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Conceptions of care and feelings of the caregiver of children with cancer

Concepções de cuidado e sentimentos do cuidador de crianças com câncer

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Abstract

Objective: To analyze the conceptions of care and the feelings which permeate the daily life of the family caregiver of children with cancer.

Methods: Qualitative research conducted with nine family caregivers of children with cancer. Semi-structured interviews were performed. The empirical material was submitted to French Discourse Analysis, producing the discursive formation of the family caregiver of the child with cancer: associated feelings and emotions.

Results: The comprehension of care is permeated by the legacy of dedication, selflessness and moral obligation from the perspective of parents who are caregivers. The feeling and emotions experienced in this trajectory, such as guilt, punishment and sin, were revealed between the lines of the caregiver.

Conclusion: The conceptions of care are a boon, a feeling of exclusive dedication to the child with cancer. In the discourse analysis it was possible to dive into the feelings and the relationship of ambiguity experienced by the parents, who often feel overwhelmed and powerless, but who do not accept being replaced in their role as caregiver.

Resumo

Objetivo: Analisar as concepções de cuidado e os sentimentos que permeiam o cotidiano do cuidador familiar de crianças com câncer.

Métodos: Pesquisa qualitativa realizada com nove cuidadores familiares de crianças com câncer. Foram realizadas entrevistas semiestruturadas. O material empírico foi submetido à Análise de Discurso francesa, sendo produzida a formação discursiva cuidador familiar da criança com câncer: sentimentos e emoções associados.

Resultados: A compreensão do cuidar é permeada pelos legados da dedicação, abnegação e obrigação moral na perspectiva dos pais cuidadores. Os sentimentos e emoções vivenciados nessa trajetória, como culpa, castigo e pecado, se revelaram nas entrelinhas do cuidador.

Conclusão: As concepções do cuidado são de uma dádiva, um sentimento de dedicação exclusiva a criança com câncer. Na análise dos discursos foi possível mergulhar nos sentimentos e na relação de ambiguidade vivenciada pelos pais que, muitas vezes, sentem-se sobrecarregados e impotentes, mas não aceitam serem substituídos na sua função de cuidador.

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Introduction

Cancer in children and adolescents, up to about two decades ago, was considered an acute disease with small possibility of cure, resulting in death in the majority of cases. With scientific progress, childhood cancer is presented as a disease with the prospect of a 70% cure rate, with early diagnosis and when treated in specialized centers. To ensure a good quality of life for these children is a growing concern, bringing to health teams the necessity to offer assistance aimed at health promotion and protection of the family as a unit of care, focusing on physical, social and emotional aspects.^(1,2)

After the diagnosis, family dynamics undergo transformations. The primary caregiver, being closest to the child, experiences an intense suffering due to changes and deprivations that compromise his or her quality of life.⁽¹⁾ Understanding caregivers is not only about perceiving them as beings who provides care, but also as individuals who need to be taken care of, because their feelings are weakened by the child's disease, their routine is modified to perform tasks that were previously nonexistent, and there is the need to withdraw from other family members, home, work and friends.

When seeking a rapprochement with the family, the nurse must comprehend how the care has been historically and socially constructed from the perspective of the family caregiver and how it has emerged among the adversities that underlie childhood cancer.⁽³⁾ When considering care, there is the possibility of understanding the human being and the conception of life that guides its existential projects. Care involves a practical dimension that requires the dialectic of comprehension-interpretation-application, furthermore, it involves attachment and responsibility.

The aim of this study was to analyze the concepts of care and the feelings that permeate the daily life of the family caregiver of children with cancer.

Methods

This was an exploratory and descriptive study of qualitative approach, developed in a institution

called Children's House, that receives children with cancer and their families. It is a civil, non-profit association, which is part of the Center for Support of Children with Cancer of Paraíba, located in the city of Joao Pessoa, Paraíba state, in northeastern Brazil.

The inclusion criteria were: family caregivers that were assisting a child, aged between two and 12 years, with the diagnosis of cancer for at least 30 days, and who needed to leave their homes and other relatives to accompany their children during oncological therapy. Caregivers of children up to two years old, and adolescents, were excluded because the care provided in these age groups is different. Nine interviews with eight mothers and one father were conducted, using the criteria of sufficiency for ending the data collection.

The production of the empirical material occurred during the period of February to April of 2011, and was produced through semi-structured interviews, directed by a script including identification data and the following guiding questions: what is your conception of caring? How do you feel taking care of a child with cancer?

The records of impressions about contact with the caregivers, the environment in which the interview took place, and the difficulties encountered during the production of the empirical material were made in a field journal.

The statements were analyzed using the French Discourse Analysis technique, which consists of analysis of text units beyond sentence analysis, in which the language makes sense as a symbolic work. The speech, as the object of analysis, is social historical, is the specific materiality of ideology and the technique works on the relationship of language-discourse-ideology, perceiving, therefore, that there is no discourse without a subject and there is no subject without ideology: the individual is intimated as subject by ideology and that is how the language makes sense.

The first stage is the passage from the linguistic surface to discursive object, in which readings of the transcribed interviews were conducted with the purpose of identifying signs, traces and clues that pointed to the thread of the discourse, with this process denominated as *deepening*. Next, it the

discursive corpus was formed, considering the study and their objectives. Starting from the *discursive corpus*, the statements of the caregivers' discourse were observed. In the second stage, traces of the relationship between *discursive formation* and ideological formation were sought, i.e., linguistics marks produced by the meaning effects among the interlocutors. After this process, the discursive formation "family caregiver of the child with cancer: associated feelings and emotions" was identified. From this stage, the statements that characterized the subjects' discourses were analyzed for the subjects' ideological positions, their relationship with other discourses, historical affiliation networks, and regarding the interdiscourse and the discursive memory.

The relevance of discourse analysis in this study arose from the possibility of this technical analysis to reveal both the worldview and the position of the subject in relation to the theme.

The development of this study met the national and international ethical standards requirements in research involving human beings.

Results

The analysis of the empirical material allowed the identification of the comprehension of care from the caregiver perspective and the feelings lived by the relatives in this trajectory, such as guilt, punishment and sin, thoughts and emotions that were revealed between the lines of the caregiver speech. Besides that, it was possible to apprehend in the statements the fear of death in the imminence of losing the child and the oscillations between hope and hopelessness that divided the experience of these relatives.

Comprehension of care

Care becomes the life goal for caregivers of children with cancer. In the thread of the discourse, a singular dedication of those who see themselves essentially in the role of protector, supporter for the child, was perceived. The position of the subject was that care was revealed as taking care of what belongs to her, in the case of a human being, a child. In the

discursive fragments, the caregiver sets the child in first place, assuming a position of self-denial for the sake of the child's life: *Take care of my daughter? Wow! She is my life goal. Sometimes I look at her and say 'you are the reason for me to live', so, to take care for me... I pass through things and people of my city when they look and say, 'this woman locks herself away', but no, people, it is not that painful. I am taking care of what is mine.*

The act of taking care did not emerge as an obligation to these caregivers, the circumstances determined the choice of self-renunciation and self-denial to achieve the success of the child in overcoming the vicissitudes that the childhood cancer imposed: *I called my husband and he wanted to send someone to substitute for me [...] I said to him, no [...] nothing is better to a mother than taking care of the child, because a mother has that care, that is very different.*

The guilt, the punishment and the sin

In their testimonials, the caregivers seek to justify the disease as a consequence of some misconduct, or even as a will or divine punishment. The lack of explanation for the child's disease tends to place guilt, punishment and sin as determinants for the illness in the minds of these families: *I feel very guilty for it, to put a child in the world to get ill, to suffer! [...] I regret having left him alone, despite being with his grandmother, with his aunt, but in that time I did not see the error, only today I see. Sometimes I feel anguish, asking myself why he has to be like this [...] We end up without an answer, right? Seeking an answer for that. Sometimes we find ourselves wondering "is it for us to pay something?" But if he is not guilty of anything?*

The fear of death in the imminence of loss

The family experiences the fear of failing, being negligent, being punished, rupturing, included within the life perspective and future projected for the child. However, when facing death, or its possibility, the individuals live feelings of anguish, pain and fear, especially confronting a severe chronic disease, as in the case of cancer that itself brings the culturally determined consciousness of death. When this possibility extends to the child, it be-

comes even more painful because the family feels betrayed by life, with the premature removal of that being. The discourse of the caregivers highlights the fear of death, confronting their own limitations: *(I felt) a lock inside of me [...] I used to say "oh my God! R. was so happy, jumped, played and now, R. has this disease!" and I thought, "now he is really going to die" and I saw him almost dead. The people that stay at home know nothing of what we pass through here (in the hospital)! It was a very big fever [...] he was fading.*

Oscillations between hope and hopelessness

With each relapse or complication of the child, the family feels that the child's life hangs by a thin thread that connects life and death in cancer, experiencing oscillations between hope and hopelessness: *And now, because I saw what a relapse is, and for having experiences of seeing other relapses, and knowing that if she has other relapses she will not have more chances, I was afraid [...] all that insecurity from the beginning was back [...] After all that happens (relapses) and she starts taking the medication and feels nothing, she keeps playing, there is a very small hope that all of that may have been a mistake, that it was a mistake, or maybe, it was true that she had a relapse, but she will survive. I keep inside of me the certainty that my daughter will be fine, but then, at the same time, comes another disappointment, because you go to the hospital and see other children dying because of that disease and suddenly comes that negative feeling that my child will not get through, but with God willing she will pass through it.*

Discussion

The study sought to analyze the conceptions of care of the family caregiver through the means of discourse analysis, which proposes the understanding of a discursive plan that articulates language and society, interspersed by the ideological context. However, the comprehension brought in this study demarcates the border among subjects in the same position (family caregiver of child with cancer), but

who brings with themselves their own ideology, socio-historically constructed.

In the context of the caregivers, the relationship between the human being providing care and the limitation of the caregiver presents itself so deeply that there is an abdication of self for the other. Caring in this context is not represented as overload, but as a donation to a human being that belongs to you. By assuming the role of caregiver, parents also absorb the responsibility of restoring their children's health. The care involves feelings of affection, attachment, pleasure, but also reinforces feelings of collection, surveillance for promotion and maintenance of the child's health.⁽⁴⁾ There is a rediscovery of their own role and of all that it is possible to do after the diagnosis of the child's cancer, because there is a perception of their value and ability to overcome any obstacle in the struggle for the child's life. Caregivers position themselves in a way of not admitting the possibility of delegating to another person the child care, and take upon themselves the obligation and responsibility of providing welfare to their child, and, thus, they consider the care a determined intrinsic necessity.⁽⁵⁾ This position, often taken by the mother, is anchored in a sense of duty, being an position entered into since the immemorial times in the human action, in which the mother is seen as indispensable to the creation and protection of her children.

The attitude of these caregivers is shown based in the decision of providing care and the feeling of heroism towards their children's disease. The dimensions of the caregiver of a child with cancer exceed the dimensions of care, being expressed by behaviors and actions mediated by the deep relationship that is established with the child and by the need to exclude any possibility of losing him.⁽⁶⁾ In yearning to avoid the worst, i.e., the loss of the child to the disease, the relative establishes a relationship of dependency with the child, seeking strength to overcome the uncertainties of the future.

Although the caregivers recognize the necessity of someone to help with caring for the child, at the same time, they deny this feeling when taking care of them. The ambiguity is revealed in their statements because they feel exhausted, but do not

admit another caregiver. It is noticed that the discourse of the caregivers permeates between the gift of being able to care for the child while they can and the charge of being there regardless of any other situation. The care is a constant transition that goes from overwork to privilege and, although the suffering of parents of a child with cancer results in high levels of stress and anxiety, this feeling reveals itself in commitment and dedication of family members experiencing a constant struggle for the child's life.⁽⁷⁾

When faced with the reality of having a child with cancer, the caregivers seek a meaning for their and the child's pain. The suffering that comes from cancer sets families at the edge of life and this experience connects itself to spirituality, in an attempt to derive meaning for their suffering. Uncertainty creates an impact on the family, unleashing moments of confusion, despair, worry, exhaustion, and depression, characteristic of suffering in the arduous journey of cancer.⁽⁶⁾ The role of caregivers in this experience is complex, involves negative feelings such as anguish, due to the pain and impact that the diagnosis brings, in addition to physical and psychosocial burden that the family needs to bear. However, even the caregivers realize themselves to be frail, attempting to gather forces to support the child as well as its entire family, in the hope of living a future away from cancer.⁽⁸⁾

Despite the limitations imposed by the children's disease, their caregivers, as they approach the losses, learn how to deal with them and to not give up the battle. In this process, they need support and qualified listening from the health professionals so they can have their energies replenished and their strengths reactivated. Therefore, changing the focus from the disease to the care centered in the family teaches the nursing team to deal better with the suffering family facing this experience and to comprehend the position of the caregiver in this context.

Conclusion

The results showed the care understood as a boon, a feeling of exclusive dedication to a being that be-

longs to you. In the discourse analysis it was possible to dive into the feeling and the relationship of ambiguity experienced by parents, who often felt overwhelmed and powerless, but did not accept being replaced in the role as caregiver.

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Collaborations

Amador DD and Collet N participated in the conception of the project, analysis and interpretation of results, drafting of the article, relevant critical revision of the intellectual content and final approval of the version to be published. Reichert APS and Lima RAG participated in drafting the article, relevant critical revision of the intellectual content and final approval of the version to be published.

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