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## From hospitalization to grief: meanings parents assign to their relationships with pediatric oncology professional\*

Da hospitalização ao luto: significados atribuídos por pais aos relacionamentos com profissionais em oncologia pediátrica

De la hospitalización al duelo: significados atribuidos por los padres a las relaciones con profesionales en oncología pediátrica

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### ABSTRACT

**Objective:** To understand the meanings assigned by bereaved parents to their relationships with healthcare professionals during the end-of-life hospitalization of their child. **Method:** Qualitative-interpretative study based on hermeneutics. Data were collected from interviews with parents who were grieving the death of a child with cancer in the hospital and participant observation in an oncology ward. Deductive thematic analysis for data interpretation ensued. **Results:** The experience of parents is the sum of all relationships during treatment. Therefore, meanings form a tangle of interrelated senses built not only in the interaction with these professionals, but also with the child and with grief itself. In relationships with professionals, meanings related to the memories of the child, negative emotions and regret were identified. **Conclusion:** The experiences and meanings of grief are shaped by the social processes and interactions experienced by the family in the hospital. The relationship with the professionals represents part of the support in coping with the grief after the child's death in the hospital, due to the perpetuity of the love shown for the child as a possible legacy in the legitimacy of the experienced interactions.

### DESCRIPTORS

Child, Hospitalized; Neoplasms; Professional-Family Relations; Family Nursing; Death; Bereavement.

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## INTRODUCTION

Cancer is the disease that causes the highest number of deaths of children and adolescents between 1 and 19 years of age in Brazil<sup>(1)</sup>. A child's illness and death affect several members of the family and triggers intense reactions and problems of coping and family adaptation after the loss<sup>(2-3)</sup>.

Despite the lack of statistics that measure the impact of a child's death on the social milieu, it is recognized that the grief for a child's death is highly devastating<sup>(4-5)</sup>. More specifically, the grief for a child increases mortality and the incidence of psychosocial symptoms that affect the continuity of activities after the loss<sup>(5-6)</sup>.

Several areas of investigation on the adaptation of bereaved people after the loss of a loved one have produced new perspectives on bereavement and its complications. The most accepted model is the Dual Process Model of Coping with Bereavement<sup>(7)</sup>. In addition to clarifying the need for grieving, this model emphasizes the importance of getting involved and, at the same time, moving away from it. This way, the bereaved one oscillates between coping with loss and confronting restoration. The oscillation between both movements, albeit not linear, portrays the process of coping with bereavement.

The analysis of meanings associated with the losses inherent to human life reveals some important processes for the experience of bereavement, of death and of dying itself. The meaning is related to the sense that is found or built in one's experiences. This is known to be fundamental for the individual's adjustment after the loss<sup>(8)</sup>. Considering that these meanings can change as new experiences and new senses are experienced, understanding this process requires the study of relationships, language, and dialogues built in one's interaction with the world<sup>(9)</sup>.

Literature on nursing often fails to address meaning-building processes related to grief and bereavement in its practical approach to the care for patients and families. This study sought to enhance the planning of the care given to the families who experience the end of their child's life in the hospital, based on an analysis of the meanings assigned by bereaved parents to the relationships with healthcare professionals during the hospitalization of a child with cancer. Considering that the parents' impressions on the care they received may last for many years after the treatment ends<sup>(10)</sup>, and that grief is not something that simply disappears over time – rather, it involves a psychic process<sup>(8,11)</sup> – this study sought to understand the meanings assigned by bereaved parents to their relationships with healthcare professionals during their child's hospitalization.

## METHOD

### STUDY DESIGN

This is a qualitative-interpretive study, guided by the philosophical hermeneutics of Hans-Georg Gadamer<sup>(12)</sup>, about the meanings assigned by bereaved parents to their

relationships with healthcare professionals at the end of the life of a hospitalized child with cancer.

### SETTING

Field observation in the intensive care unit of a hospital specialized in pediatric oncology was performed and semi-structured interviews with bereaved parents were conducted.

### POPULATION

The participants were recruited based on the indication of healthcare professionals from pediatric oncology units, following the snowball technique, in which the first respondent indicates the next, and so on. Another strategy was to use social media to share and exchange information with people who were interested in the study. These two recruitment strategies helped us diversify the context of end-of-life care, aiming at a comprehensive understanding of such relationships. After identifying the participants, a first approach was conducted, with a brief introduction of the research group, explanation of the reason for the contact and how that family was indicated. They were encouraged to talk to other family members about their participation in the study. They were contacted again later and, if they confirmed their interest in participating in the project, a date and a place for a meeting was chosen.

42 families were identified (30 through healthcare professionals and 12 online). Of these, seven agreed to participate in the study, eight refused, and the rest could not be contacted. Among the refusals, some mentioned the following reasons: *I'm not ready to talk about it; it still hurts a lot to talk about that; maybe I can talk to you later, but now I do not feel comfortable.*

### SELECTION CRITERIA

Selection criteria varied according to the data source: participant observation in specialized oncology hospitals or semi-structured interviews with parents grieving the loss of a child in the hospital.

For the interviews, the inclusion criteria were: parents who had accompanied their late child in the hospital, aged over 18 years, living in the state of São Paulo, Brazil, and who had suffered the loss of the child at least 6 months ago. The time of 6 months was determined considering that, at the beginning of the process, the bereaved person is extremely vulnerable and consumed by the pain of loss<sup>(13)</sup>. Participants who were more vulnerable, like those undergoing treatment for life-threatening illnesses, mental illness, pregnancy or substance abuse were excluded.

The inclusion criterion for the observations was the assessment made by at least two physicians responsible for the child that the death could possibly occur within 6 months. After evaluating the criteria for inclusion of the observations, we introduced ourselves to the family, parents and child, as researchers from the university, clarifying our presence in the unit and highlighting the absence of a working relationship with the hospital.

## DATA COLLECTION

Data were collected from November 2013 to June 2016. Data were collected by two of the authors with previous experience in qualitative research and generated 150 hours of field observations and 11 hours of interviews with parents mourning the loss of a child due to cancer in the hospital.

Participant observations in pediatric oncology units are warranted so the data are refined by the presence of the researcher in the end-of-life context in which the relationships occur. The researchers had no connection with the institution. To carry out the field observations, the research project was presented to nurses and physicians – managers, supervisors and employees. There were weekly visits to the hospital. The interactions between parents, children and healthcare professionals within the rooms, the agenda of the multidisciplinary and shift change meetings regarding end-of-life children were observed.

The interviews took place mostly at the participants' homes. At the beginning the research group and the research objectives were presented. Further detail was also given about their participation, although this had already been discussed at the time of recruitment. Thus, the Free and Informed Consent (FIC) was read and signed by the participant. After authorization, the family was characterized and their genogram was outlined. These steps aimed to establish rapport between interviewer and respondent. Subsequently, some context about the study, followed by guiding questions, were briefly given: How was your relationship with the professionals during the last days that you were with (child's name) in the hospital? Today, when you remember the professionals who took care of your child, how do you feel?

Data were collected until theoretical saturation of the studied phenomenon was achieved, that is, sufficient theoretical density to meet the proposed objective<sup>(14)</sup>.

## DATA ANALYSIS AND PROCESSING

Unlike other qualitative research methods, hermeneutics does not aim to form topics, categories, theoretical constructs or theories. Rather, it focuses on deepening the understanding of the phenomenon to present it in a different, logical and applicable way in the context that is pursued. Nonetheless, the creation of topics, categories or theories may be welcomed if it enables the presentation and explanation of the interpretations<sup>(15)</sup>.

This study included groupings of sentences with similar meanings to understand the meanings of relationships with healthcare professionals assigned by parents mourning the loss of a child with cancer in the hospital. Thus, units of meaning were identified and grouped into categories.

In order to clarify and reveal the meanings found in the parents' experience, these categories were deductively analyzed according to Gillies, Niemeyer, and Milman's<sup>(16)</sup> codebook. These authors proposed a comprehensive coding system to analyze the meanings built after the

death of a loved one, producing a 30-category codebook with negative and positive topics that emerge while the bereaved person tries to make sense of the loss. The categories of this study were articulated with the codes proposed by these authors.

In order to ensure the reliability of the results, the initial coding and categorization were performed independently by two researchers. Discrepancies were discussed with other researchers, specialists in qualitative research, to attest that the analytical categories were in agreement with the data and the objectives of the study.

## ETHICAL ASPECTS

This study was based on Resolution 466/2012 of the National Health Council and on ethical considerations of studies with bereaved people<sup>(13)</sup>. It received a favorable opinion for the collection of data by the Ethics Committee of the Nursing School of the Universidade de São Paulo under Opinion 486.204 of December 10, 2013 and by the Committee of the institution participating in the study, Opinion 504.822, of January 22, 2014. The interviews were performed after the participants' agreement through the signature of the FIC. Participants were identified with the letter M (mother) or F (father) followed by Arabic numerals, according to the sequence of the interviews.

## RESULTS

A retrospective analysis of the experience of parents who lost a child to cancer in the hospital enabled the understanding of meanings they make of their relationships with the professionals. Participants included 6 mothers and 1 father aged 21 to 54 years. These parents lost children between 3 and 17 years of age, with different diagnoses and length of the disease. The period between the diagnosis and the death of the child ranged from 1 year and 11 days to 7 years. The time between the death of the child and the interview ranged from 11 months to 10 years and 6 months.

The analysis of the parents' narratives results from a constant effort to reach the fusion of horizons, a fundamental concept for hermeneutics, which means to unite the horizon of understanding with that of another person to envision new possibilities of interpretation<sup>(12,15)</sup>. Although the initial focus of the research was on the relationship between parents and healthcare professionals on the last days of a child's life, the participants guided it to a fundamental point of analysis, revealing that the experience of the parents is the sum of all the relationships lived in the hospital throughout the treatment. This way, looking only at the interactions that occurred at the end of the child's life or at a single professional, such as nurses, does not capture the breadth and impermanence that subjectivity brings to relationships in the context of bereavement. Thus, involved with the parents' narratives about events, passages and memories of the relationships lived during the time they were in the hospital, there

were meanings built not only in their relationship with the professionals, but also with the child and with family grief itself, as shown in Chart 1.

**Chart 1** – Category of meanings assigned by bereaved parents to relationships with healthcare professionals during their child's hospitalization – São Paulo, SP, Brazil, 2016.

Categories of meanings	
Parents and professionals (through relationships with professionals)	<b>1. Memories of the child</b> 1.1. Perpetuating the child's memory 1.2. Evoking positive feelings 1.3. Leaving a legacy
	<b>2. Negative emotion</b>
	<b>3. Regret</b>
Parents and child (in the relationship with the child)	<b>4. Impermanence</b>
	<b>5. Valuing the time shared with the child</b>
	<b>6. Affirmation of the child's identity</b>
	<b>7. Preparation of the child to the death</b>
	<b>8. Acceptance</b>
	<b>9. Release from suffering</b>
Parents and bereavement (loss) (in the relationship with the loss/ bereavement)	<b>10. Valuing relationships</b>
	<b>11. Coping</b>
	<b>12. Moving on</b>
	<b>13. Improving prospects</b>
	<b>14. Spirituality</b>
	<b>15. Missing their child</b>
	<b>16. Lack of understanding</b>
	<b>17. Lost identity</b>
	<b>18. Meaning found (not specific)</b>
	<b>19. No meaning</b>

Source: Adapted from Gillies, Niemeyer and Milman<sup>(16)</sup>.

The meanings built through the relationships with the professionals were: memories of the child, negative emotion, and regret, as shown in Chart 2. The *memories of the child* category revealed the relationship with the professionals as a memory of the child's life and of the child's permanent identity. Within this category, *perpetuating the memory of the child*, *evoking positive feelings* and *leaving a legacy* were meanings assigned to the relationships experienced with the professionals that had repercussions on the parents' bereavement, since the feelings linked to the relationships seemed to favor or hinder the bereavement process.

**Chart 2** – Category of meanings assigned to the relationships with the professionals – São Paulo, SP, Brazil, 2016.

<b>1. Memories of the child</b>
1.1 Perpetuating the child's memory <i>You pass by the hospital and you get a good feeling, because there your child was well cared for and supported in difficult situations. It was a hard time, but it was also part of the experiences we lived with him (F7).</i> <i>The nurses. Some in particular took care of him more often, so we have a special affection for them (...). If I ever meet this person again I will remember that she also knew my child! It's a living memory of my child (M5).</i>
1.2 Evoking positive feelings <i>You will remember that moment with more affection if there was a good relationship, if there was good care! (M3).</i> <i>That year, we spent New Year's eve there. She (the nurse) brought some shrimp, (...) which she loved! (M2).</i> <i>There were also some nurses he loved to hug, he'd run to give them a hug (M4).</i>
1.3 Leaving a legacy <i>The ICU team was told to respect my will (...) it is not an easy experience. I can tell you for sure that it was the greatest proof of love I could give her. I gave up that selfish need to have her near me (M2).</i> <i>L. (the nurse) (...) said he still keeps the plate my son gave him (cartoon-themed plate). You see, sometimes this makes a difference, the professional also takes something home (M6).</i>
<b>2. Negative emotion</b>
<i>If they failed my son, the feeling I get is that I failed my son too. But now there is no coming back to do things differently (notes of observation).</i> <i>I had no support after he passed away. Everything was cut. It all ended. It was as if we no longer existed. (...). When he died, I felt as if I had died together, as if I no longer existed. I think they could have been more supportive during our grief (M4).</i> <i>There is nothing worse than neglect, you know? It was neglect (pause in speech). I missed more attention from the doctor and her team (cries while speaking) (M1).</i>
<b>3. Regret</b>
<i>There is no treatment with more than six consecutive sessions. B. made 10! It was wrong. ... No one in their right mind can imagine that a body will survive a carbon isotope bombardment like that, but B. did that twice (M3).</i> <i>He could die, but we decided to try again. If it were not for Dr. H. (doctor's name), it would have been better. She's great, but she should have paid more attention to us (M1).</i>

The *negative emotion* category of meaning refers to the memories of the treatment and of the professionals. These memories include uncertainties about the conduct toward the child or the family. The *regret* category shows that for parents, pending or unresolved issues about treatment or care result in grievance, uncertainties and anguish about the child's illness. If these issues are not dealt with, they can remain unchanged, even after years of the child's death. Very aggressive and futile treatments are questioned by parents after the loss. The need for integral care and support, as proposed by the palliative care philosophy, stands out in their memory.

In the situation of cancer illness and death, parents need the certainty that everything and the best was provided for the child. Parents have somehow expressed the meaning

involved in the effort to meet all the child's needs and exhaust the best possible alternatives, as shown in Chart 3. This certainty helps in the bereavement process, since it contributes to the construction of meanings, such as understanding the *impermanence* of life, *valuing the time shared with the child*, *affirming the identity of the child*, *preparing the child for the farewell*, *acceptance of death* or the understanding of death as *release from suffering*.

**Chart 3** – Categories of meanings assigned in the relationship with the deceased child – São Paulo, SP, Brazil, 2016.

<b>4. Impermanence</b>
<i>We talk about Dr. N. or all that money, but she would have died anyway. (...) She had to go. There was nothing we could do, she was going to die anyway (M1).</i>
<b>5. Valuing the time shared with the child</b>
<i>I have the certainty that I did everything I could for her. (...) I did not postpone anything. Today, I put my heart at ease and think: I did EVERYTHING (emphasis) I could do! EVERYTHING! That calms down my heart (...) that's one consolation (M2).</i>
<b>6. Affirmation of the child's identity</b>
<i>He had everything, all our lives we gave him everything. Not that we knew this was going to happen, but he was a beloved child, he was much loved! (M5). He was very understanding. I am sure that all the nursing staff and team of doctors who had contact with B. (son) learned a lot from him (M3).</i>
<b>7. Preparation of the child to the death</b>
<i>She knew she was going to die and when she was going to die. She knew everything... She left in peace. I feel calm because I prepared her to death. She went without a tear. It was a good thing I did for her (M1).</i>
<b>8. Acceptance</b>
<i>She accepted death very well, she left us feeling very resigned (M1). She (daughter) had the dignity to accept death and tell me it was over for her: 'I don't want this anymore. It's over!' (M2).</i>
<b>9. Release from suffering</b>
<i>That girl deserved some peace. Peace. She struggled a lot, she lived a lot, she proved herself to the world (M2).</i>

The memories of their relationships with healthcare professionals inevitably refer to the various meanings attributed to the loss. Thus, the narratives show processes of bereavement for the death of a child with cancer in the hospital, as shown in Chart 4. In the *valuing relationships* category, social support and support are protective factors that help alleviate the suffering resulting from the loss.

For parents, the relationship with their own feelings has revealed ways of coping that change over time, as they cope with bereavement. Admittedly, this is different for each family member. Thus, the categories of *coping*, *moving on* and *improving prospects* result from different perspectives in relation to loss.

The categories of *missing the child* and *lost identity* refer to the continuity of the relationship with the deceased child, in memory or in a new space for the child within the family.

These meanings continually emerge along with the cognitive processes related to the experience with the child. Likewise, the parents are expected to reconstruct events and seek explanation for the loss. In this process, their beliefs are challenged. In this sense, the categories of *spirituality*, *lack of understanding*, *meaning found* and *no meaning* show the movement of parents toward seeking explanation for the disease and for the loss. Recognizing these expressions is fundamental to envision coping strategies that may favor or hinder the process of bereavement when parents are still in the hospital.

**Chart 4** – Categories of meanings assigned to the loss of a child with cancer in the hospital – São Paulo, 2016.

<b>10. Valuing relationships</b>	<i>To have the support of family, friends, faith, to believe in something, whatever it is. (...) Let's share it with the others (M2). I had support from school, church, friends, everyone helped me and to this day some give me the support I need (M4).</i>
<b>11. Coping</b>	<i>After a long time we start to become more serene. (...) Nothing is replaced, nothing changes, but we become more serene (M2). I am different from my mother. She thinks too much and suffers more. I do not know if I suffer less than her or if I suffer less than I can (M5).</i>
<b>12. Moving on</b>	<i>I do not think much. That's why I'm like this, moving on. If you keep thinking about every detail, you'll lose your mind (M2).</i>
<b>13. Improving prospects</b>	<i>I would like people to see that there is another way to live. Even in a critical situation like death (M2).</i>
<b>14. Missing their child</b>	<i>I think it's an eternal grief (M6). An eternal missing him. Some days I'm better, some days I'm... But every year I grow more serene (M2).</i>
<b>15. Lost identity</b>	<i>People ask me how many children I have. And I don't know what to say! If I say one, he (brother) gets mad at me. He doesn't accept it. My husband does not accept it either. So it's complicated, you know? (M1).</i>
<b>16. Spirituality</b>	<i>My husband is still revolted. He will not talk about God because of the girl (M1). 'Lord (weeping voice), I never asked You to heal him, I always asked You to keep him from suffering... I'd rather You take him than to see him suffer' (M4).</i>
<b>17. Lack of understanding</b>	<i>I don't know how this illness came in, I do not know how it got here, all I know is that it took K. (daughter's name) away. My God, how can such a girl leave us? I thought she would never go (M1).</i>
<b>18. Meaning found (not specific)</b>	<i>You will never get some answers! Depending on your religion, the day you meet your God, you may ask them (...) But here you will never get an answer. Will this bring my child back? No! Then that's it! One day I may ask God, when I'm gone (M2).</i>
<b>19. No meaning</b>	<i>I ask: 'God, why my daughter?' Because my family is huge, my sisters have many children, right? Is there a reason why? No. There is no reason (M1).</i>

In the interviews, when there were memories of moments at the hospital that brought back positive feelings, a cadence in the narrative and a fluency in the thoughts were observed. Like in the situations where they

perceived that the child was being well cared for by the professionals, with their identity and preferences respected. The fluency in the narratives captured spontaneous and natural memories that were full of meanings about the relationship with the child.

However, similar fluency was not identified in situations in which parents did not have positive feelings. The pace of the conversation and the tone of voice were different, there were more pauses and less fluency in the choice of words. In the history of loss, these meanings were spontaneously present, integrated into the narrative about their relationships with the professionals, carrying emotions and feelings that were relived in detail.

## DISCUSSION

The results of this study provide a description and interpretation of how the experience of bereaved parents can inform about the relationships experienced during the hospitalization period. During the research, the experience of parents losing a child in the hospital is understood as filled with meanings and senses that intertwine throughout the bereavement process. Therefore, the results captured meanings beyond those established with the professionals, since a cutout in the object of analysis, like the relationship with the professionals, would not demonstrate the complexity that the tangle of meanings assigns to the memories of the time that the parents were with the child at the hospital.

Data about the bereavement process, such as the Dual Process Model (DPM), can help reflecting broadly on relationships with healthcare professionals from the perspective of bereaved parents<sup>(7)</sup>. The results of this study show how relationships can be reconstructed in the memory of parents. With that, the feelings that emerge from the memories trigger dubious coping processes, either focused on loss and aspects that are not solved or focused on life change and in the positive aspects of these relationships in the new identity of the child, built in the bereavement process.

This process is inevitably overwhelming for a bereaved parent and it cannot be ignored, since it is fundamental for the understanding of problems related to physical and mental health<sup>(7)</sup>. There are stressful factors in these two spheres that can overwhelm the bereaved parent and reveal different forms of complicated grief<sup>(7)</sup>. Thus, bereaved parents construct meanings throughout the entire disease trajectory in face of the multiple losses experienced. The consequent physical overload related to the psychosocial demands of the caregiver has repercussions on the relationships experienced with the professionals. Therefore, through the relationships built with healthcare professionals, factors that may trigger physical and emotional overload during the process of grief can be previously identified, helping to prevent future complications.

The construction of meaning is a process that involves finding meaning or an explanation for the loss based on a model of beliefs and world view<sup>(16-17)</sup>. In this study, the experience of bereaved parents with professionals during

the process of a child dying in the hospital revealed several meanings related to the illness, death, loss and grief that they experience. Therefore, since the relationships are present in the history of the loss, the meanings that emerge from it are part of the bereavement process.

This study showed that the relationship with the professionals involves the continuity of the bond with the deceased child and the construction of a social space that keeps the child's identity alive. In this respect, it is known that when relationships had positive and essentially human values, parents keep restorative and protective memories<sup>(18-19)</sup>. However, parents showed regrets and negative emotions regarding the experience. In this sense, it is well known that the discussions enabled by advanced care planning when engaging the family's objectives can alleviate the child's suffering and the regret associated with the child's end-of-life care<sup>(20)</sup>.

The need to maintain the bonds with a deceased child appears during the illness and, especially, at the end of the child's life<sup>(4,18)</sup>. Thus, the analysis of the data showed, through the meanings attributed in the relationship with the deceased child, the importance of the recognition of bonds established between parents and child in the disease process for the bereavement process. This evidence should encourage these professionals to set up strategies that can help parents build meanings that perpetuate their relationship with the child. In this study, these meanings were related to the impermanence of life, valuation of the time spent with the child, affirmation of the child's identity, preparation of the child for the farewell, acceptance of death or understanding of death as release from suffering. The hope of maintaining a connection with the child beyond life may be a coping strategy for bereaved parents<sup>(21)</sup>.

Continuing bonding is especially important for parental bereavement, as it allows parents to nurture the child's memory according to their personal judgment<sup>(19,21-22)</sup>. This study reinforces contributions about this (re)connection with the child through memory and feelings about relationships with professionals. In this context, anticipatory grief – “grief before an impending loss” – can guide strategies in the preparation of caregivers, professionals or family members, to ensure favorable results in the grieving process after death<sup>(23)</sup>. Caregivers may experience intense reactions of anticipatory grief, particularly from the parents of children with severe illnesses<sup>(24)</sup>. Anticipatory grief can be concealed by the determination of a caregiver who does not reveal their physical and emotional overload, which is experienced when they foresee the loss of the loved one. Thus, the grief experienced in advance of the loss cannot be explicitly acknowledged<sup>(25)</sup>.

By identifying how the experiences and meanings of bereavement are shaped by relationships, this study sheds light on the social and interactional processes found in the life of a family that experiences the process of death of a child in the hospital. In this sense, parents hope that the professionals can fight together with them for the survival of the family<sup>(26)</sup>. The possibility of relationships being dynamic, according to the families' demands, and gradually

disengaged<sup>(27)</sup>, can help promoting family integrity after the loss. In addition to this close emotional bond, this study reinforces that relationships help maintaining the collective memory of their child, a continued connection with the child, and therefore a space to construct meanings and deal with the coping process of loss.

Data analysis also enabled us to identify several meanings in the relationship between parents and their own bereavement, revealed by the category of *meanings assigned to the loss of a child with cancer in the hospital*. These data show that the relationships established in the hospital at the end of a child's life become part of the expressions of the family's bereavement process. Corroborating this evidence, progress can be made by offering follow-up programs aimed at ensuring the continuity of communication between family and healthcare professionals and a space of support for the expression of grief and care for the bereaved family. This could benefit both family members and healthcare professionals<sup>(28-29)</sup>

The data from this study has enable to establish the interface between psychosocial aspects of bereavement and the interaction processes in providing care to a family that experiences the loss of a child in the hospital. Thus, by recognizing the meanings pointed out in this study, nurses can act in a preventive way to avoid complications in the bereavement process. This knowledge is fundamental to identify effective long-term care strategies for the well-being of bereaved people. Furthermore, the data reinforce the importance of a continued space for relational practices, even after the loss. This is because strategies to maintain the bonds and the possibility of coping with emotions that may arise during the bereavement process are needed, seeking to nurture positive meanings along the way.

## CONCLUSION

This study showed an intimate association between relationships and meanings. Both are complex, since they allow for a diversity of possible outcomes, but rich in information about a very particular universe and difficult to unravel when parents experience the loss of a child from cancer in the hospital.

The researchers' exposure to field observations and interactions with the family could be indicated as a limitation of the study, due to possible bias in relation to difficulties in staying neutral in a context of pain and mourning. However, the observations were performed in pairs, aiming at greater reflexivity in the process. In addition, one of the researchers had more experience in studies with bereaved people, leading weekly debriefing meetings about the impressions and difficulties encountered in the observations, as well as in the interviews. The number of participants in the interviews could also be a limitation, however, the density of their stories and the richness of data they provided minimized such limitation. Moreover, in hermeneutics, the concern about the data involves the depth of detail about the investigated phenomenon. Future research is needed to enhance practical capabilities for nurses to develop strategies to help families cope with the loss of a child with cancer in the hospital.

Various meanings are intertwined in the memories of the relationships lived at the time the parents were in the hospital, whether with their child, with friends, with relatives or with professionals. Over the years, the emotions involved in these memories can change, as new meanings are integrated into the experience. These meanings, when recognized during the end of the child's life in the hospital, give nurses the opportunity to act in the prevention of future complications related to bereavement process.

## RESUMO

**Objetivo:** Compreender os significados atribuídos por pais enlutados aos relacionamentos com profissionais da saúde durante a hospitalização do filho em final de vida. **Método:** Estudo qualitativo-interpretativo, baseado na hermenêutica. Os dados foram coletados a partir de entrevistas com pais enlutados pela morte de um filho com câncer no hospital e de observação participante em unidade oncológica. Seguiram-se passos da análise temática dedutiva para a interpretação dos dados. **Resultados:** A experiência dos pais é a soma de todos os relacionamentos durante o tratamento, e, portanto, os significados formam um emaranhado de sentidos inter-relacionados e construídos não apenas na interação com os profissionais, mas também com o filho e com o próprio luto. Nos relacionamentos com os profissionais foram identificados significados relacionados às memórias do filho, emoções negativas e arrependimento. **Conclusão:** As experiências e os significados do luto são moldados pelos processos sociais e interacionais vividos pela família no hospital. O relacionamento com os profissionais representa parte do suporte no enfrentamento do luto após a morte da criança no hospital, pela perpetuidade do amor demonstrado ao filho como um legado possível na legitimidade das interações vividas.

## DESCRITORES

Criança Hospitalizada; Neoplasias; Relações Profissional-Família; Enfermagem Familiar; Morte; Luto.

## RESUMEN

**Objetivo:** Comprender los significados atribuidos por los padres en duelo a las relaciones con profesionales sanitarios durante la hospitalización del hijo en final de vida. **Método:** Estudio cualitativo interpretativo, basado en la hermenéutica. Los datos fueron recogidos mediante entrevistas con padres en duelo por la muerte de un hijo con cáncer en el hospital y de observación participante en unidad oncológica. Se siguieron los pasos del análisis deductivo para la interpretación de los datos. **Resultados:** La experiencia de los padres es la suma de todas las relaciones durante el tratamiento, por lo que los significados forman un enmarañado de sentidos interrelacionados y construidos no solo en la interacción con los profesionales, sino también con el hijo y con el mismo duelo. En las relaciones con los profesionales fueron identificados significados relacionados con las memorias del hijo, emociones negativas y arrepentimiento. **Conclusión:** Las experiencias y los significados del duelo los moldean los procesos sociales e interactivos vividos por la familia en el hospital. La relación con los profesionales representa parte del soporte al enfrentamiento del duelo después de la muerte del niño en el hospital, por la perpetuidad del amor demostrado al hijo como un legado posible en la legitimidad de las interacciones vividas.



## DESCRIPTORES

Niño Hospitalizado; Neoplasias; Relaciones Profesional-Familia; Enfermería de la Familia; Muerte; Aflicción.

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