

DEATH OF CHILDREN BY CANCER: EXPERIENCES OF BEREAVED MOTHERS UNDER HEIDEGGERIAN OPTICS

MORTE DE FILHOS POR CÂNCER: EXPERIÊNCIAS DE MÃES ENLUTADAS SOB A ÓTICA HEIDEGGERIANA

MUERTE DE HIJOS POR CÁNCER: EXPERIENCIAS DE MADRES ENLUTADAS BAJO LA ÓPTICA HEIDEGGERIANA

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Objective: to understand the maternal experience of the loss of a child due to neoplasia. **Method:** qualitative study, based on the Heideggerian phenomenology. Participants were four mothers with children between 2 and 18 years who died of cancer in 2014, at a reference hospital in oncology in the Western Region of Paraná, Brazil. The interviews took place in the mothers' homes between October and November 2015 and were analyzed in the light of Heideggerian hermeneutics. **Results:** two thematic units emerged: Being-mother – realizing that the death of the child is near; and re-signifying the son's life after death – which evidenced the feelings of anguish and frustration of these women. **Conclusion:** the maternal experience of the loss of a child due to neoplasia is comparable to the loss of an important part of oneself, passing through the fear of loss, a search for a re-signification of the care taken until that moment and the life remaining.

Descriptors: Family Power. Death. Pediatrics. Oncology Nursing.

Objetivo: compreender a experiência materna da perda de um filho por neoplasia. *Método:* estudo qualitativo, com base na fenomenologia heideggeriana. *Participaram* quatro mães com filhos entre 2 e 18 anos que morreram por câncer em 2014, em um hospital de referência em oncologia da Região Oeste do Paraná, Brasil. *As entrevistas*

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ocorreram nas residências das mães, entre outubro e novembro de 2015 e foram analisadas à luz da hermenêutica heideggeriana. Resultados: emergiram duas unidades temáticas – Ser-mãe: percebendo que a morte do filho está se aproximando; e Ressignificando a vida após a morte do filho – que evidenciaram os sentimentos de angústia e frustração dessas mulheres. Conclusão: a experiência materna da perda de um filho por neoplasia compara-se à perda de uma parte importante de si, passando pelo medo da perda, busca de ressignificação do cuidado desempenhado até o momento e da vida que resta.

Descritores: Poder Familiar. Morte. Pediatria. Enfermagem Oncológica.

Objetivo: comprender la experiencia materna de la pérdida de un hijo por neoplasia. Método: estudio cualitativo, basado en la fenomenología heideggeriana. Participaron cuatro madres con hijos entre dos y 18 años que murieron por cáncer en 2014, en hospital de referencia en oncología de la Región Oeste de Paraná, Brasil. Entrevistas ocurrieron en las residencias de las madres, entre octubre y noviembre/2015, analizadas a la luz de la hermenéutica heideggeriana. Resultados: emergieron dos unidades temáticas – Ser madre: percibiendo que la muerte del hijo se está acercando; y resucitando la vida después de la muerte del hijo – evidenciándose sentimientos de angustia y frustración de esas mujeres. Conclusión: la experiencia materna de la pérdida de un hijo por neoplasia se compara con la pérdida de una parte importante de sí, pasando por el miedo a la pérdida, búsqueda de resignificación del cuidado desempeñado hasta el momento y de la vida que queda.

Descriptores: Poder Familiar. Muerte. Pediatría. Enfermería Oncológica.

Introduction

Childhood cancer is the second leading cause of death in children and adolescents. It has as main characteristic the greater aggressiveness and the smaller period of latency, growing faster when compared to the neoplasias in adults⁽¹⁾. In this perspective, people in this age group with cancer are in a condition of vulnerability before illness, diagnosis, and at the mercy of the possibility of death and anti-neoplastic treatment⁽²⁾.

For parents, a child's death from cancer comes with a lot of pain and suffering, considering the cognitive and emotional difficulty that sets in when the child ceases to be a presence and becomes a lifeless body⁽³⁾. Because it is in the inverse logic of the natural development of life, the post-death experience is further hampered, harboring, for a long time, the pain and suffering of absence.

The literature reveals that mothers who lost their children have negative effects on their physical and mental health, especially during the first years after death, and may develop depression, posttraumatic stress, and even attempt suicide⁽⁴⁾. In addition, bereaved mothers have an increased mortality rate in the first two years after their child's death compared to mothers who did not experience such loss⁽⁵⁾.

It is important to emphasize that the experience of the process of death and mourning of mothers is also closely related to the degree of quality of the relationship shared with the child who died, as well as the circumstances in which the parents experienced this loss⁽⁶⁾. The child's suffering in the moments before his or her death can cause parents to feel remorse or guilt, making the moment of their child's farewell a painful memory⁽³⁾.

However, parents who are able to talk to their children about death present positive feelings during mourning, and it is of the utmost importance for the health team to attempt to intervene and stimulate the decision of parents in situations of imminent death⁽⁷⁾. Thus, the provision of palliative care for the family of a child in imminent death can help parents to better cope with mourning, thus preventing this process from becoming long and painful⁽³⁾.

Given this scenario and considering that the mother presents herself as the person most involved in the care of children affected by cancer^(6,8), it is imperative to know the ins and outs of the experience of mothers who have experienced the illness and the death of a child by cancer and are facing a new phase of their existence.

Thus, the objective of this study is to understand the maternal experience of the loss of a child due to neoplasia.

Method

This is a qualitative study based on the existential phenomenology of Martin Heidegger⁽⁹⁾, which is based on the possibility of reflecting on the existence of man, placing it in an ontological dimension, making possible to understand what is hidden in the manifestation of language.

In phenomenology, it is necessary to enter into the worldliness of those who are meant to understand, that is, to be in their human world, where they experience the phenomenon that will be unveiled, and this is the region of inquiry⁽⁹⁾. Following this thinking, the study was developed with bereaved mothers whose children died of cancer.

The study participants had the following inclusion criteria: to be the mother of a child or adolescent who died between September 2014 and October 2015, that is, up to a year after they had experienced the process of illness and antineoplastic treatment. It is emphasized that all children up to 12 years of age were considered as children; and adolescents, those aged between 12 and 18 years old⁽¹⁰⁾.

The bereaved mothers were located after consulting the medical records of children and adolescents who died in the established period, in a High Complexity of Oncology Center (CACON, acronym in Portuguese), located in the western part of the state of Paraná, specialized in the care of patients with cancer⁽¹¹⁾. Mothers were contacted to explain the research objectives and to schedule a home visit, if they accepted the participation. There were four deaths of children and adolescents with cancer in the established period. All accepted to participate in the study.

When working with phenomenology, the number of visits is not stipulated, as the desire to express the phenomenon must emerge from the participants themselves. For this study, two to three visits per family were performed. In addition, phenomenology is not a matter of problems, but of an interrogation, because, when

one questions oneself, one begins a journey towards the phenomenon, which manifests itself through the language of one who experiences the situation researched⁽¹²⁾. Faced with the phenomenon to be questioned in this study, the interviews were conducted based on the guiding question: "How did you experience the illness and death of your child?"

The interviews were recorded on a digital recorder and later transcribed in full. The anonymity of the subjects was guaranteed through the use of goddess names related to the myths that refer to the phenomenon of death and dying: Aphrodite, Athena, Thêmis and Panacea⁽¹³⁾.

In order to capture the fullness of meanings expressed by the subjects, it was opted for the individual analysis of each language, starting from a trajectory that reveals the ontic until the ontological dimension of the mourning mothers. For that, the starting point was the vague and medium understanding, when one tried to apprehend the daily facts revealed by the mothers, stripped of any assumption or opinion that could transgress that perception. This analytical moment sought the facts that the individual usually shows to all, since they have essential meanings and structures still veiled, that make possible the understanding of the phenomenon⁽⁹⁾. The second moment, called interpretative understanding, sought to clarify what was still obscure in languages based on the interpretation of their senses; the sense of being of each individual before the phenomena revealed was interpreted, culminating in the Heideggerian hermeneutics⁽⁹⁾. After this step, the ontological themes were established, analyzed in the light of some ideas of Heidegger's analytic, some oncology assumptions and authors that deal with such topics.

The research project was sent to the Permanent Committee on Ethics in Research with Humans (COPEP, acronym in Portuguese) of the State University of Maringá (UEM, acronym in Portuguese) and authorized by the protocol No. 1,284,032. All the ethical precepts established by Resolution No. 466/2012, of the National Health Council, were fulfilled.

Results and Discussion

The inspiration of the pseudonyms came from the Greek myths about death⁽¹³⁾, by the similarity between the characteristics of the protagonist goddesses and the personalities of the participants. This identification was followed by the number corresponding to the years that elapsed from the diagnosis to the death of the children.

The first mother was named Aphrodite, goddess of love, compassion, and fertility. She was so called, for having isolated herself from the world to love her daughter in the most intense way she could, transforming her pain for the death of her daughter in love. After just over 12 months of love and dedication in treating leukemia, her two-and-a-half year old daughter died.

Athena, the second mother interviewed, refers to the goddess of strategy, battle, arts and wisdom, protector of her armies. As a way to keep her son around, she preferred to relive the 10-year struggle against neuroblastoma until she lost her 14-year-old son.

Thêmis, the goddess of justice, represents the third mother, who demonstrated a balance between reason and judgment and, despite the commotion, demonstrated acceptance “of the will of God.” Her son died at age seven after four years of treatment for leukemia.

Finally, Panacea, the goddess of the cure of all the ills of humanity is portrayed by the fourth mother, who did not measure efforts to seek therapeutic resources in the struggle for the life of her son. After five years of battling leukemia for his son’s health, she realized that the cure she sought was to let him go, die at home, in the comfort of his home, at the age of 18.

Results were organized and presented based on the expressions of maternal experiences regarding the treatment and death of the child, according to two ontic and ontological themes that are in line with two significant moments in the journey that these mothers began when they discovered the first symptoms: the impossibility of healing their child until the moment of death.

Recognizing the impossibility of healing and the possibility of dying with/of your child

Although death is part of human development, it is undeniable the reluctance to accept it, especially when it comes to the dying of a being who lived little, as a child. The relentless struggle to maintain life is clear in the attempt to deny any possibility of loss.

On receiving the news about the exhaustion of treatment resources that could safeguard the life of the child, the process of anticipatory mourning was initiated, especially in the mother, which began with the ratification of the announced possibility of the death of the child:

When the doctors told us that there was nothing to do [silence] that the disease had relapsed again, and that there was no chemotherapy anymore, that there was nothing else to do [emphasis] that it would be only for God... [Cry, pause] of course, it was a thump. (Thêmis, 4).

We were already using all the possible tools, and nothing. Until then I was solving [long pause]. But on the day of the news [silence] when there was nothing else to be done in medicine, and on the day the doctor told us, we got really shocked. And from that day everything changed. It was very, everything was very dark. It seemed that nothing else made sense. (Aphrodite, 1).

When we received the news [...] that by the end of those ten years death was coming, it was one of the most difficult times. We do not accept it because we believe in so many things, and we end up believing that there is always something to do, that what has been done has not yet [...] not yet been fully done; was everything done? (Athena, 10).

Faced with the facticity and possibility of death, the pain experienced by mothers is so great that it represents the experience of a nightmare. Heidegger, in *Ser e Tempo* (Being and Time), shows a new perspective to see man, on the basis of *existence*, which is understood as that which emerges, unveils itself or leaps out of itself, opening itself to the world⁽⁹⁾. In this opening, these mothers are sent to manifest a new perspective of seeing themselves and the sick child. At the very moment when a trustworthy professional transmits to them the human incapacity of the healing of their children, the possibility of finitude materializes, revealing the fears hitherto veiled⁽⁹⁾.

In Heidegger’s analytic, perceiving the inevitable brings to the fore the anguish, a

fundamental characteristic of human existence. At this moment, you perceive nothingness as a shadow that hangs over all things. In anguish, man realizes that he is a being-to-death. It is death that removes the whole meaning of life⁽⁹⁾.

However, the anguish, which among all human feelings is that which can bring man back to the center of his essence, making him out of the monotony and indifference of life, is the feeling that can bring him back to his totality as a being⁽⁹⁾. In the midst of the anguish experienced by the mothers in the face of the possibility of the death of their children, it was possible to understand that this meeting has led them to reflect on the care that had been devoted to them and, consequently, on the time that still remained with their child:

We got the news in one day; on the other day [silence], she [...] won a toy she wanted [a long pause]. And I started to enjoy every minute I was with her. We had enjoyed it since the diagnosis, but not so much [sigh, almost regret], not with the same intensity after the day that the doctors told us [long pause], because there was nothing else to be done. (Aphrodite, 1).

Being present in pain, in suffering, transforming him into happiness was painful [silence]. Things got a little better over time. We were [...] getting used to it [sigh, almost crying] but not so much, you know? Because getting used to it means living that moment, providing the pleasure of life to her, little things to her; it is a magic thing. (Thémis, 4).

After all these years of treatments, transplants, after this transplant, I thought he would be healed [...] Jesus, I thought it would be his healing [emphasis]. He came home, felt amazed; he went out, went to his grandmother's house, went to see some friends. Many people came. He knew the whole city. We did a trip [...] he wanted to get to know the Falls. After a few days, he said he wanted to recover [...] He stayed here at home a few days, only with me and his father. (Panacea, 5).

Before the unveiling of the finitude of their children, the mothers were faced with a new situation, which required a new posture before themselves and others. *Dasein* is a world-being, launched into the world, who can acquire two modes of being-in-the-world – the inauthentic mode and the authentic mode – that refers to the property of existence in which *Dasein* happens to be recognized as a being of presence⁽⁹⁾. Thus the being-there is launched into the world and begins to live a situation of ambiguity, which means that it is free to make its own choices. And they can indicate the freedom of the being-mother

to be with-the-other in an authentic way. Then, the care for the children, provided by them, acquires a characteristic that Heidegger points out as ontological, that is, of understanding what really matters.

This new version of the roles of mother, child, treatment and illness brings with it a reflection about life, which translates into an emerging desire to be-with the loved one in an authentic way. Nevertheless, Heidegger tells us that being-in-the-world lives in the spatiality of its field of action, that is, where the being can show itself and exercise its freedom of movement, approaching the other as being-with, or distancing themselves from it, configuring itself as being-together⁽⁹⁾. In approaching being-with, *Dasein* relates in a meaningful way to other beings, with the possibility of getting involved and caring for the other, showing concern⁽⁹⁾.

The solicitude of caring makes it possible for the being-mother to grasp the temporality of the life of her child, in search of experiencing daily life in the most profound and meaningful way possible. Thus, when the Being encounters finitude, it opens up to its essential constitution, accessing the integral structure for the phenomenon of care in its existence⁽¹⁴⁾.

In the uniqueness of the acceptance of the moment when death is inevitable and in the attempt to bid farewell, the children signaled what would be their last goodbye, providing their parents with the opportunity of a memorable last moment, a serene farewell, cherishing their hearts and leaving the peace of a quiet death, as the speeches show.

We were in the room, he and I, and he said, "Mom, do you know how to sing that hymn, "Hold on to God's hand"? And I said, "Yes, I know". He began to sing. When I got close to him, he asked me to give him a hand. So I gave it and he held my hand and said, "Let's sing" [crying]. I could hardly sing because I knew what [prolonged silence] would happen when he said he wanted to hold on to God's hand. I knew that something... that at that time [emphasis] God was really going to take him away. (Athena, 10).

He came home; he didn't want to stay in the hospital [silence]. As the days passed, I didn't want to see many people [silence]. He went to meet God. He stayed here in the house, with me and his father. He simply stopped breathing without suffering [silence]. His suffering ended. It was quiet. And he said before he left that he was going to die. He used those words: "I'm going to die." And he was just gone. (Panacea, 5).

For mothers, death acceptance by the child, as well as their peaceful farewell at their side, can bring chilling and serenity, softening the burden of separation, by building a memory so tender and permeated with meanings. Death, for man, is like a shadow; something that lurks, from which we have to flee. However, man is a being-to-death, for to him is guarded the possibility of constructing his unique finite historicity. He only understands himself in his own Being when he ceases to Be⁽⁹⁾. It may be said that the children accepted their own death and acted authentically in their departure, for they understood the end of their existentiality as being-in-the-world.

However, the understanding of death is particular to the Being who experiences it, and who is not able to convey to the other his experience and understanding about the matter. In this sense, mothers are hard to believe in the death of their children, even when, inevitably, it is imperative to experience this loss.

The studies show many things about death to us, like how death is, but to say that I am prepared and that death will come now [emphasis]?! You can't. You can't see that now is the time, even if you are there, and you know it! You look and see that it's all stopping and there's still that minute that you say it's not true: "No, he's not dead!" (Athena, 10).

I called him [...] he didn't answer. I started to cry, I took a deep breath. I knew [...] death did come, now he died, he died! I knew he had died [silence]. I kept waiting for it to happen, but it happened in another way; he went well, very quiet [...] so suddenly, so quiet. The Technician arrived with the medication. I said, "No need, he's not here anymore." She was astonished: "Don't worry, it's okay with him." Then I said, "No, he's not here. No need to medicate him." "So I stopped and thought, "My God! Death is something you will never, ever, ever be able to imagine. One moment he's there, the next minute, he's gone." (Athena, 10).

These excerpts reveal that the moment of death is not really understood by the other in the same way as by the one who died. That is, experiencing/reflecting on the death of the other does not allow us to be able-be more properly⁽¹⁵⁾. Thus, at the instant of death, the mourners seem to be shaken and without prospects, for they are required a new meaning in the absence of

the other and their new configuration of life. From now on you will no longer be in charge of safeguarding the life of your child. Thus, in having to deal with funeral rituals, the sentence that the deceased is no longer in his midst is proven⁽¹⁵⁾, as follows in the next category.

Reviving to a new existential condition from the death of the son

In order to mitigate the impacts of loss, it is common for bereavers to think about restructuring their future. The greater the space occupied by those who died in life than they were, the process may be even greater and more difficult, which is frequent in the case of a child.

Death is something that no one will ever be able to say: "Oh, I can accept death with open arms!" To say that dying is easy and natural is a natural thing in life; we are all born, grow and die! We will all go through this! The only thing is, it should be forbidden, in my thinking, for a mother to lose a child. The right thing would be for us, mothers, to die first, for them to live. (Athena, 10).

The mother gives life and, with the children's lives, her identity immortalizes. With the death of the child, this linearity is broken. The being-mother, who abdicated herself to take care of the child's life metaphorically, dies when the life of her offspring is gone; her existence becomes pointless and meaningless. Her reason for being is based on the pain of the loss of those who she loves the most, this being the most overwhelming pain, in terms of degree and fullness that affects all her feelings and her life⁽¹⁵⁾.

For these mothers, it is not only their children who have died, but also their way of existing as mothers. This occurs even when mothers have other children, as the interviewees in the study, who affirmed that the death of one of them is an irreparable loss, which is also emphasized in other studies⁽¹⁶⁾. However, reliving difficult and sad moments of the illness, treatment and death process is gradually replaced by memories of the child's life. In addition, returning in their temporality, mothers can understand

the magnitude of their being-mother, while those who, in the face of their commitment to existentiality, feel authentically realized in the role played for their children:

At the time they put him [...] in the tomb, I sighed and said, "I did everything I could and it didn't work [sigh]." But she [...] must have understood that I was the mother and that she was everything to me and that I was everything to her. (Aphrodite, 1).

[...] my conscience is like, "Look, I tried." I think everyone has to try, because if you don't, in your mind, you will accuse yourself: "Oh, but you could have tried, why didn't you try?" "Others will say, "Oh, why did you try?" Look, I tried to do my best, and if I could go back in time, a lot of things I would do again, without a second thought. (Athena, 10).

If time could come back, I would simply give him a kiss, a big kiss, so I could stop missing him. In addition, regarding regrets about what was done, what was taken, what was left behind, and what was prayed for, I have no guilt or regret [silence]. "I would do everything with the greatest affection in the world. I would do everything I did during those five years, with the greatest pleasure and love in the world." (Panacea, 5).

The mothers revealed in their speeches that the experience of the care for the child was, in its intensity, full of love and dedication, which exceeded any feeling that something was not done. In this sense, these discourses turn to the concept that refers to care as the fundamental relationship of being. It is worth emphasizing that, according to this understanding, care is based on the possibility of the condition of the possible relationship, reflected in love, well-being and benevolence in the relationship of being-with⁽¹⁷⁾.

These mothers, through total care and self-denial of their lives for their children, translate the love that has become an attitude of care that brings the peace and individual well-being necessary to resume their journey. Thus, slowly, they realize that the child has taken up a particular place and feel able to handle the situation. The following speech is illustrative:

Things happen for a purpose. You end up not exactly having more faith, but end up believing that life is not just happy moments. Facing sad moments is important because they also serve to learn to enjoy life, so that it is a lesson that will contribute to your future. (Aphrodite, 1).

In Heidegger's analytic, man, in his existentiality, can advance in his possibilities, to transform them, in order to overcome himself,

projecting himself into the world⁽¹⁸⁾. This movement is called transcendence and is shaped by the encounter of existentiality in existence, that is, the moment when man, as Dasein, can come to light⁽¹⁹⁾. In this sense, it is understood that these mothers transcended the essence of their existentiality after the death of their child, returning to exist as a Being in their world.

The elaboration of the mourning process is essential for rebalancing the life of those who lose a loved one, seeking the understanding of life as beings-for-death, but intertwining projects and goals while their own death does not come. This reflection allowed the understanding that these mothers possessed the feeling and the strength necessary to redo their lives and start a new journey.

Moreover, a study carried out in the Netherlands points out that bereaved parents, when accompanied and guided, end up achieving the loss in up to 13 months⁽²⁰⁾. In this sense, it is preponderant for nursing to assist the bereaved family to transcend feelings of pain and frustration after the death of the child, in order to resignify the experiences during the treatment and death as good memories, which refer to peace and longing.

As a limitation of the study, we highlight the time elapsed between the death of the child and the interview, which may have caused some moments to have been omitted or even forgotten by the mother as part of a psychological blockade of suffering experienced.

Conclusion

This study allowed, through the Heideggerian analytic, to understand the maternal experience of the loss of a child by neoplasia. It was generally understood that the experience of losing a child begins at the moment when the mother recognizes the possibility of the death of the child and goes through the existential anguish before the facticity of life and the acceptance of finitude. After the death of the child, the mother-being transcends to a new existential condition,

when she begins to redefine herself existentially as a mother.

Thus, reflecting the experience of mothers, taking care of their children diagnosed with cancer and their understanding of the possibility of their finitude, demands availability with depth, uniqueness and emotion, since it transcends any loss imaginable to the human being in life: mother-without-son goes through the ruin of her existence, only then to take the first steps towards the reconstruction of her world.

Understanding the death/grieving experience of these mothers enables nurses to empathize with and strengthen the bonds established between the team and the family at all stages of the illness, as well as contributing to holistic care, encompassing physical, emotional, and spiritual care. Thus, authentic nursing care may arise in this context, when caregivers are recognized and recognizes in caring.

It is reiterated that nurses are the health professionals who more closely experience this process with mothers, and that the actual or potential fears of the terminality itself can cause them to remain emotionally distant from these mothers and patients. Given this, it is recommended that nursing review its position before death and dying, to be ready and available to be quiet to accommodate the family/mothers in the amplitude of their needs.

Collaborations:

1. conception, design, analysis and interpretation of data: Josane Rosenilda da Costa, Eleandro Prado, Rubiane Beal, Julia Wakiuchi, Catarina Aparecida Sales and Sonia Silva Marcon;

2. writing of the article and relevant critical review of the intellectual content: Josane Rosenilda da Costa, Eleandro Prado and Julia Wakiuchi;

3. final approval of the version to be published: Julia Wakiuchi and Sonia Silva Marcon.

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