receive government benefits to solve the financial problem. Others, as a result of bureaucratic obstacles, claim that the financial transfer is being barred and/or the waiting time for receipt is being prolonged and, due to this situation, they experience moments of financial difficulties.

In this context, as a measure to supplement income and reduce the economic impact of the disease, the federal government seeks to provide better conditions for children and their families during cancer treatment. Among the rights for children and adolescents, the Organic Law of Social Assistance (LOAS) stands out, which guarantees a minimum wage benefit to children from zero to ten years old, and adolescents from 12 to 18 years old. Therefore, it is essential that the family income is less than a quarter of the minimum wage, and this calculation is based on the number of people living in the household.[14]

Social media were also cited as an instrument for supplementing income or supplying specific expenses for the child/adolescent, such as the purchase of medication, orthopedic materials, or examinations. Electronic means are used to publicize charity events, in which the situation experienced, the description of the charity event and the amount to be collected are presented. In the national literature, no published research on this topic was found, standing out as a differential of this study and which requires future research.

Changes in the functionality and daily life of families caused by the disease drive the search for coping strategies, which can also be found in religious and spiritual practices. Studies carried out with families of children towards the diagnosis of childhood cancer showed that religion helped to strengthen hope and faith.[15-16]

Informative support, such as sharing knowledge through guidance to the family/individual or research in the different means available, takes place naturally. Health professionals are a source of informational support, providing the articulation of information in a clear, objective, and repeated way, to ensure a real understanding of the guidelines shared and accessed.[1]

The health team should provide parents with the security to develop a positive view of the care process, minimizing anxiety and fear of the unknown.[17] Informational support in the hospital environment aims to clarify the doubts of families. Health literacy must be exercised by all health professionals, in order to allow the strengthening of people's knowledge, motivations, and skills to be able to understand what happens to them, assess the situation, and use the information acquired, in order to be able to make decisions and judge what is relevant and feasible in their daily lives, regarding health care to maintain and improve their quality of life, as well as adhere to treatment.[18]

In this sense, literacy must be incorporated into professional practice, not only as the act of people reading and understanding information, but also as a means of assuming responsibility for health, empowering themselves and becoming resilient in the face of situations caused by illness.[18]

A study carried out with families of children diagnosed with retinoblastoma revealed that, despite communication between the family and health professionals, the information is still available in an incomplete and fragmented way.[19] The information was recognized by the family as informative support when the time is respected, there is honesty, includes information about the disease, treatment, prognosis and perspectives for the future, and it has a dialogical space to welcome and clarify existing doubts.

The limitations of this study are related to the performance of data collection in a single health institution, in each reality, whose family members were accompanying the child/adolescent with cancer in the hospital environment.

CONCLUSION

This study made it possible to identify the social networks that help the family of the child/adolescent with cancer in coping with and highlights their role and subsidies for families to overcome their difficulties during the diagnostic and therapeutic journey.

Social networks were characterized by social interaction between people and through these interactions, support networks emerged: instrumental, religious, and informative. This study points to the importance of professionals knowing who and what the support networks are, as well as valuing the support coming from their own family, extended family, friends, acquaintances, co-workers, hospital staff and community members, as this network helps the family throughout the course of the child/adolescent's illness.

The present study provides subsidies for health professionals to incorporate care models in their practices that have the family as the protagonist of care, and encourage spaces for dialogue within health services, in addition to the construction of informative material, such as support and welcoming spaces.

This study points to the need for the development of new research covering other contexts and situations experienced by families of children/adolescents with cancer, mainly related to the influences of electronic media on the daily life of the family that experiences the diagnosis of cancer in children and adolescents, since there were few studies on this topic in the literature.

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