

HOW FAMILY CAREGIVERS PERCEIVE THE CHEMOTHERAPY TREATMENT IN CHILDREN AND ADOLESCENTS

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ABSTRACT: Family caregivers' perception of chemotherapy treatment supports the development of effective and humanized nursing care plans. This study, which aimed to describe family caregivers' perception of chemotherapy treatment in children and adolescents, is characterized as qualitative and descriptive; it was undertaken in a Chemotherapy Center with 10 family members. The data, organized using the ATLAS-ti software, were analysed using content analysis, from which the following categories emerged: *Ambiguity of the feelings regarding chemotherapy treatment*, *Chemotherapy as a resource for achieving a cure* and *Religiosity and faith*. It was observed that the family members perceive the chemotherapy treatment as the only means of obtaining a cure, and that this process includes the search for balance between the contrasting feelings, through belief and faith, pervaded by a perspective of hope.

DESCRIPTORS: Chemotherapy; Caregivers; Child; Adolescent.

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INTRODUCTION

Childhood cancers occur in individuals under 19 years old and represent 2 to 3% of all malignant tumors; death from neoplasias in the age range of 1 to 19 years old is among the primary causes of death in Brazil. Leukemia, lymphoma and tumors of the central nervous system have a higher incidence and, among adolescents between 15 and 19 years old, the principal tumors found are the carcinomas and other epithelial neoplasias, lymphoma and leukemia⁽¹⁾.

Advances in the understanding of molecular biology, and magnetic resonance have made a significant improvement possible in the choice of efficacious therapeutic plans, benefitting the elaboration of the prognosis of childhood cancers. The treatments for childhood cancers include surgery, chemotherapy, radiotherapy, and immunotherapy, undertaken individually or in association⁽²⁾.

Chemotherapy stands out among the treatments due to the high incidence of hematological cancers in this age range. Therapeutic protocols form the basis of the treatment and are adopted according to the type of neoplasia, how far it has spread, where it is located, and the age and general conditions of the patient. This treatment's most frequent side-effects are apathy, loss of appetite, weight loss, alopecia, hematomas, bleeding from the nose and mouth, nausea, vomiting and diarrhea⁽²⁾. The actions of the antineoplastic chemotherapy drugs cause side-effects in the hematopoietic tissue and cause the patient to have low immunity and an increase in morbidity and mortality due to infectious processes⁽²⁻³⁾. For this condition of low immunity, guidance and care measures are adopted so as to minimize the risks of complications, whether the child is in the hospital or outpatient setting⁽⁴⁾.

The needs related to the side-effects presented by the patients receiving outpatient chemotherapy are met by their caregivers in the family framework and are frequently considered complex and difficult to manage⁽⁴⁻⁵⁾.

The family is considered a primary unit of care, and is made up of members who interact and provide mutual support in the presence of problems. The appearance of an illness in the family ambit causes behavioural changes in its members and the relationship between them is altered, with a tendency to deepening, broadening or breaking affective bonds⁽⁶⁾.

During the chemotherapy treatment, the family members have difficulty in helping to resolve the

child or adolescent's physical and psychological suffering and, concomitantly, in maintaining healthy relationships and interactions among the family members⁽⁶⁾. The family of the child with cancer undergoes a process of restructuring, each member developing new skills and tasks in the family routine, with the objective of minimizing and resolving conflicts referent to the outpatient chemotherapy treatment and the requirements resulting from the disease, which encompass the physical, psychosocial and financial aspects⁽⁷⁾.

Inserted in a context of complex therapeutic demands and bio-psychosocial implications, the family confronts a feeling of helplessness. The sadness caused by the confirmation of the diagnosis is accompanied by various feelings described in the literature, such as rebelliousness, refusal to accept the situation, anger and recrimination, directed at the figure of God or themselves⁽⁵⁻⁷⁾. Family behaviour is changed when the child has a chronic illness; the inability to deal with the new situation leads the family to seek strategies and alternatives, aiming for the comfort and satisfaction of its weakened entity⁽⁶⁻⁷⁾.

The knowledge of how family caregivers of children and adolescents perceive the chemotherapy treatment supports the nurses in the development of effective and humanized care plans. It may be observed that the caregivers' perceptions and perspectives contribute to the development of the care plan, allowing their participation as active agents in the antineoplastic chemotherapy treatment, with a consequent improvement in the interaction of the decision-making processes referent to the child or adolescent's clinical picture⁽⁸⁾. In this context, the present study's objective was to describe how family caregivers perceive the chemotherapy treatment in children and adolescents.

METHOD

This is a qualitative and descriptive study, which allows one to become closer to the phenomenon based on the subjects' perspective in the broadest way, considering the context in which these are inserted⁽⁹⁾.

The research was elaborated in accordance with the ethic principles of research involving human beings and was approved by the Research Ethics Committee of the Federal University of Triângulo Mineiro under protocol N. 2107/12.

The study was undertaken in the Chemotherapy Center of a university hospital in the interior of the State of Minas Gerais. The research participants

were 10 family caregivers of children or adolescents receiving chemotherapy treatment, who had previous knowledge of the treatment which the children and adolescents received. Data collection was undertaken in the months of February and March 2012.

In order to meet the objective, individual semi-structured interviews were held, composed of open questions on how the family caregivers received the chemotherapy treatment, the aim being to elicit experiences relating to this process. The data were collected by the researcher, subsequent to the participant signing the Terms of Free and Informed Consent (TFIC). The interviews were recorded digitally, and were organized and stored on the ATLAS-ti software. The following steps were used for analyzing the data: ordering of the data (transcription of the recordings; rereading of the material; organization of the accounts); classification of the data (reading of the texts; making a corpus of communications; transversal reading of each corpus with the selection "recording units"; classification by the most relevant themes) and final analysis (considering the work's objectives, the theoretical framework and the issues which emerged from the clients' statements), with the accounts being grouped by convergence⁽¹⁰⁾. The research participants were identified using Arabic numerals, preserving the interviewees' anonymity.

RESULTS

Of the caregivers, nine were female and one male; eight were mothers, one was a grandmother, and one the father of the child/adolescent receiving treatment. In relation to the work routine, four reported abandoning their professional careers to accompany the treatment, two did not work, three continued their work routine and one was retired.

Based on the identification of the recording units, grouping into themes was undertaken, which allowed the construction of three categories, presented below.

Ambiguity of the feelings regarding the chemotherapy treatment

The discourses evidenced the ambiguous feelings of the family caregivers in relation to the chemotherapy; the grief and the suffering resulting from the weakness imposed by the treatment were reported by all the interviewees. In a contrasting and complementary position one finds the feeling of hope and progress in the search for the cure, and the perception of the chemotherapy as

the only means available for confronting the disease. These assertions are evidenced in the discourses below:

[...] it's a feeling of pain, which we feel, a little distress because I feel his pain, it is my pain, but at the same time it is a feeling of relief because he's getting this medication to get better, to be cured. (S4)

The chemotherapy, oh my God, a sacred poison, a necessary evil [...] It causes unpleasant effects, but there is no other medicine, there's no way around it, so we submit to it. (S9)

In contrast to perceptions evidenced in the discourses, one divergent account stands out through the family caregiver's lack of knowledge regarding the disease and the therapy adopted, as in the statement below:

I still don't understand what chemotherapy is, I haven't asked the doctor, so I don't know, he never explained it to me so I don't understand what chemo is. I never thought about it, never asked the doctor what it was, why it is that he is having chemo, what type of disease it is that he has, whether it is benign or malignant, I don't know, you know. (S6)

Chemotherapy as a resource for achieving a cure

Chemotherapy is understood by the family members in this study as the only method available for achieving a cure, and is related to the positive perception of the treatment considering the duality of feelings. This fact is evidenced in the following accounts:

Chemotherapy is a treatment, through medications. It is the opportunity which we have, just as well that the medicine is advanced and what is possible to be done, is being done through the chemotherapy. [...]. The importance of the chemotherapy is the feeling that everything that can be done is being done. (S1)

The importance of the chemotherapy is this, seeking a cure for his problem, because it is the only way. (S3)

Religiosity and faith

The discourses evidenced the family caregivers' feelings in relation to the need to submit the child/adolescent to the chemotherapy treatment and to the consequent side-effects. They also demonstrated the

perception of the therapy and the absence of any other method of treatment for substituting chemotherapy. These factors cause a feeling that all the means available are being applied for achieving a cure.

The adaptation resulting from the situation being experienced, and the submission to any type of treatment necessary for obtaining a cure, is characterized as being human, thus maintaining the need to hope and wait for divine intercession.

So I ask for strength and the chemotherapy is what we can do here on earth and relying on the medical team, the nurses, on everything is all that we can do, you know, beyond that it's a matter of respecting the will of God and trust, and that's all. (S1)

[...] when we start chemotherapy, we feel fear, terror, because you don't know what is coming later, the consequences, but we have to have a lot of hope, a lot of faith and confidence and put everything in the hands of God and the doctor and always hope for the best. (S4)

[...] today, we have first, God, and second the treatment, which is already well advanced, so knowing this gives us a bit more tranquillity. (S7)

DISCUSSION

Mothers of children receiving chemotherapy report feelings of ambiguity, the suffering is mainly related to the physical changes resulting from the alopecia. However, the hope for a cure through the chemotherapy supports the need for that treatment and becomes a reason for continuing with it⁽¹¹⁾.

Carers for adults with cancer receiving chemotherapy present a similar feeling of ambiguity in relation to the chemotherapy. The interviewees identified the treatment as the factor responsible for the physical weaknesses of their family member, changes in image, in the routine and in the emotional state, which promotes sadness, nervousness, fear, distress and depression. However, the chemotherapy is also considered a factor which provides the cure and which nourishes the hope of a healthy future⁽¹²⁾.

One can observe in this study that the trust in the treatment mitigates the caregiver's suffering. However, the caregiver's self-perception as a passive being, unable to impede the appearance of the chemotherapy's side-effects on the family member receiving treatment, intensifies this negative feeling.

The family performs a relevant role in the cancer treatment process. The period of diagnosis is considered sad, calamitous, and characterized by uncertainty regarding the side-effects of the chemotherapy^(6,12-13). In this context, the study undertaken with caregivers of children with cancer evidenced distinct abilities with which the family members coped with the disease⁽¹³⁾.

The perception by the caregivers of chemotherapy as a resource which can provide a cure reflects the real situation of possibilities in the treatment of neoplasias. In this context, therapeutic protocols are developed and updated for effective treatment of hematological cancers, with important emphasis on chemotherapy⁽¹⁴⁾. Studies with caregivers of adults receiving antineoplastic treatment corroborate the findings and evidence the perception of the therapy as a resource capable of curing or as a possibility for prolonging life⁽¹⁴⁻¹⁵⁾.

The new context in the routine of mothers who are caring for children with cancer raises the need for strategies of adaptation, among which belief in God stands out. This attitude is demonstrated through prayers, attributing the hope for improvement in the experience lived through to God. Religiosity and faith are strongly present in the people's lives, principally in the hardest times⁽¹⁶⁾.

The impossibility of functioning actively in the cure of the disease and in mitigating the child's suffering, associated with the self-perception of impotence in the face of the cancer, is a factor which is linked to the apparent acceptance⁽¹⁷⁾. As a characteristic specific to this study, the absence of the feeling of rebelliousness and non-acceptance of the illness stands out, as, in the literature, accounts which are resigned or characterized by acceptance are accompanied by discourses from caregivers who are outraged because of having experienced the cancer^(13,18).

FINAL CONSIDERATIONS

This study sought to describe the perception of the family caregivers who experienced the chemotherapy treatment along with the children and adolescents. In this context, reality is permeated by doubts and uncertainty as to the future of the child or adolescent undergoing chemotherapy treatment. The effort made to ensure the treatment necessary for achieving improvement and a cure does not mitigate the feeling of impotence in the face of the physical and emotional weaknesses presented. Faced with this helplessness, one may observe the search for a balance between

contrasting feelings, through belief and faith permeated by a perspective of hope.

The inclusion of family caregivers in the treatment of childhood cancers provides the patient with greater support and security; in this context, emphasis is placed on the need of these caregivers to have full conditions for carrying out their roles throughout this process.

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