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STRATEGIES USED BY FAMILY CAREGIVERS TO PROMOTE WELL-BEING OF CHILDREN IN CHEMOTHERAPEUTIC TREATMENT

ESTRATÉGIAS UTILIZADAS POR FAMILIARES CUIDADORES PARA PROMOVER O BEM-ESTAR DE CRIANÇAS EM TRATAMENTO QUIMIOTERÁPICO

ESTRATEGIAS UTILIZADAS POR FAMILIARES CUIDADORES PARA PROMOVER EL BIEN ESTAR DE NIÑOS EN TRATAMIENTO QUIMIOTERÁPICO

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ABSTRACT

Objective: to understand the strategies used by family caregivers to promote the well-being of children with cancer in chemotherapy treatment. **Method:** this is a qualitative, descriptive and exploratory study, carried out with seven relatives of children with cancer undergoing chemotherapy. The data were collected by recorded interview, performed at home, submitted to the Content Analysis Technique, Thematic Analysis modality. **Results:** two thematic categories emerged: "Care taken to confront the disease" and "Repercussions arising from family care". **Conclusion:** apprehending family adaptations in the context of having a child with cancer shows the importance of working in a singular and humanized way in family-centered care, leading us to not merely assist them in a technical and scientific way, but also to listen to their longings, fears, doubts and contemplate their biopsychosocial needs. **Descriptors:** Nursing Care; Child Care; Family Relations; Caregivers.

RESUMO

Objetivo: apreender as estratégias utilizadas por familiares cuidadores para promover o bem-estar de crianças com câncer em tratamento quimioterápico. **Método:** estudo qualitativo, descritivo e exploratório, realizado com sete familiares de crianças com câncer em tratamento quimioterápico. Os dados foram coletados por meio de entrevista gravada, realizada no domicílio, submetido à Técnica de Análise de Conteúdo modalidade Análise Temática. **Resultados:** emergiram duas categorias temáticas: << Cuidados adotados para o enfrentamento da doença >> e << Repercussões decorrentes do cuidado familiar >>. **Conclusão:** apreender as adaptações familiares no contexto de ter uma criança com câncer mostra a importância de trabalhar de forma singular e humanizada no cuidado centrado na família, levando-nos a não os assistir meramente de forma técnica e científica, mas também a ouvir seus anseios, medos, dúvidas e contemplar suas necessidades biopsicossociais. **Descritores:** Cuidados de Enfermagem; Cuidado da Criança; Relações Familiares; Cuidadores.

RESUMEN

Objetivo: apreender las estrategias utilizadas por familiares cuidadores para promover el bien estar de niños con cáncer en tratamiento quimioterapéutico. **Método:** estudio cualitativo, descriptivo y exploratorio, realizado con siete familiares de niños con cáncer en tratamiento quimioterapéutico. Los datos fueron recogidos por medio de entrevista grabada, realizada en domicilio, sometido a la Técnica de Análisis de Contenido modalidad Análisis Temática. **Resultados:** surgieron dos categorías temáticas: << Cuidados adoptados para el enfrentamiento del niño >> y << Repercusiones decurrentes del cuidado familiar >>. **Conclusión:** apreender las adaptaciones familiares en el contexto de tener un niño con cáncer muestra la importancia de trabajar de forma singular y humanizada en el cuidado centrado en la familia, llevándonos a no asistirlas meramente de forma técnica y científica, pero también a oír sus anhelos, miedos, dudas y contemplar sus necesidades biopsicosociales. **Descriptores:** Atención de Enfermeira; Cuidado del Niño; Relaciones Familiares; Cuidadores.

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INTRODUCTION

Cancer has a negative impact on the lives of individuals, coming from their social and economic repercussions, but also from the emotional wear the patient and his family are exposed. Although in many situations cancer can be cured, especially when diagnosed early, it remains socially stigmatized with doubts and sufferings. This illness causes a series of weaknesses in the life of the patient, implying in conditions of dependencies that generate the need of a caregiver.¹

There are 420,310 new cases of cancer estimated for 2016 in Brazil, about 3% (12,600 cases) will occur in children and adolescents up to 19 years old. Among childhood cancers, the most common is leukemia (about 25% to 35% of cases), followed by lymphomas and tumors of the nervous system.²

To meet these estimates, advances in the area of molecular biology and magnetic resonance have provided optimization of effective therapeutic plans favoring the development of the prognosis of childhood cancers. Currently, treatments include surgical procedures, chemotherapy, radiotherapy and immunotherapy, which can be performed individually or in combination.³

Due to the high incidence of hematological cancers in this age group, chemotherapy is the type of treatment most used in childhood, despite the numerous side effect. The most frequent effects are apathy, inappetence, weight loss, alopecia, bruising, nasal and buccal bleeding, nausea, vomiting, and diarrhea. Chemotherapy can also cause hematopoietic tissue damage, trigger low immunity, and increase morbidity and mortality through infectious processes.⁴ Thus, childhood cancer is considered a devastating event, causing unexpected transformations and reactions, not only in the patient's life, also in the lives of all who surround him, passing the parents to have a hard experience, which is full of pain and despair.⁵

The vicissitudes caused by cancer to the patient and his family have been present in the literature for several decades. However, there is now a tendency for responsibility for patient care to be transferred directly to the family, increasing family responsibility for patient care.⁵

The family constitutes a significant support network for cancer patients, especially in the case of children, since the patient does not face the problem alone, needing support to confront the process of fighting the disease.⁶

The relative plays a primordial and beneficial role in the involvement and permanence with the child with cancer, acting in the development of actions of well-being and in the recovery of health. The management of symptoms and the approach to home care, attributed in this study by the mothers of children undergoing chemotherapeutic treatment, presented a great challenge, both for the child and for the family, by providing relief of symptoms, improvement in quality of life and to reconcile the care offered by the family caregiver with the medical treatment.⁷

However, having a child with cancer represents an extremely debilitating event for the parents, capable of compromising various aspects of their lives.⁸ Complications and treatment intensity are rarely modifiable, leading them to face a reality of threats characterized by separations, losses, frustrations, and changes from the onset of illness.⁹

Values, prior knowledge, family history, and treatment expectations interfere with how the family caregiver deals with the illness. Knowing the reactions, the feelings of relatives of patients who receive the diagnosis of cancer and the strategies they adopt in the home environment to deal with this situation can contribute to the development of clinical practices that reduce the suffering of both and improve their quality of life.⁸

There is a range of research in the literature addressing the experiences and perceptions of caregivers about the context of childhood cancer in the family environment. However, there is a gap in the main sources of scientific knowledge (SCIELO, BIREME, VHL, LILACS) of studies that show the care strategies adopted by families to cope with the disease. In this context, the question that guided this research was: "What are the strategies used by family caregivers of children with cancer in chemotherapy to improve their quality of life and well-being?"

OBJECTIVE

- To apprehend the strategies used by family caregivers to promote the well-being of children undergoing chemotherapy.

MÉTHOD

This is a qualitative, descriptive, exploratory study.¹⁰⁻¹ Family members living with cancer in chemotherapy were enrolled in a philanthropic institution to support cancer patients and their families, located in a municipality in the northwest of Paraná. The

entity assists patients of the low financial condition, providing nursing services, physiotherapy, psychology, pharmacy, social assistance and legal advice.

The registry of all pediatric patients with cancer under chemotherapy treatment was initially established at the institution to have access to the study subjects. Thus, the age range from 0 to 11 years old, 11 months and 29 days, established by the Child and Adolescent Statute was used as a parameter.¹² Afterwards, a caregiver was selected who had a strong family bond with the child (inbred or emotional ties), who were 18 years old or older and accompanied the child in cancer treatment for a minimum period of three months, and who resided in the municipality of Maringá-Paraná.

Three of the 11 subjects who met the criteria for participating in the study were unable to establish contact due to address change and one refused to participate in the study, totaling seven participants. After the previous contact with each family member via telephone and accepted to participate in the research, the best time was set for the interview in their homes according to their availability.

Data were collected in May 2014 through an open interview recorded on digital media. These had an average duration of 25 minutes, using a questionnaire, addressing sociodemographic characterization data and the following guiding question: "Tell me how it is to care for a child with cancer in chemotherapy treatment."

The statements issued were transcribed in full and the reports were analyzed through the thematic content analysis. This method is developed from the phases of pre-analysis, material exploration, treatment and interpretation of the results. In the first phase or pre-analysis, detailed readings of the testimonies of the relatives of the children in chemotherapy treatment were carried out to raise the relevant points. Subsequently, in the second phase, the material was exploited by means of exhaustive readings of each deposition and the raw data were transformed systematically and aggregated into thematic units. In the last step, the stage of treatment and interpretation of results, the categorization was performed, based on the classification of the elements according to similarities and differences, with the subsequent regrouping according to common characteristics¹⁰, thus emerging two thematic categories: "Care taken to cope with the treatment process" and "Repercussions arising from family care".

In compliance with the ethical precepts disciplined by Resolution 466/2012 of the National Health Council, the study was appraised and approved by the Standing Committee on Ethics and Research with Human Beings of the State University of Maringá under Opinion Number 667.943/2014. All the subjects were oriented on the ethical precepts involving the research and signed the Term of Free and Informed Consent in two ways.

Avoiding generic names, names of flowers (Rosa, Orquídea, Margarida, Azaleia, Dália, Tulipa, and Lírio) were used as pseudonyms.

RESULTS AND DISCUSSION

Seven of the relatives of children aged 3 to 10 years in chemotherapy treatment participated in the study, being four males and three females. Only three attended school. As for the medical diagnosis, five had Acute Lymphoid Leukemia, a Multifocal Histiocytosis, and a Caroma in the Choroid Plexus.

The seven family caregivers interviewed were all female and the mothers of the children. Their ages ranged from 32 to 47, six were married and one single. Among them, two had completed elementary education, three complete high schools, and two complete higher education. According to the occupation, two worked and five were currently unemployed. Most of the deponents had a family income of one to two minimum wages and one of them had an income of two to five minimum wages.

From the exploration and analysis of the statements, the thematic categories emerged:

♦ Care taken to cope with the treatment process

From the analysis of the testimonies, it was possible to identify and apprehend the feelings experienced by caregivers during the course of their child's illness, as well as the comfort strategies adopted by their families to cope with the chemotherapy treatment process and to maintain the daily activities of the child.

Cancer triggers changes in the health of the family as a whole, to a greater or lesser degree, so family members are directly affected by the adversities arising from the disease.¹² When there is a family that suffers from cancer, all other family members are subject to stress and anxiety.¹³ We must also consider that when care is transferred to the home, it becomes an opening portal in which reveals the daily life of families or people living under the same roof.¹⁴

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The important thing is that we try to make him feel that he is not a victim of the disease, he needs to interact with others. (Dália)

We leave him quite at home, he plays with ease. We try to make him have a normal and more comfortable life. The days that he can leave or if there is any child that we know is not going to school and he is not sick, we let her come and play with him. Because he feels very happy when we do this. (Tulipa)

Caregivers seek ways to keep their children motivated so they do not feel stigmatized by the disease and continue to face the treatment process. For this, they use different resources in an attempt to promote this motivation, such as dialogue, emotional support, and adaptations in the social environment.

There are many changes manifested in the family with the presence of a child with cancer, requiring families to reorganize in different dimensions. The intrinsic aspects of the experiences of parents of children with cancer, who have already passed or who are undergoing treatment and who have experienced the changes that have occurred in family life, lead them to desire not only the control of the disease, but above all, the cure to ease the suffering of the child.¹⁵

We woke up in the morning when we had to go to the hospital and I say, "let's choose the most beautiful clothes you have in the wardrobe because you're going to have to go to the hospital for the doctor to see you beautiful." I always raised her self-esteem. (Rosa)

She was two years and two months old, and I said, "My husband is bald, I told you, you'll be bald like Daddy", there you go (laughs). She never complained again about having to shave her hair. (Orquídea)

The reports were expressed impregnated with experiences and, in some cases, it was possible to perceive reorganizations in the family dynamics through the use of adaptations and rearrangements in the search to accommodate the physical and emotional needs of the children in their daily life.

The news of the cancer is stressful and able to change considerably the family organization, especially when the patient is a child. The discovery that a child has cancer still tends to be an experience as painful and disturbing as death, which can lead to the emergence of family conflicts generating the need for constant adaptations and changes in life habits.^{16,7}

From time to time he leaves, he plays soccer with an umbrella, he plays "bets" with an umbrella and he's going his way [...] We fit an umbrella for him [...] We die from laugh at his way. (Azaleia)

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So now, without wanting to eat, he asks his father, "Father, is it Monday, right? Well we could make a barbecue for me" [...] He thinks that barbecue meat is not the same as normal meat, so we always make roast beef on the barbecue. (Margarida)

When I had a sore in the mouth I always passed a little oil, and to not let the skin rest it was the same thing, it moisturized a lot, I bought the smell that he likes. (Tulipa)

The presence of mothers as caregivers in the treatment process of the child with cancer involved the recognition of care and its different dimensions, including the motivation, use of resources and family adaptations to reduce feelings of anxiety, distress, fears, and uncertainties revealed in these children. The presence of the caregivers collaborated significantly to improve the child's self-esteem and emotional aspects, minimizing their physical and social repercussions and changes in the routine of daily life.

During the process of cancer treatment, the family plays a fundamental role, acting as a support network, performing the necessary care, providing physical, social and psychological support, as well as helping and motivating the patient in coping with their illness.¹⁷

● Repercussions arising from family care

In the presentation of the testimonies, it was observed that the caregivers were motivated to promote the well-being of their child by establishing empathy and communication, obtaining, in this way, good results when carrying out the care with the children. The presence of cancer in childhood affects the existential dimension of the patient, involving several facets, which may affect their social participation, education, sports, leisure, relationships with family members, group and interpersonal relationships, status and also change their planning in relation to the future.¹⁸

Look, I do what I can, I think I have good results because he never got an infection, his skin was never so dry to bleed or hurt, so I think I have good results, yes, because he is very happy because I do not either. I leave him alone in the house locked, I take him to leave too [...] but that's how it goes, we win. (Tulipa)

The results are good, we try to treat him like everyone else, so he does not feel sick. (Margarida)

The importance of the family in providing guidance to the child, clarifying it about the process of coping with the disease, minimizing their doubts, fears, and traumas from a

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childhood affected by cancer is noted in the reports. This support directly influences how the child will deal with their illness, and there is evidence that the strategies used, such as motivation, dialogue, and emotional support, play an important role in providing well-being.

Thus, the sickness due to neoplasias imposes modifications in the daily life from the establishment of the diagnosis, requiring re-adaptations before the new situation and strategies for coping with the disease. Within this perspective, the games, material conformations, dialogues, and clarifications are inserted as a form of resource for the psychological intervention with the child.¹⁹

So, when he is in an environment that has a lot of kids who do not know his story, he comes in and shows the ball that is the catheter. Then he says, "Look, I have a ball here so you cannot hit me, you cannot bring me down, and if I fall, it can break my bones." He even explains it to the other kids. (Azaleia)

I think so because she has no trauma at all going to the hospital, for her the only problem is to puncture the catheter, that's all. (Orquídea)

All the care, love, and caring the mothers gave their children have been recognized by them as effective in the process of adaptation and treatment of the disease. However, they expressed in their intimate feelings of suffering and anguishes when experiencing limitations related to food preparation and restraint and leisure activities.

The speeches revealed the anguish of family members when experiencing food restrictions and leisure activities, which are essential and indispensable for the promotion of appropriate treatment. Caring involves feelings of affection, attachment, pleasure, but also reinforces feelings of recovery, vigilance for promotion and maintenance of the child's health.²⁰ It is a constant journey from overload to privilege, and although parental suffering results in high levels of stress and anxiety, this feeling is revealed with commitment and dedication by family members who experience a constant struggle for life.²¹

If she wanted cake we had to buy the pasta in the bag the ground meat and do well done, everything sanitized, because it has to be the same people to do and give. But then she did not want to, she wanted the bought. So I suffered because of that too, I suffered with her because I saw that she wanted to, we wanted to give, but she could not because there's no way you could give and then she would feel bad[...] then she would get nervous. (Rosa)

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When he is in the chemotherapy season, if he wants to walk, he says: "Mom, I put on a mask, I do not rejoin anyone, I swear I do not care about anyone!" (Dália)

No refrigerator, everything done at the time, nothing to go to a place that had a lot of people: supermarket, church, these things like this[...] If it is to leave it had to be in open place, avoid crowding and preferably with a mask, but she never stayed [...] it's very difficult to leave with a mask, she would not accept it. (Orquídea)

The caregivers reported that the guidelines, care, and dedication provided were expressive and fundamental for coping with cancer. However, they cannot meet all the needs imposed by the illness on the lives of their children, generating an ambiguity of feelings of suffering or satisfaction.

Despite the limitations imposed by the chemotherapy treatment process, family caregivers learn to deal with them and do not give up facing the situation they were exposed. These need the support and qualified listening of health professionals so they can have their energies replenished and their forces reactivated. Therefore, the need for the nursing team to change the focus of the disease to the care centered in the family and to understand the real position of the caregiver in this context is evident.²²

The nursing team should develop actions to include family members in the caring process, not only in the perspective of caring for them but also in the possibility of their demands being met, and the nurse should be aware of the patient's and family members' difficulties, acting as facilitator in the implementation of care.²³

CONCLUSION

Identifying the care strategies adopted by caregivers of children with cancer in chemotherapy allowed the understanding of the experiences and unveiling the feelings, opinions, difficulties and the processes adopted by them to confront the existential situation of their child in the daily life of their family.

The resources and reorganizations used by caregivers and family members in face of the imposition of illness and treatment were fundamental for the maintenance of the daily activities of the child and the transcendence of all. They used strategies of care, comfort, dialogue and emotional support in the search to minimize the feelings of anxieties, fears, and uncertainties presented by all.

Care for the child with cancer implies considering the care received at home,

because the involvement of the caregiver in this study characterized by the maternal figure was essential to provide the child with improved self-esteem and social insertion, minimizing stigma and feelings of apprehension and protection internalized by parents and children.

The results show the need for nursing professionals to know the forms of care given by the family caregivers to the children undergoing chemotherapy. It is believed that this study will contribute to the extent that it proposes to deal with the issue in a timely manner, seeking to collaborate in the planning of care actions and assisting them in their practice, as well as unveiling their anxieties and anguishes, offering support.

Searching for the singularities and the experiences of family members in the context of having a child with cancer at home, enabled to work effectively as nurse professionals, singularly and humanized in family centered care. Taking them not merely to watch them technically and scientifically, but also to listen to their yearnings, fears, doubts, contemplate their biopsychosocial needs and support them during this journey.

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