

“We felt lost”: the loss of a child with cancer
“Nós ficamos sem chão”: a perda de um filho por câncer
“Nos quedamos sin norte”: la pérdida de un hijo por cáncer

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This research aimed to understand the experience of a family who faced the bereavement after the death of a child to cancer. It was a cross-sectional, qualitative, exploratory research, during the second half of 2016. Participants were assessed using convenience sampling. Participants in this research were, a couple who had two daughters, with one died because of cancer. The instrument used was a semi-structured interview. For data analysis, it was used the single case study, considering the peculiarities of the case. The survey results showed the difficulty of the couple in addressing the issue of their child loss, requiring assistance to religion and support groups that made possible the family restructuring. The loss generated impact on family homeostasis, but enabled the strengthening of the relationship between the couple. The arrival of the youngest child in the family reflected feelings of hope, giving new meaning to the family's expectations.

Descriptors: Bereavement; Death; Family.

O objetivo desta pesquisa foi compreender a experiência de uma família que vivenciou o luto pela perda de um filho por câncer. A pesquisa teve caráter qualitativo, exploratório e corte transversal, ocorreu no segundo semestre de 2016. Os participantes foram acessados por critério de conveniência. Participaram desta pesquisa, um casal que teve duas filhas, sendo uma falecida em decorrência de câncer. O instrumento utilizado foi uma entrevista semiestruturada. Para análise de dados utilizou-se a técnica de estudo de caso único, considerando as singularidades do caso. Os resultados da pesquisa evidenciaram a dificuldade do casal em abordar o tema da perda da filha, necessitando recorrer à religião e grupos de apoio que possibilitaram a reestruturação familiar. A perda gerou impacto na homeostase familiar, mas possibilitou o fortalecimento do relacionamento entre o casal. A chegada da filha mais nova na família refletiu sentimentos de esperança, resignificando as expectativas da família.

Descritores: Luto; Morte; Família.

El objetivo de esta investigación fue comprender la experiencia de una familia que vivenció el luto por la pérdida de un hijo por cáncer. La investigación tiene carácter cualitativo, exploratorio y corte transversal, ocurrió en el segundo semestre de 2016. Os participantes fueron elegidos por criterio de conveniencia. Participaron de esta investigación, una pareja que tuvo dos hijas, siendo una fallecida en consecuencia de cáncer. El instrumento utilizado fue una entrevista semiestructurada. Para análisis de datos se utilizó la técnica de estudio de caso único, considerando las singularidades del caso. Los resultados de la investigación evidenciaron la dificultad de la pareja en abordar el tema de la pérdida de la hija, necesitando recurrir a la religión y grupo de apoyo que posibilitaron a reestructuración familiar. La pérdida generó impacto en la homeostasia familiar, más posibilitó el fortalecimiento del relacionamiento entre la pareja. La llegada de la hija más nueva en la familia reflejó sentimientos de esperanza, resignificando las expectativas de la familia.

Descriptoros: Aflicción; Muerte; Familia.

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INTRODUCTION

Childhood cancer is understood as a disease in which there is uncontrolled proliferation of abnormal cells, focusing on any part of the body, being the cause of death of 7% of children between one and nineteen years old in Brazil¹. One of the most frequent types of cancer in the age group zero to 14 years is the acute lymphoblastic leukemia (ALL)², equivalent to 78% of cases of leukemia in children, and the treatment of this cancer from the diagnosis has shown progressions in the last decade³.

The time prior to receiving the diagnosis of cancer is understood as a pre-diagnostic stage, and results in an anticipatory bereavement process that accompanies the family to the final result of the tests and treatment plan⁴. Frequently, changes in the behavior of children, as well as signs and symptoms are noticed by parents, placing them on alert⁵.

Receiving the diagnosis of cancer in the family, especially when it is a children's cancer, is a moment of great distress for the child or adolescent and family. After this time, the family turns to the conditions of treatment and current status of the disease⁶.

From the diagnosis of cancer, there are major changes in the family that affect not only the members, but everyone who participates in their circle of relationships. When in contact with an exaggerated amount of technical information, parents tend to feel oppressed and called to face their fears to make decisions about the post-diagnosis steps⁵. In this sense, the treatment process of children and adolescents with cancer becomes a major challenge for family and professional involved⁷.

Regarding the family system, its functionality is based on rules and responses that enable a harmonious dynamic. Families are constantly changing and interacting and may, at some point, become dysfunctional⁸. When a case of childhood cancer is discovered, the natural order is reversed, being reflected in the family system, making it a painful experience for the members of the family⁹.

In the cancer patient follow-up phase,

the illness causes changes to the family unit, and interventions usually focus more on the child or the caregiver¹⁰, leading to helplessness the other members. In addition, there is the need for restructuring of family activities with changes related to financial and social aspects¹¹.

Throughout the process, the couple conjugality is affected, so that both can fail to express their emotions and relate more closely, due to the hospitalized child. Similarly, significant changes in communication and family functioning caused by cancer can interfere with healthy resolution of the problems¹².

Before the stigma of cancer and diagnosis disclosure, the nuclear family can go through crises and instability, associating the situation with the possibility of death and suffering with the loss of a child¹².

The affected anxiety is not related only to the loss itself, but with the bereavement elaboration process, because it makes the family feel powerless regarding the one who died, frequently presenting difficulties with it. In this sense, how parents will handle the child's illness is determined in part by their personal experiences and the availability of resources in the community to deal with stressful events¹³.

The grief experienced by parents facing the loss of a child can be a traumatic event and, in many cases, it may be one of the most painful losses and difficult to face⁴. It is considered a slow and expensive process, which, several times, entails anguish and suffering for the rest of life. The pain of loss is characterized by a crisis that demands a reorganization of individuals who are related to it¹⁴, with the bereavement experience dependent on the family system, before, during and after the loss. Thus, when the family is well functioning, the bereavement adjustment process may become less painful.

Faced with this, it is believed that the bereavement caused by the loss of a child is still a complex issue, little investigated and deserves further scientific investment, since many families experience this reality. Therefore, the objective of this research was to understand the experience of a family who

faced the bereavement after the death of a child to cancer.

METHOD

This is a qualitative, exploratory study¹⁵ and used the single case study for data analysis¹⁶. The case study allows preserving the characteristics of the case event in its context, being a unique analysis, with no generalization¹⁶.

The participants of this research were a couple who had a daughter who died from cancer. It was used a semi-structured interview to address family experiences, loss perception and bereavement elaboration process after the loss of a child with cancer.

Participants were contacted using convenience sampling¹⁷, being presented the interview script and later signed the Informed Consent Form (ICF). After acceptance, the interview was conducted and recorded in the couple's home, lasting approximately an hour and a half. Data collection took place during the second half of 2016.

Data were analyzed based on the assumptions set by the case study as proposed by Yin¹⁶. The interviews were transcribed and analyzed with a focus on evidence, with interpretation and on the most significant aspects.

The research project was submitted to the Ethics Committee of Faculdade Meridional and approved under number 1,663,826, following the ethical recommendations for conducting human studies, according to the guidelines of Resolution 466/2016 of the National Health Council (CNS). Participants signed the Informed Consent Form (ICF) and the possibility to terminate the interview at any time without any damage was appointed to them. The data of the participants were preserved and shall be kept by the researcher for a minimum of five years.

RESULTS

John is 45 years, Marta is 39 (fictitious names), both industrial workers in the northern of Rio Grande do Sul state with service time between 20 and 23 years. John and Marta had two daughters, Bruna (15 years – fictitious name), who died of cancer

seven years ago, and Paula, with seven years old at the time of the survey.

John and Marta started dating too early and had a peaceful relationship. At the time of the interview they were married for 23 years. Marta became pregnant with 16 years of their first child, which was not planned, but they understood it as a gift from God. Bruna brought joy to the family, she liked to go out together and they enjoyed it a lot. Before the loss of the eldest daughter they lived peacefully and in harmony; the mother reports that:

Our life was good, very quiet, we went out for games, spas, we got along very well, both with me and John (father) she was a sweetheart.

The family reported that they went through moments of great suffering when having the daughter's diagnosis and were taken by surprise:

She was well, on January 5th, 2009 she started getting sick, she was bad, she said she was feeling bad, so we took her to the doctor's, there she took medication and the doctor ordered tests, but these tests took long and we returned home, I never thought about this diagnosis.

Bruna and her parents discovered the diagnosis, this fact made them "feel lost", as the mother reported:

Oh, it was the same thing as running out of the ground, it was horrible, it seemed to have a hole around us, I could not believe, it was awful. The treatment period was not long, but for the family and especially for Bruna it was a process of much pain and suffering: she said she'd rather die than have her hair cut, she did not want to undergo chemotherapies.

Family members were key to the couple from the moment of discovery of cancer to the time of loss, as the father said:

Everyone suffered a lot, it was horrible, but they gave us a lot of strength, it was our family and friends who made us continue.

Bruna was 15 when he died of leukemia; it took a month between the time of discovery and the treatment, which caused surprise in the whole family, generating, according to the parents, many changes in family dynamics:

Much has changed, it seems that me and John were more united, it seems that we want to be more together, it seems that before it was not like that.

The family struggled in the beginning to get over the loss. The bereavement process was very complicated and painful because of family model in which they used to live, because they are strictly reserved and are not

used to discuss the issue or comment with any family about what was going on (in the interview, the couple did not talk much, and the father was even more reserved):

The bereavement was very complicated because our family is very reserved, and when she died and now we here at home, my mother my father, John's parents, nobody says anything up to today, we do not speak, for it is all tears, it is the first time we are talking to someone this way.

Due to the complexity in accepting the loss of their daughter suddenly and for having this difficulty talking about it the family was contacted by people from a group of mothers from the same town that also experienced some sort of loss similar to their family:

Julia (a mother of this group) explained to me that we have to talk about it, but we cannot make it.

Even with this difficulty talking, the family attended a few times the spiritual center indicated by another mother from the group and Marta think she had a significant improvement after the meetings:

I felt better when I spoke to Julia, she lost a son the same age that Bruna, not because of a disease, but due to an accident, but she showed me that I am not the only mother who went through it, and that in some way comforted me, I even went on some spiritual gatherings, it was good for me, but then I found out I was pregnant, I started thinking that I had to fight for the child who was coming, Paula was key to our improvement.

After seven years of Bruna's death, parents report they still cry when they talk or remember something about their daughter, but one thing that comforts the family is that before Bruna died they could provide her the 15th birthday party in the previous year in September, a dream she had:

Bruna's dream was the 15-years-old birthday party, but we did not want to do because we have a big family and we had no money, you know, well, John even promised her a Biz [motorcycle] but it was not possible, so we did, and thank God, because I was not going to forgive me, because what also comforts me is that what she wanted most was to party and we did it, she was so happy.

It could be perceived that even after a few years of their daughter's loss, the couple still finds it very hard to talk about it. The birth of the youngest daughter, as reported by them, brought them strength to move on.

DISCUSSION

This study identifies the difficulty of the couple to talk about the loss of their daughter. It points out that the interview was the first

time they addressed the fact, with the mother being the most communicative and the father more introspective when facing the subject.

There were several breaks throughout the conversation, as the couple often becomes emotional, showing that it can be understood the fact that feelings related to bereavement can be revived when one talks about it, as well as elaborated in each memory¹⁸. Similarly, one can understand the need to transform the reality of the family, dealing with the frustration of expectations regarding the development of their daughter¹⁹.

The discovery of their daughter's disease is presented as a moment of great difficulty, being also identified as a trigger of fear and insecurity feelings due to the immersion in an unknown situation²⁰. Falling ill with cancer carries the social stigma of death, even though in infant cases, being understood as something cruel about the future, resulting in feeling of impotence in parents who witness this experience regarding the child's healing and the care dedicated to him^{11,21}.

The couple fell silent after their daughter's death, supporting the idea that the subject remains a taboo in the family and society²². This loss is not the "natural" order and can have effects that destabilize the family roles, since this experience is understood as traumatic and can have an impact both on parenting and conjugality²³.

Loss is part of the life cycle; when you lose someone who is already ill or it is an old person, pain is often more quickly assimilated²⁴. However, when this cycle is stopped early, taking a young person or whose disease sets in and leads to death in a short time, deeper marks are left. In a family nucleus passing by the loss of a loved one, feelings of sadness, helplessness and anxiety are common, enunciating breaks in family daily life²⁵.

The death of a child can be understood as a vertical stressor that represents the breakdown of family homeostasis. The family life cycle has variations over time and crisis that settle in it, being necessary a family reorganization in order to face the difficulties¹⁴. Given this context, it is clear that

the loss of their daughter approached the couple, who sought support mainly in their relationship; so, conjugality can be understood as a resource, so that the experience of loss was shared and divided²⁶.

The search for support groups and religion also appears as an important factor for the couple. The spiritual center was searched in order to find answers to absorb the loss. Through religion one seeks the necessary support to face the battle against cancer, as well as the redefinition of existence before the disease²⁷. Religious practice can be considered another resource to overcome the loss, as it is an environment that generates comfort and can promote more resilience to the grieving ones²⁸.

Another factor that may be related to the form of pain coping is the perception that the person who died lived well²⁹, as told by the parents when reporting the fulfilling of their daughter's dream, making the moment as an important point for the girl's life, as well as comfort for the parents.

Death is understood uniquely by each person, in which factors such as personal characteristics of the bereaved, the person who dies and the relationship they had, influence the way to experience the grieving moment²⁹.

Even with limited data regarding the birth of the second daughter, after the death of the first one, it is clear that the second daughter's birth reflected feelings of hope, providing new directions and perspectives of life.

Being pretty celebrated, the birth of the first child alters the dynamic already established in the father-mother-firstborn triad. In the experience of the second pregnancy, the mother needs to reorganize her identity with regard to the roles she plays in family³⁰. It is believed that every family can live this experience in a particular way; however, one realizes that suffering is inherent to loss.

CONCLUSION

This research allowed us to explore the uniqueness of a family life from the death of a child from cancer, given the particularities of

the case and the importance of understanding them in its context.

It is considered that further information about the family relationship with the birth of the new daughter would be necessary, in the future, to understand her perception of parental grief, which was not possible in the survey occasion, since the age of the child.

The limitations of this study, facing the results of a specific and unique case, it is pointed out the need for other perspectives and views on the phenomenon. Thus, future studies are necessary, because one sees the relevance of the subject of childhood cancer and the family relationship in the context of the disease.

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CONTRIBUTIONS

Daiane de Lima was responsible for the definition of the subject, conception, design, collection, data analysis and interpretation. **Josiane Razera** guided the work and performed the critical review. **Eduarda Lima de Oliveira** and **Brenda Thamires Comandulli** worked on writing and critical review.

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