

## “I literally did not know what it was to feel pain”: the grieving process in families of pediatric oncological patients

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**Abstract.** Objective: Cancer is one of the most feared diseases, for being the second leading cause of death in Brazil and for presenting an extended and painful treatment. When the child is sick, the family experiences the getting ill, the losses that result from the treatment and the anticipatory grieving process by the possibility or certainty of close death. It is a difficult and little discussed theme, that requires more research investments. In face of this demand, the present study aimed to analyze the process of grief experienced by the caregiver relatives of children with cancer. Method: It was made an exploratory research, of qualitative approach. Because of overload standard, it counted with the participation of 10 caregiver relatives (father or mother) of children with cancer, that answered a semi-instructed interview script, understood by the textual analyzes in the IRaMuTeQ software (*Interface de R pour les Analyses ultimensionnelles de Textes et de Questionnaires*). Results: The results showed that the grieving process is present since the diagnosis and remains during the whole treatment. It is experienced due to the suffering, caused by all the losses that come from the treatment and by the possibility or certainty of the child's death. Conclusion: There is the necessity of unveiling this theme, inviting parents to talk about the unspeakable – the grieves lived during the treatment -, and offer support to the family in all treatment's phases, with special attention to the care of the caregiver.

**Keywords:** Pediatric oncology, child, relative caregiver, grief, death, daily losses.

## [es] “Yo, literalmente, no sabía lo que era sentir dolor”: el proceso de duelo en familiares de pacientes pediátricos con cáncer

**Resumen.** Objetivo: El cáncer es una de las enfermedades más temidas, por ser la segunda causa de muerte en Brasil y por presentar un tratamiento prolongado y doloroso. Cuando la enfermedad afecta a un niño, la familia vive el enfermarse, las pérdidas derivadas del tratamiento y el proceso de duelo anticipatorio por la posibilidad o certeza de muerte inminente. Este es un tema difícil y poco discutido, que requiere una mayor inversión en investigación. Ante esta demanda, este estudio tuvo como objetivo analizar el proceso de duelo que viven los cuidadores familiares de niños con cáncer. Método: Se realizó una investigación exploratoria con enfoque cualitativo. Por criterio de saturación participaron 10

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familiares cuidadores (padre o madre) de niños con cáncer, quienes respondieron un guión de entrevista semiestructurado, comprendido a través del análisis textual en el software IRaMuTeQ (*Interface de R pour les Analyses Multimensionnelles de Textes et de Questionnaires*). Resultados: Los resultados mostraron que el proceso de duelo en el cáncer infantil está presente desde el diagnóstico y permanece durante todo el tratamiento. Se vive desde el sufrimiento, provocado por todas las pérdidas derivadas del tratamiento y por la posibilidad o certeza de la muerte del niño. Conclusiones: Es necesario desvelar este tema, invitar a los padres a hablar sobre lo indecible –los duelos experimentados durante el tratamiento–, y ofrecer apoyo a la familia en todas las etapas del tratamiento, con especial atención al cuidado del cuidador.

**Palabras clave:** Oncología pediátrica, niño, familiar cuidador, duelo, muerte, pérdidas diarias.

**Sumario:** 1. Introduction 2. Method 3. Results 4. Discusión and conclusiones 5. References.

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## 1. Introduction

Cancer is characterized as a severe worldwide public health problem. When expressed in numeric data, it is responsible for 12% of world's death, with more than six million deaths every year. In Brazil, it is the second leading death cause of the population, with 190 thousand cases every year, being 60% diagnosed in an advanced stage<sup>(1)</sup>.

Among these numbers, it is the child cancer, understood as every malignant neoplasia that affects kids under 15 years old, and which represents the main cause of death in this group<sup>(2,3)</sup>. In this age range, the most frequent tumors are leukemia, lymphoma and the ones that affect the central nervous system<sup>(4)</sup>.

The care for child cancer has had a great progress in recent years, as nowadays, approximately 80% of the children and adolescents are cured, from early diagnosis and treatment in specialized places that facilitate their quality of live in the following years<sup>(4)</sup>. On the other hand, many families receive the diagnosis in denial and delay it until the appearance of symptoms of a more severe condition of the disease, so the diagnosis can be confirmed and accepted, so this is one of the obstacles in this initial phase<sup>(5)</sup>.

At the moment when a family is faced with the cancer diagnosis, it can be observed the emergence of various emotions and feelings, such as fear and sadness, by the loss of health and possibility of the child's death. After the beginning of the treatment, some changes and losses occur for all involved, altering the day-to-day life of the child and relatives<sup>(6-8)</sup>.

The life and routine of children with cancer change. The small patient is hospitalized and needs several invasive procedures, that cause nuisance, fear and discomfort, with shots, serums and medicines, marking a new routine very different from their experience as a child. He or she starts to suffer with a series of limitations that make it impossible for him or her to do what he or she likes, not being able to play with friends, eat what desires, or run, because he or she gets easily tired<sup>(9)</sup>. The child continues, at each stage of the treatment, suffering gradual and cumulative

losses, that often reduce him or her as the place of “child with cancer”, affecting them and generating devastating effects for an indefinite period of time<sup>(10)</sup>.

This treatment routine also affects his entire family context<sup>(11)</sup>. Financial, social and psychological changes occur<sup>(12)</sup>. The family, and especially the child’s main caregiver, experience several symbolic losses during the illness process, such as: the abandoning of the home; the distance from the family, work, friends and from the social relationships; the loss of identity and life plans. The parents often start to live for the child and assume the identity of “parents of a child with cancer”<sup>(6)</sup>.

In this process, the family has a very important role in the care and support of the child<sup>(11)</sup>. On the other hand, its members also have to deal with the challenges, the frustrations and the suffering caused by the disease<sup>(10)</sup>. Therefore, the family is an agent of care for the child, but the members are also subjects who demand care since the beginning of the treatment, through the support and reception of healthcare professionals and their support network.

Amidst these adversities, the grieving process of everyone involved can start since the diagnosis and go through the entire treatment against cancer. It occurs as a result of the losses deriving the disease and its treatment; but also through anticipatory grief, experienced by the possibility or certainty of the child’s death, helping its elaboration and realization<sup>(6,10,13,14)</sup>.

When the patient is in the treatment process, usually the family’s attention is concentrated on the search for a cure<sup>(13)</sup>. Despite this, ambivalent feelings arise: the hope of a miraculous cure, the desire of the patient’s death so the suffering can be alleviated, and the feeling of guilt. The feeling of impotence prevails when the caregiver is unable to relieve and help in the patient’s well-being<sup>(14)</sup>.

In this moment, if the disease advances and the curative therapies do not work, the possibility of changing the approach utilized appears, through the transition of a drug curative treatment to palliative care<sup>(15)</sup>. Several reactions arise with this possibility of change, bringing sadness, pain and suffering to the family, due to the proximity of death; and relief and peace due to the end of invasive and painful procedures in the patient<sup>(15,16)</sup>. The balancing of benefits and prejudices will affect the choice of the family between two possibilities: the acceptance of palliative care or its refusal, with the maintenance of curative care in dysthanasia.

In any of these forms of care, the possibility of losing a child is something disturbing for the whole family. Its members face the difficult task of imagining a future without him or her and, consequently, they live the ambivalence between the desire of alleviating the suffering and the avoidance of his or her death at any cost, generating the feeling of impotence, anguish and tiredness to bear all this<sup>(15)</sup>. In some moments, the feeling of hopelessness and exhaustion arises due to the long periods that the treatment requires, even more so for experiencing the death of other children in the hospital context, during this process<sup>(13)</sup>. In this phase, the grieving process experience started since the diagnosis is intensified<sup>(13)</sup>.

The grief arises as a natural, emotional, cognitive and biological reaction to a significant loss (or the possibility of it) of a bond with something or someone<sup>(17)</sup>. It appears when our presumed world, as we know it with that person/object, is shattered by its loss. Lived in the midst of an intense and penetrating reaction, the grief is the price of love. This is because love is the strongest feeling that binds individuals, which causes resistance and non-acceptance to the rupture of the bond between those who live and what/who dies<sup>(18)</sup>.

The grieving process is heavy, painful and complex, from which many changes occur, generating profound changes in the bereaved person<sup>(19)</sup>. It is a unique and subjective experience, which can not be generalized, occurring in different ways, varying from person to person, according to their experiences, relationship with the person/object lost and resilience<sup>(20)</sup>.

It is possible that the family caregivers experience some grief stages, as stated by Kubler-Ross<sup>(21)</sup>: denial and isolation, which occur at the moment of announcement and difficulty in facing the possibility of death; anger, in which it is observed the feeling of outrage for no longer being able to deny the diagnosis; bargain, in which one seeks to commit to the treatment to achieve the cure; depression, for the losses that have been experienced, such as the loss of the body, work; acceptance, in which the person is already calmer within the process, seeking to no longer fight against death. It is important to emphasize that these stages are not linear, mandatory and do not necessarily occur in this order. It is recognized, however, that, respecting each subject's singularity, these stages help understanding grief<sup>(14)</sup>.

Within a younger generation of theorists about the subject, mourning is understood as an essential, unique and dynamic process. For example, based on the Dual Process Model of Grief, by Stroebe and Shut<sup>(22)</sup>, it can be understood that the parents of a child with cancer have moments of oscillation between the orientation toward the loss, recognizing it and accepting it, and the orientation toward restoration, dealing with the adaptations of a life without the lost person. Similarly, Bonanno, Westphal and Mancini<sup>(23)</sup>, based on the theory of the four trajectories of grief and trauma, state that there are a variety of ways to deal with potentially traumatic events, highlighting the main mourning trajectories: resilience, recovery, chronic suffering and late suffering, being the resilience the most common response. Complementarily, based on Worden's Four Tasks of Mourning<sup>(24)</sup>, it is understood that four tasks must be performed by the bereaved family: (1) accept the reality of the loss; (2) elaborate/work the pain of the mourning; (3) adjust to an environment in which the deceased is absent; and (4) relocate, emotionally, the deceased person and move on with life.

To bear this grieving process of family members of children with cancer, different strategies can be used, such as trust in God and faith in divine power, because, often, when the powerlessness is noticed in face of the disease, this is the way hope can be maintained<sup>(25,26)</sup>. Support can also be found with relatives and friends that offer strength and courage to continue<sup>(13)</sup>, or even in other families that are experiencing similar situations<sup>(25)</sup>.

It is important to highlight that this experience of having a child with cancer does not end when he or she is cured or dies. The marks of this process will influence the parents' lives, their way of seeing the world and of being<sup>(25)</sup>. After year of dedication and care, if/when the child dies, what is established is a feeling of emptiness, difficult to fill. The family seeks to reorganize after the loss, trying to accept it and start a new life, something that could take years<sup>(14)</sup>. On the other hand, when there is a cure, all the pain and adversity overcome can also generate a redefinition and appreciation of life, which significantly transforms them.

Understanding this experience is important to base the decision-making on intervention strategies to support family members of children with cancer, during their process of diagnosis, treatment, dying and death. In response to this demand, this study aimed to analyze the grieving process experienced by family caregivers of children with cancer. Its assumptions are that: (1) families receive the cancer

diagnosis as a death sentence; (2) families are grieving for daily losses arising from illness and routine treatment; (3) family members experience anticipatory grief over the possibility of the child's death; and (4) family members utilize spirituality to face anticipatory grief.

## 2. Method

### *Type of research*

It was developed an exploratory, descriptive, transversal research with a qualitative approach, which sought to delve deeper into this topic that has been little explored in the literature.

### *Participants*

According to the saturation criterion<sup>(27)</sup>, 10 family caregivers (father or mother) of children with cancer participated. The inclusion criteria were: being over 18 years old; being a family caregiver of a child with cancer; having a bond and proximity to the child undergoing cancer treatment.

Table 1. Sociodemographic data of participants

Nº	Relationship	Place of Birth	Age	Profession	Religion	Type of Cancer	Family Members
1	Mother	São Benedito	71	Retired	Catholic	Osteosarcoma	Mother, 4 children (1 adopted)
2	Mother	Trairi	37	Farmer	Catholic	Lymphoma	Mother and 2 children
3	Mother	Fortaleza	41	Adm Assistance General Services	Catholic	Ewing Sarcoma	Mother, father and 1 child
4	Father	Pará	47	Physiotherapist	Catholic	Oropharynx Carcinoma	Mother, father and 2 children
5	Mother	Fortaleza	37	Financial Manager	Evangelical	Leukemia	Mother, father and 3 children
6	Mother	Fortaleza	41	Judge	Catholic	Leukemia	Mother and 2 children
7	Mother	Fortaleza	40	Professor/Freelance	Catholic	Acute lymphoblastic leukemia	Mother, father and 2 children
8	Mother and Father	Fortaleza/Pará	28/33	Occupational Therapist	Evangelical	Leukemia	Mother, father and a child
9	Mother	Fortaleza	36	Psychologist	None	Leukemia	Mother, stepfather and 2 children
10	MOther	Fortaleza	40		Spiritist	Embryonal Rhabdomyosarcoma	Mother, father and 2 children

### *Instruments*

A semi-structured interview script was used, consisting in 15 questions addressing the following themes: (1) Anticipatory grief in family caregivers of pediatric cancer patients; (2) Loss processes during the treatment of child cancer; (3) The perception of family members about the possibility of losing the child; and (4) Family member's coping strategies during the grieving process.

### *Ethical and Data Collection Procedures*

Considering the ethical aspects related to research involving human beings, this research was approved by the Brazilian Research Ethics Committee, under report No. 3.773.755. Subsequently, the participants were contacted following the snowball sampling, from which a participant (chosen intentionally or according to the researcher's convenience) indicates another participant to constitute the sample<sup>(28)</sup>. After accepting the invitation, the interviews were conducted individually, with the aid of a recorder, in a place chosen by the participants, with an average duration of 42 minutes. Throughout the process, all ethical aspects involving research with human beings proposed by resolutions 466/12 and 510/16 of the Brazilian National Health Council were respected.

## **3. Data analysis**

The interviews were understood through the IRaMuTeQ software (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), a free program, developed by the French researcher Pierre Ratinaud, which seeks to apprehend the structure and organization of the speech, being able to inform the relation between the most frequent lexical worlds enunciated by the research participants. It is a software increasingly present in qualitative research in Human, Social and Health Sciences, which brings data to be analyzed with a large textual volume and seeks greater methodological rigor<sup>(29)</sup>.

The analyzes were carried out in three stages. Initially, the Word Cloud grouped the words and organized them graphically according to their relevance, being the larger ones the most frequent used, disregarding those with a frequency lower than 10. Next, classical lexicographical analyzes were obtained for statistical verification of the number of text segments – TS (text cuts of approximately three lines), evocation and shapes. Finally, the Descending Hierarchical Classification (DHC) was extracted for the recognition of the dendrogram with the classifications that emerged, where the greater de  $\chi^2$ , the more associated is the word with the category, disregarding the words with  $\chi^2 < 3,80$  ( $p < 0,05$ ). In this last stage, the material comprehension and categories naming were carried out by two judges and, based on the material that emerged in each category, a content analysis by Bardin was performed for greater depth in the analysis of the material.



Figure 2. Descending Hierarchical Classification Dendrogram

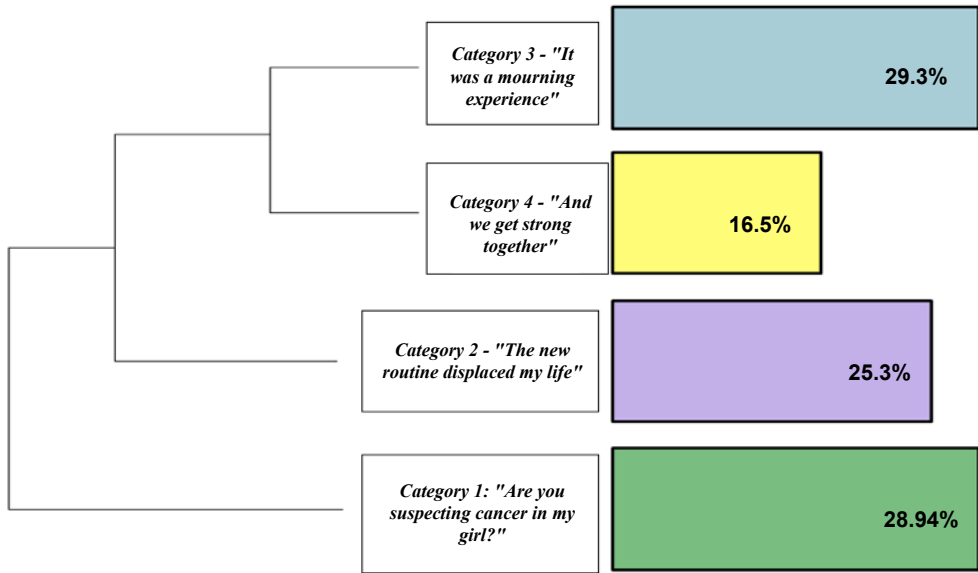
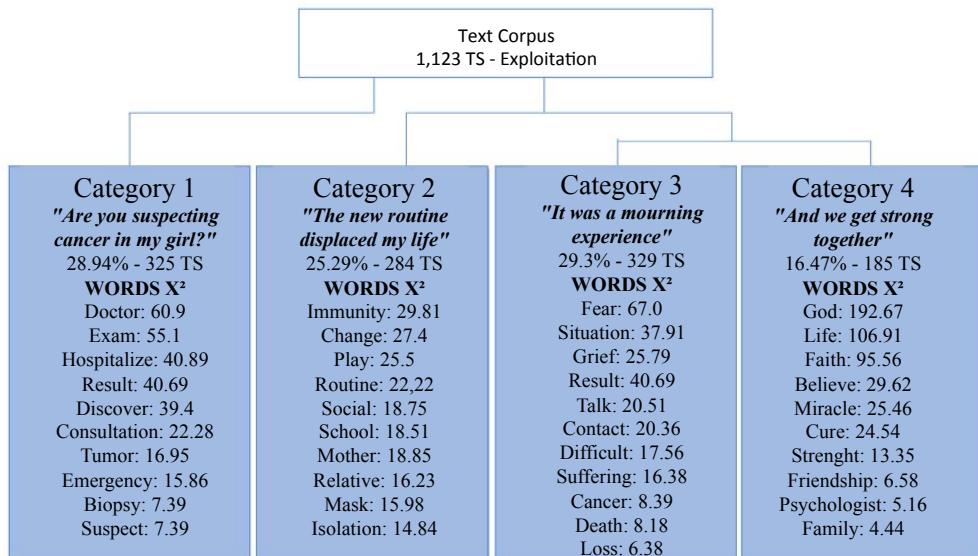


Figure 3. Categories Diagram





### **Category 1- – “Are you suspecting cancer in my girl?”**

It Involves 28.94% ( $f=325$  TS) of the total analyzed corpus. Consisting of words and radicals in the range between  $\chi^2 = 3.85$  (Until) and  $\chi^2 = 69.97$  (Day), this category is composed by words such as “Doctor” ( $\chi^2 = 60.9$ ); “Exam” ( $\chi^2 = 55.1$ ); “Hospitalize” ( $\chi^2 = 40.89$ ); “Result” ( $\chi^2 = 40.69$ ); “Discover” ( $\chi^2 = 39.4$ ); “Tumor” ( $\chi^2 = 16.89$ ); “Biopsy” ( $\chi^2 = 7.39$ ) and “Suspect” ( $\chi^2 = 7.39$ ). The category addresses the difficulties that are encountered during the search for the diagnosis of child cancer, since the onset of the first symptoms until the need for hospitalization for the realization of a series of exams and consultations. This process is characterized by feelings of uncertainty, despair, fear and anguish. On the other hand, the discovery period is marked by ambivalences: there is an intense suffering for the whole family, but also a relief for having found the disease and being able to start the treatment.

*You imagine a child entering a hospital, thinking he or she had only a constipation and, suddenly, going through a biopsy [...] through a lot of super painful procedures. There, hospitalized, out of nowhere, suddenly having to be there and see he or she going through all that, without knowing it, because it could be everything. The hypotheses were around 6 different types of cancer that were part of the initial hypotheses. And we had the diagnosis [...] and I think that the worst moment was this until we knew what was happening, because the hypotheses we each worse than the other (Participant 10).*

*When we got there, the doctor told me he had cancer. Then I didn't tell him, because I didn't have the courage, so I just cried, cried, went to the bathroom and cried. (Participant 2).*

*In the third or fourth hemogram which had already been ordered by an infectologist, when the result came out, the doctor had stopped the antibiotic, he warned that she was going to have a high fever again. She had a fever of nearly 40 degrees Celsius. When I received the blood test, which I had sent him, he already called me ordering me to get masks, that we would have to be hospitalized for a myelogram, which is an exam in the spinal cord [...] We were in the investigation phase and, truly, hearing that she was going to have to be hospitalized was my first despair. (Participant 7)*

*I tapped a doctor on the shoulder and said: - “Hey, tell me something [...] Are you suspecting cancer in my girl?” Then the doctor looked at me and said: - “We are, and it is”. She said like this, the doctor. She left [...]. She just said that, with that word [...]. Then I left the hospital, to an area that's there, there I cried, cried, cried. (Participant 1)*

*In fact, for me it was kind of a relief, like, knowing what it was, even though it was a cancer. I think that the most painful was the process of identifying what it was. We started in April, she was already feeling some pain. In fact, since the end of February she had been complaining of some pain. And then you're like, let's identify. One time the foot hurts, the other the shoulder, the other the ankle hurts, after is the knee. (Participant 9)*

## Category 2 - “The new routine displaced my life”

It involves 25.29% ( $f = 284$  TS) of the total corpus analyzed. Consisting of words and radicals in the range between  $\chi^2 = 3.83$  (Treatment) and  $\chi^2 = 41.36$  (Change), this category is composed of words such as “Immunity” ( $\chi^2 = 29.81$ ); “Change” ( $\chi^2 = 27.4$ ); “Routine” ( $\chi^2 = 22.22$ ); “Social” ( $\chi^2 = 18.75$ ); “School” ( $\chi^2 = 18.51$ ); “Mother” ( $\chi^2 = 18.85$ ); “Relative” ( $\chi^2 = 16.23$ ); “Mask” ( $\chi^2 = 15.98$ ) and “Isolation” ( $\chi^2 = 14.84$ ).

It refers to the changes that occur in routine and family organization during the treatment of a child with cancer. Changes were observed, mainly, in nutrition; cleanliness, due to fear of contamination; hospitalization routine and exams. In addition, family members reported numerous losses to the family resulting from these changes during the treatment, such as social isolation, family distancing, loss of childhood and leaving school and work.

*She has a little brother, he was very small so he could not get in touch with her so much. They started sleeping in separate rooms, because he could bring her diseases. Her immunity was null. She had to change sheets every day, bed and bath every day, we had to have alcohol to clean the house every day, alcohol all the time to clean the hands, like a newborn. The plate and spoon part was also separated, blanched. Everyone with masks at home, couldn't receive any visit. It is a social exclusion. The first year itself is an exclusion, she could not visit, receive visits from friends [...]. There was the family distance, from the younger brother, I spent a lot of time without seeing him, he stayed in his nanny's hand. For those who have more than one child, it is very difficult, because there is this division of attention. But as she, in this case, was getting attention at the time, I had to stay with her, but the change is 100%. You don't have a normal life anymore, you look on the internet, in this case, I looked people's lives. Even a stupid family lunch, a walk, I found it impossible to have that again in my life, I looked and thought it was so distant from my reality. (Participant 6)*

*We are having to deal with it, managing the different routine, the financial stress, the treatment, there's a lot, isolation. Since she started, she can not go to school. So, this is something that she mourns the most, because she is super social, my daughter is super social, super like, she loves being with friends, company. So, this is one of the things she feels the most, being isolated, not being able to go to the bakery, because she can only be in a controlled environment [...]. I think this is the part that she suffers the most. She suffered, she felt a lot when she lost her hair. The hair loss, I think it was so shocking for her, so much that she didn't want to cut it at all [...]. Today, we are very tired of the routine, of this whole thing, of all the tensions that are built around it. (Participant 10)*

*So, there was this family separation and some additives that we used, like cleaning all the time. I slept using mask, my husband slept using mask. She didn't go anywhere as soon as it was confirmed. I left my job. I must have spent about 3 months without going to a supermarket, without going to a drugstore, without going an otolaryngologist. So it changed completely, it was like a change from water to wine, overnight. And she stopped going to school, she totally lost her social life, there were no visitors at home [...]. So, zero social life, nothing, nothing at all and for everyone. (Participant 5)*

*So, I think it interfered a little in the speech, this lack of social interaction with other kids and at school. In my point of view, there were these two things that were the most important things, playing and his speech that were really delayed. (Participant 8)*

### **Category 3 – “It was a mourning experience”**

It involves 29.3% ( $f= 329$  TS) of the total analyzed corpus. Consisting of words and radicals in the range between  $\chi^2 = 3.83$  (to Remember) and  $\chi^2 = 73.74$  (to Find), it is composed of words such as “Fear” ( $\chi^2 = 67.0$ ); “Situation” ( $\chi^2 = 37.91$ ); “Grief” ( $\chi^2 = 25.79$ ); “Talk” ( $\chi^2 = 20.51$ ); “Difficult” ( $\chi^2 = 17.56$ ); “Suffering” ( $\chi^2 = 16.38$ ); “Cancer” ( $\chi^2 = 8.39$ ); “Death” ( $\chi^2 = 8.18$ ) and “Loss” ( $\chi^2 = 6.38$ ).

This category presents the grief experienced by family members due to symbolic deaths, caused by the daily loss of health, but also due to everything that adds up – lost or postponed life projects, life routine, interaction with family and friends etc; and by the possibility of actual death. They also talk about the fear of talking about these feelings.

*Until we were able to understand that, in fact, there were chances, I think it was really a grief. It was a grieving experience. But, like, not later, but until the process of having the diagnosis and starting the treatment and I see that she really had a chance of cure [...]. When people said she had chances of healing, I was afraid people were deceiving me. It was very difficult for me to listen to some things. So I was afraid people were alleviating. You start imagining yourself in the situation and there is only pain. The desire is to scream just by imagining, it is very scary. It's something I don't know if I have the strength to support, for me it is in the unbearable field. (Participant 10)*

*But it is the only certainty we have. We are born knowing we are going to die. When? Nobody knows. So, like, I was afraid, the fear and maybe already missing him. (Participant 9)*

*As there was metastasis, it was even worse, because the first time we didn't know how the treatment would be, everything was new. And not on the second time, it already was more difficult, because we already knew about the suffering, we already knew what she was going to go through [...]. I fell, we feel. Mainly when they are kids, I have had a lot of adult losses, but children, I know well, that it messes a lot more. I try to cling more to her, I cling even more, I try to do with her what that mother couldn't do. (Participant 3)*

*I felt lost, I was. “My life was over”, this is what I was thinking at the moment. Stressful moment there. I even told my wife that, if he didn't live, I wouldn't want to live either. (Participant 8)*

*Yes, due to the uncertainty of the prognosis, of not knowing if she would resist the treatment and I thought immediately as if... At the time of the diagnosis, it was like a death sentence, as if I was sure that she wouldn't resist. It's the first impact. Feeling of incapacity, as a mother not being able to do anything. (Participant 6)*

*Because whether we like it or not, we see these situations and project, you know. As much as we know that each story is unique, the success stories give hope and the failure stories a despair: (Participant 10)*

The family members also discussed the difficulty of finding space and opportunity to talk about this fear of losing the child. Despite having friends and family members, they express that at the moment they feel very alone.

*When we are feeling bad, we get very lonely. When we are scared, we get very lonely, because there isn't... People can't stand to listen, you know [...]. I think they ask out of kindness, out of care, but, in fact, having someone willing to listen, like that, to ask how we are, really wanting to know, is very difficult. So, I don't know if it is so hard to talk, I think it's harder to have someone to talk to. (Participant 10)*

*So I think it was part of the process saying it was cancer. It was part of my process, because when I noticed that I got stuck to pronounce the word cancer, it showed I still had some concerns, some fears. That I still was having trouble dealing with it. (Participant 9)*

#### **Category 4 – “And we get stronger together”**

It involves 16.47% ( $f = 185$  TS) of the total analyzed corpus. It consists of words and radicals in the range between  $\chi^2 = 3.84$  (Help) and  $\chi^2 = 192.67$  (God). It is composed of words like “Life” ( $\chi^2 = 106.91$ ); “Faith” ( $\chi^2 = 95.56$ ); “Believe” ( $\chi^2 = 29.62$ ); “Miracle” ( $\chi^2 = 25.46$ ); “Strength” ( $\chi^2 = 13.35$ ); “Friendship” ( $\chi^2 = 6.58$ ); “Psychologist” ( $\chi^2 = 5.16$ ) and “Family” ( $\chi^2 = 4.44$ ).

The category discusses about the coping strategies that the family members utilize during this period. One of the strategies that most emerged in the speeches is related to spirituality, regardless of the religion, in which faith presents itself as a source of hope, strength and support, leading people to believe that everything was happening for some purpose or greater learning. Other coping strategies pointed out were the strength coming from the child, with his or her smile and projection for the future; the support network, through friends and family members that help with a word of support or with blood and platelets donations; and the help coming from the healthcare team, through the care, trust and support.

*I take my bible and read it. I take my rosary and he takes his, and we get stronger together. (Participant 2)*

*I'm Catholic, I really had faith. Thinking God was really giving it, as if it were a trial. I went on and on, seeing it as if it were like a teaching, some life experience, that I had to go through. It really was faith. (Participant 6)*

*So, like, it was projecting into a family quality of life, I think that's it. Everything will be different, but it will be for the better. I can't imagine what it's like to go through such a treatment without really having this religion issue consolidated. I have no idea, I don't know if someone can do it, because, like, it is heavy, it's heavy [...] but I can't imagine, what it's like to go through all this, without being by the side all the time and, believing that you only have that strength, because God is on your side, carrying you. (Participant 5)*

*People donating him blood and platelets, also helping other people, saving lives of other kids and adults as well. This strengthened us more and more, and faith was everything for us, like, we were going to win. (Participant 8)*

*Only the nurses at the hospital who are really good. My family can't help me because it is too far away, they can't come. (Participant 1).*

#### 4. Discussion and Conclusion

This research aimed to analyze the grieving process experienced by family caregivers of children with cancer. It was concluded that parents of a child with cancer experience grief and suffering since the diagnosis and throughout their kid's treatment. It is experienced from the suffering, caused by all the losses due to the treatment and by the possibility or certainty of the child's death. There are numerous difficulties in obtaining an early diagnosis of the child's disease. From the first symptoms perceived – hematomas, fever and pain – when the parents identified that something was wrong with their child, they sought specialized care and assistance. However, usually the first diagnoses are wrong, not associated with the cancer symptoms, extending the confirmation of the disease, delaying the diagnosis and compromising the beginning of the treatment. Furthermore, many symptoms end up persisting, leading the family to seek other professionals, so their children could have the diagnosis confirmed<sup>(5)</sup>.

The confirmation of the diagnosis and the impact of receiving it are characterized by despair, uncertainty, fear of the painful treatment and the possibility of death. Family members are afraid, caused by the stigma of the disease, by the concern about the suffering that the cancer may cause to their child. Furthermore, many family members associate cancer to its high mortality, because they do not have information about the disease and its treatment. Despite this, with the enlightenment from the healthcare team about the existence of the possibility of treatment, a feeling of relief permeates, causing a change in this stigma<sup>(8)</sup>.

In the continuity of the process, caring for a child with cancer involves a series of deprivations for the family, completely changing their routine, organization, plans and dreams. Because of the impacts caused by the treatment of child cancer on the family organization, it is possible to attest to a really painful process, especially for those who are the main caregivers. Family members suffer financial, emotional and social imbalances, because the caring for the child becomes full-time. They are often deprived of leisure activities that used to be part of their routine. The changings also affect their working conditions, as many end up choosing to take care of the child, instead of maintaining their work<sup>(12)</sup>. Another major obstacle presented by many family members is the distance from their home, as they end up needing to stay away from their family and other children, due to the treatment<sup>(13)</sup>.

Furthermore, numerous changes can be seen in the child's life, due to the deprivation from the hospital environment and the invasive and repetitive procedures to which the child is submitted to. In addition, the kid is excluded from friends and relatives, routine and school context<sup>(9)</sup>.

Family members reported the mourning experience, even without the child's death. The child and family go through several losses, such as hair loss, leaving school, caregiver's absence from work, social isolation, distancing from family members and friends, assuming a new dynamic because of the disease. With each loss, the family members face mourning processes for symbolic deaths<sup>(10)</sup>.

In addition, anticipatory grief emerges from the suffering, caused by the losses occurred during the treatment and by the fear of the possibility of the child's death. They grow up worrying about possible complications in the treatment or relapse of the disease, or by seeing other kids dying in pediatric oncology<sup>(10,13)</sup>. The approximation to the possibility of death awakens a feeling of impotence among the parents that,

when faced with their child's pain, can't do anything to alleviate it<sup>(14)</sup>, and a feeling of despair, for not imagining a future without the child<sup>(15)</sup>.

The family caregivers seek to face this entire process, showing strength, courage and hope for the child, using different coping strategies to deal with the routine and bear the suffering. Spirituality proves to be an indispensable resource for most family members, regardless of their belief or religion, achieving a safe haven, comfort and hope, in face of difficult situations<sup>(26)</sup>.

During hospitalization, the caregivers can also feel alone, because many are far from home and their family, and can't talk about this difficult topic to other people. Therefore, the support network of relatives and friends is an important coping strategy. Moreover, the healthcare professionals present themselves as one extra support, offering assistance and clarifying doubts<sup>(13)</sup>.

As a limitation of this research, the reduced number of participants and cross-sectional data collection can be mentioned. Therefore, new researches are suggested, and in a longitudinal way, aiming to obtain the integrality of the experience of caring for a child with cancer.

This research provides the reader a reflection about a topic distant from the majority of the population: the grieving process experienced by family caregivers of children with cancer. It was made an attempt to unveil the mourning for the daily losses and for the possibility of the child's death, speaking about the unspeakable, still little known in the literature. By identifying the factors involved in this process, the multiplicity of professional categories is called to think about their role in patient care, but also in their family, with special attention to the care for the caregiver. Therefore, this work does not end here, it is just an invitation for the community, healthcare professionals, experts, academics, and managers to discuss, research and review public policies directed towards the grieving process of family members of children with cancer.

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