



EXPERIENCES OF FAMILY MEMBERS OF PEDIATRIC ONCOLOGY PATIENTS IN FACING ILLNESS AND HOSPITALIZATION

EXPERIÊNCIAS DOS FAMILIARES DOS PACIENTES PEDIÁTRICOS ONCOLÓGICOS FRENTE AO ENFRENTAMENTO DO ADOECIMENTO E HOSPITALIZAÇÃO

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Abstract

Objective: the study aimed to understand the needs, difficulties and coping strategies of family caregivers of cancer patients. **Methods:** for that, a qualitative study of descriptive-exploratory nature was carried out, based on the elaboration of focal groups with caregivers of cancer patients. We sought to analyze the needs of the family caregivers of cancer patients based on the content analysis of the focus groups. **Results:** in order to analyze the content of the transcribed interviews, it was possible to form three thematic axes, from which the categories "Experienced feelings towards treatment", "Shares for coping" and "Spirituality" were derived. **Discussion:** the analysis and discussion of the findings pointed to the emotional burden of the caregivers and the child itself, the role of the care network as a source of support and

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exchange, as well as the importance of spirituality as a coping strategy. **Conclusion:** so that the particularities of care can be understood in order to protect them.

Keywords: Family; Oncology; Pediatrics; Coping.

Resumo

Objetivo: o estudo visou compreender as necessidades, as dificuldades e as estratégias de enfrentamento de familiares cuidadores de pacientes oncológicos pediátricos. **Método:** para tanto, realizou-se um estudo qualitativo de natureza descritiva-exploratória, com base na elaboração de grupos focais com cuidadores de pacientes oncológicos. Buscou-se analisar as necessidades dos familiares cuidadores dos pacientes oncológicos a partir da análise de conteúdo dos grupos focais. **Resultados:** tendo em vista a análise do conteúdo das entrevistas transcritas, foi possível a formação de três eixos temáticos dos quais derivaram as categorias: “Os sentimentos experimentados frente ao tratamento”, “Compartilhamentos para enfrentamento” e “Espiritualidade”. **Discussão:** a análise e discussão dos achados apontaram para a sobrecarga emocional dos cuidadores e da própria criança, o papel da rede de cuidados enquanto fonte de apoio e de trocas, assim como a importância da espiritualidade como estratégia de enfrentamento. **Conclusão:** dessa forma, permitiu aos profissionais da saúde reconhecer essas dúvidas, dificuldades e angústias; para que compreendam as particularidades do cuidado, a fim de ampará-los.

Palavras-chave: Família; Oncologia; Pediatria; Enfrentamento.

INTRODUCTION

According to the World Health Organization ¹, cancer is one of the main causes of death worldwide, which makes it a public health problem. Research shows that in 2030 there will be 21.4 million new cases and 13.2 million deaths from cancer worldwide, resulting from the growth and aging of the population².

The global estimate carried out in 2012 indicated that more than 60% of the 14 million estimated new cases occurred in developing countries (BRASIL, 2015).

According to the Ministry of Health (MS), through the Official Gazette 3, the National Policy for the Prevention and Control of Cancer is organized in order to provide the continuous provision of health care actions for the population through the articulation of different medical centers. They are properly structured by logistical and support systems, regulation and governance of health policies. These actions, when implemented in an articulated way, can contribute to the care process.



As part of the care process for cancer patients, there is relief from the suffering of the patient and family members during treatment and this should be the responsibility and commitment of the healthcare professional ⁴. For this reason, the team must recognize and deal with these needs in pediatric patient care, given the stressful nature of caring for a child with cancer. It is relevant to reinforce the need for health professionals to pay attention to parents who experience high tension as caregivers, especially in the early years after the diagnosis of cancer, as they are more likely to have health problems ⁵. In order to qualify assistance to pediatric cancer patients, aged from 0 to 18 years, the support for these patients' beloved ones becomes essential, be it by observing the difficulties they face or by searching ways to attend their necessities.

Realizing and respecting the unique way and the individual demands of the patient and their families is necessary, as it approaches the pre-established treatment to the peculiarities of life ⁶. The inclusion of the family as an element of integrated and participatory care in the environment in which the patient is inserted is fundamental, both because of its own potential for care, and because of the need to participate in appropriate guidelines and in understanding the particularities of the family member. During coping with cancer, family members are weakened by the suffering of their beloved one, which can make it difficult for them to be included in the care process ⁶. When a child is diagnosed and treated for cancer, parents must suddenly assume the dual roles of parents and caregivers, both with potentially competing demands. Even though the care by parental figures and their role is expected, the complexity of taking care of a child with cancer can go against parents' approach and values, leading to ambivalent sentiments of frustration and conflict in relation to their roles ⁷.

Thus, in family relationships, the worsening of the pediatric patient's illness tends to expand the caregiver's responsibility, as well as increase stress in the family-patient relationship. These facts point out that care must go beyond the specific care for the patient, also meeting the needs of family members. Therefore, contributing to the operation of changes in the production of care and,



thus, allowing an improvement in the quality and wholesomeness of the assistance ⁸.

It is necessary to understand that the caregiver must also adopt a routine of healthy habits, as their feelings are weakened by the disease ⁹. It is still necessary to identify the individual and collective demands that aggregate motivations capable of reducing the patient's stress, as well as the family members, with the principle of helping them ⁶. Therefore, investigating the demands, the experiences of informal family caregivers, as much as the ways of understanding and contemplating them, show a differential treatment.

With the everyday experience, it is relevant to promote the preparation of the health team to deal with the real needs of the pediatric patients' families. Therefore, this study aims to understand the needs, difficulties and coping strategies of family members of pediatric cancer patients, enabling improvements in care, with a view to these demands.

METHODOLOGY

This is a qualitative study of descriptive-exploratory nature. To carry out a qualitative analysis applied to health, we used a concept offered by the Human Sciences that seeks to understand the individual or collective meaning for people's lives ¹⁰. Studies that use the qualitative method are characterized by capturing and reconstructing meanings, from a conceptual and metaphorical language. The capture of information occurs in a flexible, unstructured, inductive, systemic and fulfilling way ¹¹.

The study was carried out in a philanthropic health institution in Porto Alegre, a reference unit in high-complexity pediatric treatment in Rio Grande do Sul, data collection date 05/01 to 06/30 of 2017. The research was approved by Ethics and Research Committee of the institution under opinion number 0319.0.213.000-10. Twenty family caregivers of pediatric cancer patients who followed the care of patients during the treatment period participated in the study. From the 20 respondents, 17 were mothers, 1 maternal grandmother and



2 fathers. The inclusion criteria used, taking into account the public and specific demands, were: caregiver being a family member of the cancer patient undergoing treatment and hospitalized patients using a medium and long-term catheter.

To carry out data collection in the focus groups, a script was used, with guiding questions (Appendix B) on the themes: (1) The experience of caring for a child with cancer; (2) Artifices used and that helped them in coping with the disease; (3) The difficulties and facilities found during the family's follow-up time.

For Kitzinger (2000), a focus group is defined as a type of group interview, considering communication and interaction as a principle basis. Its main objective is to collect and group information with details about a specific topic (proposed by a researcher, moderator or group coordinator) based on selected participants. The collection of information aims to understand the perceptions, beliefs, attitudes about the referred theme ¹². Four focus groups were carried out with the patients' relatives, in different shifts (morning, afternoon), but with the same script and objectives. Focus groups can have between five and twelve participants, and must always include a facilitator ¹³.

The research objectives will determine the number of focus groups, with two groups being sufficient, however three or four can be used ¹⁴. The structuring took place with four focus groups, with the presence of participants in alternate shifts (Group 1: six participants, Group 2: four participants, Group 3: six participants and Group 4: four participants). Such alternation sought to contemplate family caregivers who were in the hospital during different shifts of the day, since there may be a variation in the time of monitoring of the family member undergoing treatment. In recent meetings, it is clear that there were common points, showing data saturation.

The meetings with the focus groups took place in reserved spaces in the hospital institution, lasting approximately one hour, and were audio-recorded and later transcribed, in order to maintain the reliability of the data.



For the implementation of the groups, the following steps were carried out in each of the meetings ¹⁵: (1) Recruitment of the participants (an initial contract was carried out, in which, upon acceptance of the invitation and knowledge of the TCLE, general combinations were defined, such as time, confidentiality of information, right of withdrawal and doubts); (2) Technique of conducting the group (the interview began with broad questions and, later, followed with a more specific direction); (3) Finalization (at the end of each meeting, the group was encouraged to talk about their feelings that emerged when facing the theme).

For the analysis of the written report, the theoretical framework of Olabuénaga was used for content analysis ¹¹. From the reading of the transcripts, the lines were separated according to the combination of themes. As for the thematic axes of the focus groups, there were record units with greater similarity, which were grouped into specific categories.

As a criterion for interpreting the transcript and consequently the categories, we opted for a prior analysis with thorough reading of the transcripts, followed by the convergence of related themes (categorization) and finally, for the certification of common categorized themes, an independent judge was evaluated. Therefore, to interpret them, the type of inductive reasoning was used, which was based on inferences, as the concepts, meanings and categories derive from data, as space was opened for analysis of the statements and implicit elements of the relation between researcher and participant ¹⁶.

RESULTS AND DISCUSSION

From the analysis of the content of the transcripts, it was possible to construct three thematic axes: "Feelings experienced towards the treatment", "Sharing for coping" and "Spirituality", which were linked to the categories presented in table 1 (Table 1 – Thematic axes and categories).



Table 1: Thematic axes and categories.

AXES	CATEGORIES
Feelings experienced towards the treatment	positive feelings negative feelings
Sharing for coping	Sharing experiences among equals Sharing with children/patients
Spirituality	Spirituality and religiosity

Nota: Prepared by the authors, Porto Alegre 2018.

- Feelings experienced towards the treatment

With regard to the feelings experienced during treatment, it is understood the recognition of experiences that influence and give new meaning to this phase¹⁷. In the axis "feelings experienced towards the treatment" two categories emerged: "positive feelings" and "negative feelings", in which they confront the sensations that make it possible to sustain the path of illness in a lighter way with the unpleasant sensations characteristic of the disease.

The category 'positive feelings' refers to the verbalized contents that refer to strength, encouragement, overcoming, trust, love and care. The parental relationship is constituted in a procedural way, where the maternal and paternal functions are built through parental practices, updated through the parent-child relationship. Such interactions tend to reveal personal and identity characteristics in the parents and thus strengthen the affection between them¹⁸. As mentioned by one of the family members, who perceived himself as having a strength of which he was not even aware and which helped him to face the illness of son, as the following excerpt shows: "But with a child it's much more relaxed, the child gives you a lot of strength, bah look! Your child gives you a strength that from I don't know where it comes from" (family member D – Focus group 4).

In the disease cycle, the support of the closest family, such as fathers/mothers, helps the patient in his/her recovery and helps the caregivers themselves, as revealed by the family¹⁹: "We mothers have to give our children strength, right, we are the ones who are there encouraging them" (family member C- Focus Group 1); or even "Sometimes she was feeling down, I painted myself, jumped in front of her, told a story. I did some cool things (...)"



(family member C- Focus group 3). In this context, another positive feeling highlighted was the encouragement to the children, to encourage the child and his/her improvement. According to the report, overcoming was acquired with the development of recreational activities that could distract the children in a painful moment. When reflecting on this process, it is believed that the individual life cycle takes place within the family life cycle, and this perspective is crucial to understand that emotional problems developed by people are part of a joint movement ^{20,21}.

The crisis phase, after the problem has been clarified through a diagnosis and an initial treatment plan, includes an initial period of readjustment and management ²¹ and of approximation of the bond with health professionals ²⁰. During this phase, the family seeks to develop confidence, as reported by one of the mothers in the face of medical support: "I trusted a lot when Dr. P. said: 'Oh, your daughter will recover, mom!' I clung to that idea and to this day, I cling to it" (family B – Focus Group 1).

Among the feelings, love and self-care also gain relevance: "We mothers also have to take care of ourselves(...). I do a blood test every 6 months to see how I'm doing. That sometimes you have the bacteria, you pass it on to your child without knowing it" (Family member A – Focus Group 1). In this example, it is possible to identify the importance of self-care for the preservation of the health of mother and child, thus reaffirming the relationship with love, partnership and trust.

In the 'negative feelings' category, the verbalized contents were: of being a difficult experience, burden, fear, insecurity and discouragement. The role of caregivers in this experience is complex and also involves feelings such as anguish and sadness, resulting from the pain and impact that the diagnosis brings, in addition to the physical and psychosocial burden that the family has to bear ⁹. These feelings were pointed out in the reports from the family caregivers, who often used the word "difficult", expressing the intensity of the strain they face in the treatment, which the amplitude can reach their physical and psychological well-being. The speech of family member D (Focus group 3)



exemplifies this: "(...) I'm worried. And she's lying over there, it's hard for us. It's hard, I lost 8 Kg!". In this way, the unexpected and challenging role as caregiver of a child under risk of death can negatively impact the typical experience of maternity/paternity, as well as the parents' mental and psychological health¹⁹. These parents often reflect the unceasing search for the cure, forgetting the path to be followed in the course of healing the disease and themselves²³.

The burden of family caregivers reaches 24 hours a day, with 48% of family caregivers saying that the care process takes from 7 to 18 months, reaffirming the fatigue and weariness reported by family members²⁴. Feelings such as guilt, anguish, anxiety and anger fluctuate in the course of the disease and are expressed by all family members, especially mothers. Consequently, parents can change their roles and family functions as a way of managing the children's illness²⁵. In general, there is a burden sensation for the family member who takes care of the child full time, without the possibility of resorting to any help²⁴, as identified in: "Imagine... you abandon everything and don't even have time to go looking for paper (for sickness benefits) (...) it was 24 hours straight, 33 days in a row" (Family member A – Focus Group 4). It can be noted that chronic diseases have unique characteristics and effects on the family. The caregiver of children with a disability, for example, suffers less strain compared to the cases of children with cancer, observed that in these cases the caregiver suffers more out of fear, anxiety and complications in specific periods²⁵.

Fear and insecurity are negative feelings that were also mentioned by caregivers in the reports. In diseases whose children's lives are threatened, family members fear that they will be lone survivors in the future and there is a tendency for this experience to be as overwhelming as the death itself, generating sadness, insecurity and fear²⁰. It was observed in this study that the feelings of discouragement and fatigue persisted, as observed in the following statements: "The difficulty I think is the fear we have at the beginning" (family A – Focus Group 2); "She (the patient) is very discouraged like that, right (...) and then we also end up feeling down with them, right" (Family member E – Focus Group 3).



- Sharing for coping.

The second axis dealt with the experiences of coping with the disease. Family caregivers report using various coping strategies in the treatment of the disease with a view to overcoming and alleviating stressful moments of other family members and patients facing the disease. In this axis, two categories were identified: sharing experiences between equals and sharing with children/patients. The first is related to sharing experiences with other family members, friends, acquaintances, as presented in the statements: “It is comforting and everything, having the support of the person who is going through this (...) but I absorb the support and not... and not the disease itself (...) and like that, people I don't even know in my city and who call me, give me support” (Family member D – Focus Group 4).

The second one points to the sharing experience with the children, verifying if they know what is happening and how they can help themselves. As reported by family member D from Group 3: “I used to talk a lot, right! About the treatment and these things, right (...) to unwind, right? Because if it's going to be locked, it's going to stay inside the house, it's going to be worse and worse!” and “Since she is already a teenager, it is talking to people, with teenagers who had the same pathology (...), talking and interacting with friends (...) because she cannot lose (...) the routine that she had because of that, and that's what helped her a lot” (family member B – Focus Group 4).

Sharing experiences to face difficult treatment situations is a form of support. This support and social interaction of companions improves the health of children and teenagers, enabling them to have greater freedom from extra-hospital activities, which allow them to return to their daily lives ²⁷.

The support of friends and relatives also encourages them in the process of coping with the disease. Each family has the ability to manage the crisis phases. The history of how the family manages continuous stressors, moderate or severe, is a good predictor of adjustment in the case of chronic diseases ²⁰. When a child is affected by cancer, this episode affects all members of the family environment, causing an emotional concussion with the potential to profoundly



affect its structure, which will interfere in the evolution of its life cycle ²⁸, hence the importance of the healthcare team's perspective and support regarding the family members' needs.

It was possible to observe, through the reports, that there was little emphasis on the participation of the team in terms of support and help for coping during treatment. In the Ghodsbin study, in which the quality of life of family members of children with leukemia was evaluated, the authors suggested that health professionals contribute to the promotion of quality of life for both sick children and their families, providing them with consultancy, development and implementation of educational programs with the intent of helping them to learn healthy coping methods during cancer treatment ²⁶. Such lack of comments in this study reflects a possible gap in this regard in the participating group and about the importance of sensitizing professionals about this task, which will certainly reverberate in their care as well.

- Spirituality

In the third axis “spirituality” a single category was identified: spirituality and religiosity. Religiosity is an organized system of beliefs, practices, rituals and symbols designed to facilitate proximity to the sacred and the transcendent. In spirituality, on the other hand, the search is for the personal, for the understanding of life issues and their meaning ²⁹. Both spirituality and religiosity are pointed out as stimuli to continue the treatment and face the disease in a more peaceful way. Some pointed out the identification of a specific religion, which they already identified with, and others highlighted the faith without linking it to a specific creed: “Like he stayed 17 days intubated (...), so, you got to have a lot of faith and I thank God, God I think that gave me that strength (...). The only thing he did was listen, and then for him to understand I started to read Job's part to him (referring to the Bible)(...)” (family A – Focus group 1); “Well, I was already a Christian, right, I'm a Christian, so I already had this support, thank God, if I hadn't I would have gone crazy too” (family member C – Focus Group 2);



Spirituality, for example, was taken by the participants as a strategy for coping with the disease and stands out as a helper in the comfort of the caregiver. It was observed that the speeches presented by family caregivers do not differ, regarding the emphasis on the importance of spirituality and religiosity for coping with and overcoming the care experience³⁰. In addition to serving as a stimulus for empowerment in a time of difficulty, spirituality can serve as support in an attempt to extract meaning from the moment experienced by each family member. Spirituality and religiosity are related to quality of life, as fundamental allies in coping with adverse situations. Thus, as important as valuing them is the fact that health professionals know how to deal with, value and respect these themes, given their importance for health practices and professional training³⁰.

The use of spirituality also becomes a mechanism to strengthen the family caregiver in relation to monitoring the patient, adding confidence and hope for faith. In this aspect, family empowerment can reduce the burden level through physical and mental improvement of function, and increase self-capacity³².

Spirituality or religiosity is fundamental to the experience of many cancer patients and their families. In the assessment of quality of life, the use of specific spiritual interventions in oncology reduced stress, decreased depressive symptoms, increased peace, in addition to helping psychological well-being, and patients indicated the desire for help in relation to their spiritual needs³³.

As evidenced, the belief in a superior being becomes an important source of support for coping with cancer, helping caregivers to support social isolation, physical, financial and emotional exhaustion that arises from the task of caring. In addition, it helps caregivers to find a meaning to the family member's illness, allowing them to experience this phase of change³⁴.



FINAL CONSIDERATIONS

The analysis of the family members' reports allowed to understand the experience, feelings, difficulties and strategies linked to monitoring the children's treatment. Strength, confidence, fright, fear, difficulties, concerns, burden, overcoming, among others, were revealed in the reports, as well as sharing for coping and spirituality as important strategies used.

Variation in feelings is inherent to family members of pediatric cancer patients, since they are in the context of cancer treatment, which demands a greater degree of dependence on the patient and unpredictability in the process. Important points such as family, social and spiritual support seem to become influential in the process of relief and coping for the caregiver. In this way, it is still necessary to develop investigations followed by interventions, by health professionals, to qualify the support of families for coping during treatment and everything that follows from it. As well as training and development of health teams regarding this process and these themes.

The care actions developed by these family members are usually fundamental, for them and for the patient. Thus, it is important for health professionals to listen to the doubts, difficulties and anxieties of these families, in order to understand the particularities of the caregiver in order to support them, value them and bring them closer to the team's work. By pointing out their needs, it is intended to favor the search in the development of focal interventions, aiming to the inclusion of family caregivers in relation to looking at the quality of life of pediatric patients. This study, in a way, by demarcating some elements of this complex experience, intends to support future interventions to boost the quality of life and support for the families of cancer patients.

As a limitation of this study, barriers were noticed regarding the adhesion of the focus groups, due to the lack of support/parallel activities for the children, since this would facilitate the participation of parents in the focus group. As it is not a question of the number of focus groups, but of the technique used, it is suggested that the realization of groups with a larger number of participants (in



relation to the number of groups carried out) could favor the elucidation of data, with the expectation that there will be greater interaction between participants. Furthermore, it is worth mentioning the lack of information regarding the little participation and help of the healthcare team when facing difficulties related to cancer treatment. It is understood that this signals the need for greater involvement between the healthcare team and family members, in order to share the care and improve their assistance towards the families, reaffirming the necessity of the team's sensibilization.

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