

## Childhood Cancer: Meanings Attributed to the Disease by Parent Caregivers<sup>1</sup>

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**Abstract:** This study aimed to comprehend the meanings that parents/caregivers of children and adolescents diagnosed with cancer attribute to their child's disease. It is a qualitative, exploratory/descriptive study. Data were collected through group discussions and individual interviews with the parents/caregivers of children/adolescents and categorized using content analysis. The impressions of the researchers were recorded in a field diary, contributing to the data analysis. The results indicate that the disease and treatment involve periods of psychological suffering that affect the family structure. Cancer was reported as a real enemy to be fought through coping or avoidance, which generates expectations about the future and causes feelings of fear, as well as hope. It was concluded that the childhood cancer causes repercussions in the family relationships, the recognition of which can contribute to both the preparation of professional teams who work with this population, as well as the public health policies developed.

**Keywords:** neoplasms, children, adolescents, family relation

## Câncer Infanto-Juvenil: Significados Atribuídos à Doença por Pais Cuidadores

**Resumo:** Este estudo teve por objetivo compreender os significados que os pais/cuidadores de crianças e adolescentes diagnosticadas com câncer atribuem à doença de seu filho. Trata-se de um estudo qualitativo, de caráter exploratório/descriptivo. Os dados foram coletados por meio de grupos de discussões e entrevistas individuais com pais/cuidadores da criança/adolescente, sendo categorizados a partir da análise de conteúdo. As impressões dos pesquisadores foram registradas em diário de campo, contribuindo para a análise dos dados. Os resultados indicam que o adoecimento e tratamento implicam em períodos de sofrimento psíquico que acometem a estrutura familiar. O câncer é relatado como um inimigo real a ser combatido via enfrentamento ou esquiva, o que gera expectativas quanto ao futuro e causa sentimentos de medo, mas também de esperança. Conclui-se que o câncer infanto-juvenil causa repercussões nas relações familiares cujo reconhecimento pode contribuir tanto para o preparo de equipes profissionais que atuam com esse público, quanto nas políticas públicas de saúde desenvolvidas.

**Palavras-chave:** neoplasmas, crianças, adolescentes, relações familiares

## Cáncer Infanto-Juvenil: Significados Atribuidos a la Enfermedad por Padres Cuidadores

**Resumen:** La finalidad de este estudio fue comprender los significados que los padres/cuidadores de niños y adolescentes diagnosticados con cáncer atribuyen a la enfermedad de sus hijos. Se trata de un estudio cualitativo, exploratorio/descriptivo. Los datos fueron recolectados usando grupos de discusión y entrevistas individuales con padres/cuidadores del niño/adolescente, analizados a partir del análisis de contenido. Las impresiones de los investigadores fueron registradas en diário de campo, contribuyendo al análisis de los datos. Los resultados indican que el enfermar y el tratamiento forman períodos de sufrimiento psíquico, acometiendo la estructura familiar. El cáncer es relatado como un enemigo real a ser combatido, sea por medio de enfrentamiento o evitación, generando expectativas cuanto al futuro y causando sentimientos de miedo y esperanza. Se concluye que el cáncer infanto-juvenil repercute en las relaciones familiares. El reconocimiento de tales repercusiones puede contribuir tanto a la preparación de equipos profesionales cuanto a las políticas públicas de salud desarrolladas.

**Palabras clave:** neoplasmas, niños, adolescente, relaciones familiares

Cancer is characterized as a group of over one hundred diseases. Such diseases are caused by the uncontrolled malignant growth of cells that invade tissues and organs, with the possibility of reaching other regions of the body. National statistics between 2001 and 2005 showed that cancer

mortality in children and adolescents aged between zero and 18 years was among the top ten causes of deaths from disease in this population (National Cancer Institute [INCA], 2010).

Cancer is characterized as a chronic disease, resulting in the requirement for long and exhaustive treatment, which includes intrusive procedures (Mello & Valle, 1999). Despite the alarming numbers regarding mortality, there is ample opportunity to cure these patients, with the probability of recovery and high quality survival in 70% of the cases (INCA, 2008). Such statistics, however, do not prevent childhood cancer from standing out as a serious public health problem.

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The family, as a support in the pre- and post-diagnosis moments, has proved increasingly important in the treatment of childhood cancer, being the possible creator of a trusted environment in which the child can express his/her needs openly. It can transmit the safety and care that a child needs a lot in this situation and the presence of family collaborators is essential for full treatment (Mello & Valle, 1999; Nascimento, Rocha, Hayes, & Lima, 2005).

Thus, recognizing that many social and psychological implications of childhood cancer may be even more comprehensive than the actual physical illness (Patistea, 2005), the importance of the impact of the disease is clear throughout the family system, which may or may not assist in coping with the situation. Childhood cancer generates psychological distress, not only in the sick child but also in the family, a support group essential for the recovery of the child, which can start a process of restructuring.

In the situation of childhood and adolescent cancer, the parents are overwhelmed by the uncertainty of the future and fear of losing their child (Klassmann, Kochia, Furukawa, Hiragashi, & Marcon, 2008; Lacaz & Tyrrell, 2003; Malta, Schall, & Modena, 2008; Misko & Bousso, 2007; Moreira & Angelo, 2008). The situation of illness is permeated by high expectations and uncertainties, as the possibility of a recurrence is always present (Arrais & Araújo, 1999; Misko & Bousso, 2007; Ortiz & Lima, 2007). For some, plans for the future can cease to exist, a view where the emphasis is on coping with the disease in the present (Beck & Lopes, 2007). Furthermore, death, up to then never thought about, starts to haunt their lives as an inevitable and irreversible phenomenon. The stigma of cancer is that of an incurable disease, considered by many as a waiting room for death, which generates intense feelings of sorrow (Beltrão, Vasconcelos, Pontes, & Albuquerque, 2007; Klassmann et al., 2008; Malta et al., 2008; Silva, Andrade, Barbosa, Hoffmann, & Macedo, 2009).

Death is conceived as incompatible with childhood, as it contradicts the natural order of human development, in which the individual should go through adulthood and old age, to die only later (Freitas, 2000). Being faced with this situation can generate feelings of powerlessness (Beltrão et al., 2007; Moreira & Angelo, 2008), as the caregiver, while feeling responsible for protecting the little patient, has no power to reverse the disease or alleviate the suffering of the child (Moreira & Angelo, 2008).

Although the future is perceived as uncertain, the child's recovery and resumption of routine are ideals to be pursued through the hospitalization (Wegner & Pedro, 2009). In this sense, the hope for a better future is presented (Lacaz & Tyrrell, 2003).

In this context, it is important to highlight the semantic difference between the designations *to overcome cancer* and *to go through cancer*. In a study by Woodgate and Degner (2003), the families of children with cancer said that the disease would always be part of their lives, even after the end

of the treatment. Therefore, the experience of a child with cancer, from this concept, can be managed to the extent that it is understood that it is something that you can go through, but not completely overcome. According to this study, it is precisely this perspective that allowed the existence of a sense of continuity and recovery of freedom in the family life. Thus, accepting the impossibility of changing the reality, as well as the dissatisfaction with it, can also serve to maintain a sense of control over the situation (Tarr & Pickler, 1999). In this context, the belief remains that one day the child will be safe from the disease, which can act as a motivating factor for the parental care to be maintained, despite the exhaustion due to the function of caregiver (Moreira & Angelo, 2008).

It is known that the diagnosis, and sometimes the pre-diagnosis of cancer, may result in a process of anticipatory grief (Parkes, 1996/1998). This process does not arise only in situations in which physical death occurs, but also with respect to all loss situations. It implies the process of physical and emotional detachment from something valuable to the subject (Caballo & Simón, 2005).

Thus, anticipatory grief refers not only to the possibility of physical death, but also to the various structural modifications that the disease and treatment impose. This grief can be both for the profession the mother will have to abandon in order to accompany the child in the medical consultations, and for the role of the father that will be modified, including activities that were not previously their responsibility. Furthermore, there is grief for the loss of the home environment due to staying for long periods in clinics or hospitals, grief for the childhood routine, for the loss of regular visits to the school, for the frequent games with friends and grief for the youthful body that will undergo changes with the sessions of radiotherapy or chemotherapy (Nascimento et al., 2005).

This process also concerns the idiosyncrasies of the hospitalization. The hospital creates a number of requirements for the parents, who change their roles as the primary providers of care and become team collaborators. They maintain a passive stance regarding the decision making in relation to the child, suffering losses that relate to the exercise of their parental role, among others (Angerami-Camon, 2006; Boteaga, 2006; Quintana, Arpini, Pereira, & Santos, 2009).

The grieving process and the development of these provisional losses are important for the efficient assimilation of the new family situation. During this period, the parents can begin elaborating these losses and admitting the reality of cancer as a disease, which will help them to be fully able to engage in the process and assume the role of collaborators (Menezes, Passareli, Drude, Santos, & Valle, 2007).

The activities performed by the parents in coping with the cancer of their child involve a number of activities that may have the connotation of coping with a battle. Cancer is life threatening, and therefore an enemy (Moreira & Angelo, 2008), and, in addition to coping with a borderline situation between life and death in an ICU, the cancer treatment could

represent a military structure, in which there is *bombing with rays, chemotherapy, invading bacteria*. This war can be subtle, with covertly stipulated rules and roles (Oliveira, 2002; Quintana, Kegler, Santos, & Lima, 2006).

In this sense, the more known about the disease, the greater the sense of empowerment to face the struggle against cancer (Beltrão et al., 2007; Moreira & Angelo, 2008). From the perspective of the parents, such a struggle is experienced from them and their children coping together, as inseparable dyads. Therefore, it is necessary to become a full-time parent, without rest, and to live according to the sick child. The fuel for the fight against the disease is referred to as unconditional love for the child (Moreira & Angelo, 2008).

From the diagnosis of the disease, there are reports of the experience of despair, fear, denial, guilt, and anger (Ortiz & Lima, 2007; Silva et al., 2009; Tarr & Pickler, 1999). In this context, Kübler-Ross (1926/2008) defined five emotional stages, whereby the patient and the family can move to become aware of the severity of the disease and face the struggle for a healthy body: denial, anger, bargaining, depression, and acceptance. Referring to the feelings of the family members, denial begins when the family receives the diagnosis and acts as if the disease did not exist. It is a temporary defense until the passage to the next stage. Anger appears when denial is no longer possible and the reaction is weeping and sorrow, with the family visits to the patient being difficult and causing suffering. The bargaining, which is the third stage, occurs over a very short period, seeking a cure in all possible ways, primarily through religious promises. Depression is well known. It is divided into: reactive, which is at the beginning, where the family undergoes as a form of preparation for coping with the disease, and preparatory, which involves the imminent losses. Finally, acceptance occurs when there is grief for the imminent losses.

At the time of the diagnosis, the healthcare team is viewed ambivalently in several studies. On one side, it is seen as a group which adds to the care for the sick child, and on the other as an obstacle in measuring the correct diagnosis (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; Holm, Patterson, & Gurney, 2003).

There are experiences reports in which the medical knowledge seems to interpolate the common knowledge of the parents regarding the general health of their children, and there are parental reports of indifference, incompetence, delays, lack of action and failure of the physicians to seriously consider their concerns (Dixon-Woods et al., 2001). Furthermore, they emphasize the reports of parental perception regarding the lack of clarification from the healthcare team about waiting time, remedies and treatment, as well as their effects. However, the idea that their role is to provide continuous information for the family appears in the reports of the medical team (Tarr & Pickler, 1999).

This dates back to the dichotomy in the biologist paradigm of modern medicine, which often ignores common sense knowledge about the health-disease process and favors

scientific knowledge based on signs and symptoms (Helman, 1990/2009). From these considerations, the importance is highlighted of an attitude of recognition of the subjective aspects involved in the illness and treatment by the families of children and adolescents with cancer.

In light of the theoretic review described, the subjective aspects mentioned will be explored in this study through the use of a triangulation of data collection techniques not previously described in the scientific literature, according to the search performed by the authors of this study. Thus, the intention was to propose a methodological approach with strategies for collecting additional data, which could contribute to a deeper understanding of the topic. Considering this perspective, this study aimed to comprehend the meanings that the parents/caregivers of children and adolescents diagnosed with cancer attribute to the illness of their child.

## Method

This is a qualitative, exploratory, descriptive study. It is understood that this approach, when studying the quality of the object and focusing on the senses and meanings of the phenomena, is the best suited for the analysis of the subjective experiences of the individuals interviewed (Turato, 2003).

### Participants

Interviews and focus groups were conducted with the parents/caregivers of the children and adolescents with cancer, with the inclusion criterion that the person resided with the child when outside the hospital. It was also decided, as inclusion criteria, to select those residing in the city of Rio Grande do Sul, where the hospital is located or that attended it during the period of data collection. There was no prior delineation of a number of subjects for the study. Thus, all subjects who met the inclusion criteria were invited to participate in the study. Ten parents/caregivers participated in the discussion groups and three individuals agreed to take part in the interviews.

### Instrument

To achieve the study aims, the data were collected by conducting discussion groups and individual interviews. From the beginning of the fieldwork a diary was kept, this being a way to record and systematize all the impressions of the researcher, the contradictions in the statements that occurred in the group and interview, as well as the refusal to participate in the study. Thus, the issues raised by such work were recorded, according to the guidelines suggested by Minayo (1996), to assist in the interpretation of the interviews.

The interviews were used as the data collection instrument due to the assumption that they allow the informants to reliably express and communicate their experiences, representations, concepts and ideas (Chizzotti, 1998). The semi-structured interview format was used, as the flexibility of this

type of interview allows it to be constructed according to the personality variables of the interviewee, portraying their experiences, ideas, attitudes and behaviors (Bleger, 1980/2007).

The discussion groups complemented the interviews because in them the primary role is played by the opinions, relevance and values of their components. This strategy, due to the interaction of its members, also allows themes that emerge in the individual interviews to be clarified. Indeed, it is believed that interaction in groups enables the visualization of new forms of interpretation of the problem addressed (Jovchelovitch, 2000).

In the interviews and in the groups the following points, identified as guiding principles of the work, were addressed: the child before and after the diagnosis; the family before and after the diagnosis; the child's illness; the moment of the diagnosis; the communication of the disease process within the family; expectations regarding the future. These axes were defined from prior exhaustive reading of the scientific literature on the subject, through which some subjects that emerged more often as fundamental for the understanding of the disease process related to cancer were perceived.

The group was directed by the previously defined guiding axes, investing in the proposal of the discussion aiming to stimulate the expression of the interviewees, so that they could contribute what they considered most relevant to each topic. Furthermore, the issues presented in the group tended to resonate between the members and provide a greater exchange of information. The individual interviews were conducted aiming to comprehend the unique aspects of each experience, deepening the content or bringing new issues that were not covered in the groups.

## Procedure

**Data collection.** The groups were coordinated by appropriately trained members of the research team (one coordinator and one co-coordinator, undergraduate Psychology students). The groups started with an invitation to speak of the experience, with the themes that were covered described above. The proposal was that an informal conversation was formed about the experiences related to the theme, and the coordinators only intervened with more specific questions if the group members did not cover the previously established items.

With the consent of the individuals, the interviews and groups were recorded on a digital recorder and fully transcribed for later analysis. In the transcripts, the names of the interviewees were replaced by the following codes: G (refers to group interviews), E (refers to individual interviews) and R (refers to reports made by the researcher in the field diary). The statements of the participants were thus identified by the letters R, E or G, followed by the word *Family* and by the alphabetic letter that identifies the different subjects. For example: E, Family A.

Three discussion groups were held, composed of the group coordinator, an assistant and the parents/caregivers. After the discussion groups, the parents/caregivers were invited to participate in individual interviews. There was an

attempt to schedule interviews with the ten caregivers, however, only three individuals agreed to participate. Of the seven that declined, it was not possible to make subsequent contact with four of them, whose children were discharged. The other three showed avoidance behavior to the approach of the researchers, stating that they were unavailable. These behaviors and statements were recorded in the field diary.

**Data analysis.** As a reference for the analysis of the transcribed material the content analysis technique proposed by Bardin (1977/2008) and Turato (2003) was used. Content analysis according to Bardin (1977/2008), refers to the transformation of speech into relevant units of analysis, aiming to discover content that are implicit in the manifest content. The aim is, therefore, to create a relationship between semantic structures (signifiers) and sociological and psychological structures (signified) from those supplied by the subjects. From the perspective of Turato (2008) the use of this analysis encourages the researcher to go beyond a merely descriptive stage of data analysis, legitimizing the place of the researcher as the interpreter of the content. From this, a particularization and refinement of the technique of content analysis was proposed, which refers to the search for the latent meanings present in the narratives. This process took place from the comprehension and joint discussion of the researchers regarding the material, using a psychodynamic perspective of comprehension to guide the interpretations.

Following the directions of Turato (2003) for processing and presenting the data, after the transcription of the material, free-floating reading was performed until the point of immersion in the content. Thus, according to criteria of relevance and repetition, the emerging topics were categorized. Finally, external validation of the data was performed with the discussion of the categories by the research group, followed by the presentation of results. The data were validated by the criteria of relevance (from the comparison with the existing literature and in discussions with peers who study the subject) and frequency (from the comparison between the categorizations made individually by the authors).

## Ethical Considerations

The guidelines of Resolution 196/96 of the National Health Council, which regulate the conditions of research involving humans, were followed. The field activities envisaged in this study were only carried out after approval by the Ethics Committee of the *Universidade Federal de Santa Maria*, where the study was performed (Protocol CAAE No. 0146.0.243.000-08). All the participants of this study consented to participate through their signing the Terms of Free Prior Informed Consent.

## Results and Discussion

The results of this study are organized into categories and subcategories, described below, considering themes significant for the aims of the study.

## Cancer: A Strong Name

To say the word *cancer* in front the parents of a child in the diagnosis stage is often perceived as being a prophecy which culminates in death (Beltrão et al., 2007; Klassmann et al., 2008; Malta et al., 2008; Silva et al., 2009). This stigma goes with the concept that the child is a fragile being. The idea of death in childhood is something that contradicts the natural order of development (Freitas, 2000) and, therefore, the grief due to the existence of a malignant disease in a child or adolescent may be experienced more intensely. Interviewee 3 of family J, said: "(...) but my fear was that he would just say "I have cancer" and that would make him desperate. We know that cancer is a strong name". In this narrative it was perceived that the word *cancer* carries a stigma, which can be avoided through the use of other denominations, which may seem milder. Regarding this, in the discussion group, G2, the participant of family E, reported: "I always said it was a, it was a little tumor, I never said it was cancer because it was too strong". This, therefore, presents an implicit idea that by preventing the disease being named it can be avoided. In contrast, when the real is interposed, so that it is exposed and not "hidden" in semantically mild words, there is more intense despair, as evidenced in the following statement: "But I'm afraid, I think, I don't know, to me it looks like, none of the children here will be saved" (E1, Family E).

Apprehension that the mere utterance of the word "cancer" can already be announcing the evidence of death appeared in the statements. Accordingly, the naming of the disease seems to represent the entry into the world of expectations of losses arising from the disease situation, part of the process of anticipatory grief (Parkes, 1996/1998).

To not say the word, therefore, may represent magically not allowing the disease to culminate in finitude. In this sense, to protect the child from the diagnosis seems to have the sense of protecting him/her from the reality of death. Therefore, the child is pushed away under the pretext that this reality represents an overload that he/she can not cope with (Kovács, 1992; Kübler-Ross, 1926/2008). Conversely, when the disease is already at an advanced stage, death can appear as a relief from the suffering that the disease and treatment provoke. This can be illustrated in the story of one of the family member: "For me he was going to die on the next day. This was not living. I was already prepared for it there" (G1, Family A).

## To Deny: Between Wanting and Not Wanting to Talk

The majority of the study participants demonstrated an ambivalent stance when talking about the experiences related to the disease of their child. Such a reaction was evident in the refusal to participate in the individual interview, even after contact with the experience of speaking in the group. However, even with the refusal, many parents ended up speaking about the suffering and feelings present.

The statement below shows that, despite the need to expose their troubles, when seeking a Psychology professional, there is an attempt to escape the theme: "(...) I'll be very honest: I can not stand seeing a psychologist [referring to the psychologist of the hospital] in front of me! When a psychologist comes to talk with me I immediately say "no, no, no, I do not want to talk". The psychologist says I am, how is it? Resistant, I do not want to talk to her" (R3, Family B). In another narrative, one family member stressed that not wanting to talk about a past moment, such as the diagnosis period, can be a way of coping with the disease, "That's it, to keep remembering, speaking about bad things, of how it was when they discovered the cancer... I wouldn't want to talk about this... that day in the group I even left early" (R1, Family D).

Some parents avoided the presence of the researcher and others asked that the interview be rescheduled due to other commitments. It is understood that such a stance is understandable, due to the idea that talking can somehow mean *re-living* the suffering constructed in the history of the disease. The existence of deep pain is therefore highlighted, which could not even be signified, possibly due to the psychological impact that the knowledge of the disease causes, generating experiences of despair, fear, denial, guilt and anger (Ortiz & Lima, 2007; Silva et al., 2009; Tarr & Pickler, 1999). The posture of denial of the parents regarding the disease is also demonstrated in the attempt to hide the diagnosis from the family and the child him/herself. Often, under the pretext that it is inaccessible knowledge, the news is not passed properly: "The others [children] think he has a little problem and do not understand anything, you know. So we do not talk much..." (E2, Family H). There was a case of a mother who did not comment on the diagnosis with the adolescent son, so even after being subjected to long invasive procedures, the young man did not have the space needed to access information about the disease and treatment process. "And I never told him, I do not have the courage to tell him. If he finds out it will be from the mouths of others, because I do not have the courage to go to him and talk. I don't know how to tell him! I never told him" (G2, Family E). The contention of the information is also related to an attempt to protect the family, as expressed in the following narrative: "My family had said not to say anything to me for now, until someone arrived (...) if I heard anything I would faint" (G1, Family A). In some cases there was still a desire not to know the real facts, perhaps because there is the expectation that, by ignoring the reality of the treatment, the existence of the disease can be ignored, "Do not tell me what I want, I do not want to hear this" (G3, Family J).

According to Kübler-Ross (1926/2008), the reaction of denial is an attitude expected due to the impact of the news of the loss. It can serve as an ego defense not to succumb due to the immense psychic pain of knowing that you have a child with cancer. However, denial can be seen as deleterious

if prolonged. This reality is present in the cases in which a very extended period of denial prevents the subjects from coming into contact with the reality of the disease and seeking treatment (Botega, 2006).

### **The Fight Against Cancer: “Some Win, Others Lose”**

Cancer may be experienced as a war, in so much as it represents a constant battle with death. It therefore represents an enemy that must be fought (Moreira & Angelo, 2008). The context of the disease, thus acquires shades of meanings of a military structure, where fights and battles need to be fought (Oliveira, 2002; Quintana et al., 2006). Warlike expressions are very common in the discourses of family caregivers, “We are here, you know, fighting, but, as the nutritionist said, winning some, losing others, but it is part of the game” (G2, Family G). The use of the word *fight* to express the reactions of the family due to the discovery of the disease was also perceived in another discourse: “(...) we are fighting and will certainly succeed” (G3, Family K).

According to the claims of Moreira and Angelo (2008), such a fight is only possible due to the existence of unconditional love for the child. It should be noted that the simple fact of being able to fight the disease, for some study participants, seems to mean the chance of having a sense of control, due to the feeling of powerlessness that the disease and its treatment create (Beltrão et al., 2007; Moreira & Angelo, 2008).

### **About the Future: The Fear and Hope for Health**

Expectations about the future seem to be guided by two perspectives, namely, one that refers to the fear of the prognosis and recurrence and another that refers to the hope for a better future.

**The fear.** Cancer is a disease that brings with it devastating consequences, since despite the cure, a recurrence of the disease is possible (Misko & Bouso, 2007; Ortiz & Lima, 2007). Thus, the concept of a cure in oncology can have a sense of uncertainty, with the term *survivor* being used. This concept seems to establish a better relationship with the possibility of a recurrence. With this, the worry and resistance in declaring the cancer cured is clear (Arrais & Araújo, 1999).

It is understood that the end of oncological therapy is not sufficient to establish a possible cure, and the patient and family undergo a paradoxical experience. This reality seems to generate feelings of despair in the parents of children or adolescents with cancer, as constant precautions are required even after the hospital discharge (Arrais & Araújo, 1999). The following narrative depicts the temporariness of the situation experienced, due to the possibility of a recurrence of the disease: “(...) you can stop or advance from one time to another. So we have to be prepared, there is a cure, but it can come back after a while, they did not guarantee that it was cured and would never come back” (G2, Family F). This state of temporariness is also implicated in the ignorance of

the time involved in the treatment: “I’m already here for the third time. The first time you do not know what you will face, do not know what you will happen. (...) Then when you see, you cope. You do not know how long. No need for any more treatment, it is cured! When you see, the disease has returned! Then you know you will get it again, even stronger” (G1, Family B).

Such experiences refer to a reality in which the experience is *suspended*, always dependent on the diagnostic confirmation of the disease. In this context, it is thought that it makes sense to say, in agreement with Woodgate and Degner (2003), that one can not speak of overcoming the disease, but of the possibilities of living with the threat of recurrence.

Furthermore, the feeling of fear faced with the future expectations is expressed through the situation of treatment and hospitalization. Faced with the unknown, one might think that the anxiety level rises and the experience of suffering increases.

“So, it has been a year that I have not had peace, I cannot rest, you know. I’m always terrified (...) every time I have to come to the hospital on the examination day I am already terrified, while the doctor does not show me, does not give me the results of the examinations, while he does not say how the defenses are, whether I have to stay or not, that always makes me nervous and tense” (G2, Family E).

It is considered that the suffering present in the statement of this participant could be reduced to the extent that the more you know about the disease, the greater the sense of control over it and the strength to face it (Beltrão et al., 2007; Moreira & Angelo, 2008).

**The hope for health.** Conversely, the parental expectations of the study participants often alluded to hope for a better future, contemplating greater health for their children. This hope seemed to be based on the belief of the potential to seek health, from both the medical resources and the resources of the parents themselves. The following statement refers to a “investment” in the medical treatment as a resource for the recovery of health: “Yes, yes, she will do physical therapy, the doctors said the movements will return” (R2, Family M). Such an “investment” on the part of the parents/carers, also involves the need to maintain a hopeful attitude, tied to faith in a healthy future: “You have to hope, cannot lose hope, cannot lose faith or hope” (E2, Family H).

It is considered that this hope is one of the factors that helps support the parents as caregivers (Moreira & Angelo, 2008). Although latent in the reports of the mothers, it can be seen that the hope is fragile and that many seem skeptical about the possibilities of a cure for the children, it is interesting how the narrative expressly seeks to maintain the faith. Through the belief that better days will come, it is possible to experience the present as the construction of this desired future. Otherwise, it would be like admitting that the fight is for a lost cause. Thus, the expression of hope in the statements of the mothers can be understood as a motivation to continue the treatment.

## Final Considerations

According to the analysis presented considerations can be produced that highlight the significant implications of childhood cancers in the family dynamics. It should be noted that throughout the experience of the diagnosis and treatment, according to the reports of the caregivers, the emphasis is on a defensive posture. This posture implies denying the reality of the disease, at least partially, as evidenced in the difficulties of the research participants in talking about the experiences related to it. It seems to be a movement of protection, both for themselves and for the child/adolescent patient, to the extent that talking may mean reliving the pain.

Therefore, for the family, the disease period is characterized by intense suffering accompanying the patient. This period shows itself to be permeated by ambivalent feelings, which sometimes refer to the fear of death and sometimes the hope for a cure. Ultimately, the uncertainty about the future and the social representation of cancer as a lethal disease seem to permeate the experiences, which can be understood under the aegis of helplessness. A paradox is installed, in so much as the function of the family would be to protect the child/adolescent. However, the disease seems to leave no room for such a possibility, seeming to submit the caregivers to a sense of powerlessness.

It is known, however, that despite the borderline situation that the disease imposes, the treatment involves the possibility of reacting to the disease. The psychic support for this possibility, especially when the child or adolescent is affected by cancer, involves a family setting that allows the experience of assigning meanings to this reality. For this purpose, spaces are necessary where the free circulation of speech is permitted, in which doubts may be exposed and feelings shared, allowing the rigidity of the denial of the disease to be gradually diluted. In this sense, to construct a formal space within the hospital, where the actors involved in the treatment process can interact in a closer way, may be a possibility for strengthening the family structure. This study provides elements for the construction of such a space, in that it contributes to the comprehension of the unique aspects experienced by the parents and caregivers of children and adolescents with cancer. The discussion undertaken in this article should therefore provide the basis for the construction of healthcare actions guided by the perspective of Integrality and Humanization, which allow the protagonism of those involved in the oncological treatment.

It should be highlighted that this study provides a partial perspective, due to two aspects, regarding the experience of coping with the disease. On one side, it is an exploration of meanings from the understanding of the family structure, i.e., restricted to only one of the parties involved in the treatment. Furthermore, it is also restricted to a specific group of a particular region of the country. Despite these limitations, this study advances the broadening of the comprehension of the meanings attributed to the oncological disease in the context of healthcare for the patient and family. This contribution

mainly lies in the specificity of the method used for the data collection. It is understood that the use of group discussions, as a technique, enabled the emergence of a context of identification among the family members and caregivers, allowing the construction of meaning through the sharing of their experiences. The interviews complemented the data from the groups, however, simultaneously, the difficulty regarding acceptance to participate in them, on behalf of the family members, refers to the idea that the group context may become important to drive the construction of narratives, in the case of experiences that generate anxiety, as described in this study. It is hoped that this experience will contribute methodologically to the construction of future studies, through the exploration of similar scenarios, with the performance of research with other groups, as well as the possibility of integrating the concepts of the medical team regarding this reality.

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