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THE EXPERIENCE OF PARENTS OF CHILDREN WITH CANCER IN TREATMENT FAILURE CONDITIONS

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ABSTRACT: Study based on Heidegger's existential phenomenology. The objective was to understand the experience of parents of children with cancer in treatment failure conditions. Participants were eight parents of eight patients seen at an oncology center from January to May 2014. Interviews were conducted guided by the question: Tell me about your experience of being a family member of a child with cancer in treatment failure conditions? Three ontological themes emerged: the phenomenon unveiled in the discovery of the child's cancer; experiencing the process involving the child's cancer; unveiling the possibility of the child's death. It was evidenced that the experience of these parents was permeated by intense and devastating feelings towards the early loss, annihilating dreams of a desired future. It is essential for nursing to look more attentively at the family of terminal patients.

DESCRIPTORS: Nursing. Family. Child. Cancer. Death.

A VIVÊNCIA DOS PAIS DA CRIANÇA COM CÂNCER NA CONDIÇÃO DE IMPOSSIBILIDADE TERAPÊUTICA

RESUMO: Estudo fundamentado na fenomenologia existencial heideggeriana, cujo objetivo foi compreender a vivência dos pais da criança com câncer na condição de impossibilidade terapêutica. Participaram da pesquisa oito pais de oito pacientes, atendidos em um centro de oncologia, de janeiro a maio de 2014. As entrevistas foram norteadas pela seguinte questão: conte para mim como é para você a experiência de ser familiar de uma criança oncológica na condição de impossibilidade terapêutica? Três temáticas ontológicas emergiram: o fenômeno desvelado na descoberta do câncer no filho; vivenciando o processo que envolve a doença oncológica no filho; o desvelar da possibilidade da morte do filho. Evidenciou-se que a vivência destes pais foi permeada por sentimentos intensos e devastadores diante da perda precoce, aniquilando sonhos de um futuro desejado. Torna-se imprescindível a enfermagem direcionar um olhar mais atento à família de pacientes terminais.

DESCRIPTORIOS: Enfermagem. Família. Criança. Câncer. Morte.

LA EXPERIENCIA DE LOS PADRES DE NIÑOS CON CÁNCER EN LA CONDICIÓN DE FRACASO TERAPÉUTICO

RESUMEN: Estudio basado en la fenomenología existencial de Heidegger. Tuvo como objetivo comprender la experiencia de los padres de niños con cáncer en la condición de fracaso terapéutico. Los participantes fueron ocho padres de ocho pacientes atendidos en un centro de oncología de enero a mayo del 2014. Se realizaron entrevistas guiadas por la pregunta: ¿Dime cómo es su experiencia de ser miembro de la familia de un niño con cáncer en la condición de fracaso terapéutico? Emergieron tres temas ontológicos: el fenómeno presentado en el descubrimiento del cáncer en el niño; experimentar el proceso que implica la enfermedad oncológica en el niño; la revelación de la posibilidad de la muerte del niño. Era evidente que la experiencia de estos padres fue permeado por sentimientos intensos y devastadores antes de la pérdida temprana, aniquilando sueños de un futuro deseado. Es fundamental que la Enfermería considere con más atención la familia del paciente terminal.

DESCRIPTORIOS: Enfermería. Familia. Niño. Cáncer. Muerte.

INTRODUCTION

Over the last years, childhood cancer has been the main cause of death in Brazil among children and adolescents. The estimated number of new cases per year in 2014 and 2015 is 11,840, with a higher prevalence in the Southeast and Northeast and significant process in the treatment. The estimated cure rate corresponds to 70% if diagnosed early and treated appropriately at specialized centers.¹

When a child is struck by cancer, this episode affects all family members, provoking an emotional shock that can deeply shatter its structure, which will interfere in the lifecycle evolution. Feelings of insecurity, fear, despair and loss emerge in view of the first difficulties.² Although it is beyond discussion that the survival rates of children with cancer are increasing, a considerable quantity will not get cured, so that so-called palliative treatment is implemented until they pass away.³ Palliative care is justified as a fundamental focus of health care, because the late diagnosis of cancer influences the survival rate, complemented by the delayed search for health care and the precarious nature of the health services.⁴

In this context, communication on the incurable disease to the parents should be appropriate, as the understanding will affect the way they accept the fact and will be prepared for their children's imminent death.⁵ Psychological preparation is necessary and should be organized in this process of less⁶ but, when the child is hospitalized, the family is frequently forgotten or ignored. The family is generally considered as a mere resource,⁷ although its care, which includes the highly necessary affective component, offers support and protection.⁸ As the main social group in a person's life, the family will feel the consequences of hospitalization early.⁹

When the parents receive their children's diagnosis, the suffering is more evident, as the confrontation with the responsibility to take care of their children adds up to the feeling of rupture in the natural order of events.¹⁰ The relatives are responsible for taking care of the family's members, a process that is learned and constructed throughout its trajectory, which becomes fundamental in care as an element of family disclosure in all phases of human life.¹¹

Among chronic conditions in childhood, cancer stands out because of its high incidence and repercussions in the children and their families' lives. The disease is responsible for role changes in the family dynamics, including economic and psychological exhaustion in the entire family group.² In

this situation, aspects go beyond the dimensions of care, which are expressed by behaviors and actions mediated by the time and need to distance the possibility of losing the child. Criteria are developed to cope with this new context of life, including patience, courage and internal strength to overcome the uncertainties about the future, living between the uncertainty of hope and fear.¹² Therefore, the process of loss becomes difficult for the parents, as this progressive abdication takes place through a personal conflict between saving and letting go.¹³

Therefore, it is considered relevant for the nurse and other health professionals to get to know the experience of the parents of children with cancer in conditions of therapeutic failure, with a view to incorporating and intensifying comprehensive and humanized family care in their practices. Thus, the objective in this study is to understand the experience of parents of children with cancer in treatment failure conditions.

METHOD

This research is focused on the phenomenon the parents of children with cancer in conditions of treatment failure experience. In view of the nature of the object, qualitative research was chosen along my trajectory, using the approach based on Martin Heidegger's existential phenomenology.¹⁴

At its heart, Heidegger's phenomenology contains the Being as a typically human issue. Thus, the problem of the Being is not only the essence but also the existence. In that perspective, Martin Heidegger developed his existential analytics, which questions the meaning of the being, the *Dasein*, which is at the same time Being-there and Being-in-the-world.¹⁴

Heidegger remits to an existential phenomenology as a philosophical framework that leads to a world relation between nursing and the different specialties of care for the mode of Being of parents who have a child with cancer in conditions of treatment failure.¹⁵ The development of this research is intended to unveil the phenomenon these parents experience, in this perspective, in order to understand their experience. The need is highlighted to pay attention to the description as it is, how this phenomenon reveals itself, in its essence, to these parents who go through this experience.

Hence, the ontic-ontological region is the situation in which the phenomenon we intend to unveil occurred and the experiences of the parents going through the condition of treatment failure of the cancer in their child's life.

In compliance with the ethical principles, the research was submitted to *Plataforma Brasil* under CAAE 22482213.0.0000.5013 and received approval from the Ethics Committee for Research Involving Human Beings at *Universidade Federal de Alagoas* under opinion protocol 514.590. Next, the participants were surveyed with the help of the nurse coordinator at the Oncology center of the *Santa Casa de Misericórdia de Maceió-AL*, Brazil.

Eight children of up to 14 years of age were found, who were registered and received palliative care from that institution's multidisciplinary team, and 13 parents were contacted and invited to participate in the research.

To participate in this study, only family members who complied with the inclusion criteria were included: over 18 years of age, who had a child with cancer in conditions of therapeutic failure, who were aware of the child's disease prognosis, accepted to participate in the study and were capable of clearly expressing their experiences.

Among the 13 possible parents, five did not accept to participate in the study. The remainder, who complied with the inclusion criteria, were invited and accepted to participate by signing the Informed Consent Form. The participants included four parents and four mothers, between 26 and 38 years of age. In terms of religion, six self-declared they were Catholic and two Evangelical.

After accepting the invitation, a new meeting was scheduled for the interviews, on a day, time and place at the participants' convenience, between January and May 2014. Free interviews were held, guided by the question: "tell me what the experience has been like of being a relative to a child with cancer in conditions of treatment failure?".

The interviews were tape-recorded and then fully transcribed for further analysis. To guarantee the participants' anonymity, they were indicated by the letter "P" (parents), followed by Arabic numerals in the order in which the interviews were held.

To fully apprehend the parents' expression, each testimony was analyzed individually. Initially, each of the testimonies was repeatedly read, without any claim on interpretation, simply considering the global sense of the experience of parents of children with cancer in conditions of therapeutic failure. In a new attentive reading, the units of meaning were selected which, according to the researchers, served as fundamental structures of the existence and revealed the meaning the parents attributed to the experience. The units of

meaning of each testimony were successively analyzed and grouped and each participant's language was phenomenologically selected.¹⁶

As a result of this process, three ontological themes emerged: the phenomenon unveiled in the discovery of the child's cancer; experiencing the process involving the child's cancer; disclosing the possibility of the child's death.

The discussion was based on some of Heidegger's ideas and on authors who discuss the theme.

RESULTS AND DISCUSSION

In the search to understand the experience of the parents of children with cancer in conditions of treatment failure, departing from a set of conceptions related to the experiences and life histories involving the families, we were allowed to, based on the units of meaning in the testimonies, disclose the structure of the phenomenon under investigation. The results were grouped in ontological themes, which will be presented and discussed next.

The phenomenon unveiled in the discovery of cancer in the child

The experience was permeated by fascinations and deceptions inherent in each phase of the disease's discovery, since the moment it was perceived that something was wrong with the child's health until there was certainty about the diagnosis, turning the parents into a Being-in-the-world-with-a-child-with-cancer.

As the disease continued to be investigated, the definitive diagnosis was established and the parents gradually gained knowledge on the cancer that permitted understanding the extent of the threat on their child's health. *At first [...] I thought it was just a kidney stone, I thought it would be easy, but it got worse, until the cancer was found and he has been here since Saint John's Day (P3). Children were not born to suffer, even less by cancer, a disease of adult people [...] (P8).*

The discovery was permeated by lack of knowledge on the possible presence of cancer in childhood, linking the parents to an unknown world, filled with uncertainties related to the cure, mainly aggravated by the fact that they believe that the children are intangible and that cancer is for adult and elderly people only. The parents, as Being-there who were cast into the world, in which cancer appears as a presence in their existence, find themselves without option and obliged to experi-

ence the non-programmed and to gain awareness of the difficult and solitary course they will followed.¹⁷

Although the technological advances increase the possibility of cure and survival, cancer is still treated as a curse, considered devastating, destructive, invincible and the parents can feel discriminated against and embarrassed when they find out about their disease.¹⁰ The cancer experience is more destructive for that patients and their families than other forms of disease, and any other disease will hardly induce that many negative feelings.²

Therefore, the process of accepting the child's disease gained complexity, as it requires breaking with the belief that was part of their understanding of health-disease in childhood: *I was also misinformed, because I didn't know this cancer problem could happen to a child, I thought it only happened to adults and elderly people. I had to see it to believe it and now I know, and now all there is to do is wait* (P5).

Even in view of an intense search for a way that can hide or even eliminate the child's illness, the family members find themselves without a way out, therefore surrendering to the emotional impact of this situation.¹⁸ As the parents perceive themselves as a Being-in-the-world permeated by cancer, they understand the complexity involving the disease and the possibilities inherent in the context of the cancer, ranging from cure to a somber prognosis.

In the disclosure of the hidden phenomenon, the discovery of the child's cancer diagnosis manifested a lack of emotional stability permeated by despair, removing the former feeling of tranquility and serenity. According to P2: *my mother called me crying and desperate, only saying that it was something severe she'd only tell me when I was here, so I also started to get desperate, because I thought it was but a simple disease* (P2).

These feelings make it difficult to accept the diagnosis because they consider the child as a being who cannot be hit by something that threatening and capable of shaking that world full of health and happiness.

Cancer is seen as an intensely negative, terrifying and despairing threat, which causes an emotional misfit, permeated by the impotence to protect the child.¹⁹ The parents go through new adjustments in daily life because they are not prepared to cope with the disease that is threatening, because it carries the socially created stigma of a death sentence¹⁷ since, in childhood, the finiteness is loaded with particular cruelty, as the child is considered a synonym of joy, growth and future.²⁰

As observed in the parents' testimonies, the cancer occurs in the child's life as something shocking and fleeting: *I already knew that the cancer was a severe illness, but when I arrived... Oh dear, he was very skinny* (P6).

The discovery of the child's disease is permeated by inquiries and an intense search for answers as to why exactly their child was chosen to go through all of the suffering the condition of suffering from cancer entails: *when I discovered the disease, plenty of things went through my head, I could not understand the why, I looked for the answer and could not find it* (P3). [...] *it was difficult to accept that my child had this disease which only causes suffering* (P6).

The parents question "why" their child has cancer, due to the feeling of going through a great struggle,²¹ which is offering a life lesson and grants knowledge on the true meaning of having a child, which the child's suffering because of the disease could arouse. In that sense, attention should be paid not only to the child and the diagnosis, but also to the changes that occur in the family link, as well as in the parents' feelings, how they confront and cope with the situation imposed on them.²²

Peculiarities in the parents' experience, such as the progressive worsening of the prognosis, are deeply sensitizing, making them value life: *the first chemotherapy sessions were the hardest, the hair fell out, but I considered that as a life lesson for you to know how to value your child. [...] some situations happen for you to value life more, how I see what is happening to my child [...]. And now with this disease I see the world differently, I see people differently and I know that God has a purpose in my life with this disease that struck my son* (P2).

The Being-in-the-world-with-the-child-with-cancer in conditions of therapeutic failure allowed the parents to shed a new light on themselves and on the affective bonds in their existential condition of Being. Thus, former material values lose meaning and make room for others, such as health and union, permitting a new focus on life.⁹ Palliative care contributes to improve the child's life, centering on the quality of life the parents should also be offered.²³

Experiencing the process involving the child's cancer

When the parents discover themselves as a Being-in-the-world who experiences an existential relation with oncology, they assume a feeling of daily change that makes them cope with the process of their child's disease. To adapt, the family structure had to be reformed, considering the sick child's

care needs. In this situation, the lack of preparation to cope with the intense emotions permeating the diagnosis is uncommon, demanding help to manage the needs in this phase.²⁴

According to P1, the child's disease caused changes, imposing new routines in the family context, as the hospitalization the child needed in search of treatment demands an accompanying family member, who can give up providing and sharing care and company with the other children and the partner, causing a rupture in the family planning: *as a result of this whole struggle, what has changed is the family routine, in the sense of being at our house, our daily life [...]. The entire structure changes, everything you had planned, what we had planned for our family, I can tell you it was cut off. We used to plan at our home, his dream was to have a brother, and today I cannot even benefit from my house, I cannot benefit from my son* (P1).

The disease is an episode in the life of the person and his family that provokes a rupture in the reference frameworks. When they enter the hospital world, they are forced to adapt to a new reality, consisting of different elements of daily life.²⁵ This vulnerability these parents are exposed to permits reflections on the human being's condition of Being-cast-in-the-world, unconnected to imposed conditions that are vulnerable to the unpredictable situations inherent in life.¹⁴

The involvement in the disease process also affects the other children, who can be older or younger and, independently of their age, will not be prioritized in care. Instead, the sick child is the core point of attention until the process is overcome. Thus, the other child is vulnerable because it does not receive the parents' care for its healthy growth and development: *because when that happened to him, I had to give up my time with my other son, who's also small, to give him all care because he needs it more at this moment: [...] at this moment, who needs it more is [...], I'll be here for as long as he needs me, he's the main thing, because he's going through all this. [...] I talked about this with my husband, we are putting aside our baby, he's at my mother's, we end up not giving the education we would like to, I here and he working we can't educate him* (P1).

According to the current paradigms, the parents' presence is recommended during the child's hospitalization.²⁶ This brings about the need to take distance from the other children, making the mothers' situation more difficult, arousing important internal conflicts and intensifying the feelings of anguish and guilt about their parental responsibilities.²⁷ When they prioritize care for the sick child,

they promote distancing from the family unit and from the housework and need help from relatives.⁹

Therefore, the process of coping with the child's disease determines priorities in the parents and mainly the mother's life, who is culturally the main caregivers, whose professional career is given up to dedicate herself to the sick child. *I had already quit my job to stay with my baby, then, when this happened to him, all of my attention is focused on him. People generally say that we cannot give up our professional life because of a child. Today, I say that I will give up as much time as I can to stay with my children, time spent with a child is not lost time* (P1).

As for financial provision, the father is responsible for sustaining the family during the child's disease process, with a higher spending demand. He starts to work longer hours to attend to the family's basic needs. *I have to work extra during the day as a painter and, at night, I work at [...], so I don't have time for the baby, and at weekends too, when necessary I work to be able to attend to the needs* (P8).

The mothers feel more confident in care for the child when they are responsible for accompanying the consults. They add that the fathers are responsible for the family income, consequently abstaining from accompanying the child to the doctor and the hospital because they cannot stay away from work. In this conjuncture, the mother plays a more active role in the disease process.²

Mothers who have a child with cancer feel obliged to fully dedicate themselves, depriving themselves of activities they liked and which were part of their daily life before the disease, such as leisure, work and sociability, spending most of their time at the hospital, which turns into their housing.^{19,28}

The marital relationship can get strengthened by further approximation between the parents, in order to allow them to experience and share the difficult times during the treatment; or further distancing can occur in view of the difficulties that will require exclusive dedication, especially from the mother, who dedicates herself to the sick child, leaving her husband without her attention: *I and his mother got divorced much before we found out about this. At the moment we've been separated for two years, but we are talking and the relationship between me and her is good, we have no disagreement. We are together as father and mother, because who needs it more is he and we shouldn't mix things* (P7). *Our child's disease got our relationship much stronger, one partner supports the other [...]* (P5).

The cancer can cause problems that existed earlier or did not exist in the family context but,

mainly, it can be a source of union in the family.²⁹ A factor that tends to influence the family relationship is the child's clinical condition, which may be related with the family's bad quality of life, mediated by the burden and stress of the father or mother who is responsible for direct care for the sick child. Therefore, interventions that promote the parents and children's wellbeing need to be facilitated.³⁰

Despite some progress in pediatric palliative care, the parents' perspectives on end-of-life care support to children with cancer need to be assessed.³¹ In this context, the health professionals are responsible for granting emotional support and maintaining good communication with the parents with a view to promoting high-quality palliative care.³² Along this trajectory, care for the parents should be provided progressively, preparing them to cope with the mourning, so as to guide their lives after the child's death.³³

Disclosing the possibility of the child's death

In this ontological theme, spirituality and religiosity are frameworks for the parents in coping with the possible death of the child with cancer, in view of the therapeutic failure condition. In this situation, the palliative care team should make it easier for the parents to practice spirituality, considering the family's needs.³⁴

Belief helps the family to cope with the difficult times preceding the loss of their child. They go through moments of anguish that, in the possibility of death, can lead to situations of denial and, even when it is evidenced through an incurable disease, it is a process marked by pain and suffering.²⁸

It was observed that the parents did not accept the therapeutic failure prognosis. In a way, they looked for positive answers opposed to the reality inside themselves: *the doctors only say the opposite, that the tests are going wrong, that he's severe, that it's advancing, but I see he's so well, you can see he's reacting well [...] I know that doing without the chemotherapy and the radiotherapy won't solve anything and will only make things worse. I know he won't get well with other things. As opposed to everything the people say, he's showing the recovery, there's movement, he has already started to open his eyes, he knows anyone who gets here, I believe he's recovering little by little (P4).*

Death is the most unique, absolute, certain and, as such, indeterminate, insurmountable possibility of the Being.¹⁴ Nevertheless, its definitive arrival is something hard to accept at once, and may reveal a behavior of denial, despite the experience

of accompany the family member's agony.²⁸

Faith in cure is an unshakeable presence in all testimonies. The parents believe that God will lead to the best outcome in the child's life, whether towards death or cure. At this moment, they put the child's future in the hands of God: *for the doctors the suffering cannot be avoided, what they are doing is palliative analgesic treatment. But for God, it is awaiting God's will, that is what we have been waiting for, his will, to cure or take away (P1).*

Spirituality appears as the support point on the meanings of life for the family, the suffering deriving from the disease puts the families at the limit of life, presenting the need for a spiritual relationship with God.⁴ In view of the outcome of the child's disease, the spiritual beliefs play a decisive role in the parents' perseverance to fight for their child's life.³³

The possibility of a child's death comes with great pain and suffering. It is considered inexplicable and immeasurable. *It's a lot of pain, we are unable to explain it, who goes through it and accompanies it cannot explain [...]. At this moment, what I have felt is great pain to see my son suffering, to see that drugs are not working, nothing is working. And knowing that he is suffering and there is no way to impede it, just ask God (P7).*

At these moments of profound suffering and despair, the parents put their final expectations in divine provision. In view of the situation of imminent loss, religion, spirituality or philosophy of life demonstrated themselves positively in coping with the difficulties experienced during the palliative care period.³⁵

When death is certain, in a mother's testimony, her grandiosity and benevolence in accepting the child's loss is evidenced when she accepts the child's loss to relieve his suffering. *At first and now, I have told God: 'do your will, if you want to take my son take him, I'll suffer, I'll cry, but take him, it's better than letting him suffer'. It hurts, but it's better than watching him suffer. It's horrible. I hoped to see him grow up, marry, have a family, but if God doesn't want it, I can't do anything. [...] We have trusted in God, of course we suffer from his decision to take him. But all things considered, if God decides to take him it's the best God has for him, because at least he doesn't suffer that much (P1).*

The religious and spiritual beliefs influence the decision making, correlated with the quality of life in view of the cancer, while the spiritual needs provide psychological and spiritual support to all stakeholders in the death process.³⁶

Nevertheless, these parents' experience, permeated by conflicts and anguish, led to the understanding of their existential condition of Being-in-the-world to offer pure and sincere care to their child who is heading towards the end of life.

FINAL CONSIDERATIONS

The disclosure of the phenomenon hidden in the experience of parents of children with cancer in conditions of therapeutic failure permitted understanding its dimensions and, thus, knowing how to recognize how it is coped with when the disease is installed and entails the therapeutic failure.

This experience in the parents' life comes loaded with intense feelings in the different phases of the disease, clearly showing the difficulties these family members face to overcome the possibility of an early loss, which annihilates the dreams of a desired future.

The Being-with-the-child-with-cancer by itself can only cause an emotional misfit in the family sphere but, when it relates to a Being-with-a-child-with-cancer-in-therapeutic-failure, the completeness of the experience is evident and concrete, gaining an extreme dimension. The possibility of the child's death is imminent and considered as going against the chronological order of life, and is therefore complex. The consolation at this moment comes from faith, religion and hope in divine providence, playing a fundamental role to cope with the loss.

This study permitted reaching the proposed objective of understanding the experience of parents of children with cancer in conditions of therapeutic failure. These family members' life experience could be absorbed, from the discovery of the disease to the diagnosis of therapeutic failure. Thus, this study aroused reflections on the importance of palliative care that values human contact and the needs of the sick children and their parents. This reflection provided knowledge on this public's reality, with a view to the implementation of nursing care based on the principles of integrality, empathy and humanization.

This research is highly relevant for the framework of nursing knowledge, as the disclosure of this phenomenon will permit a more attentive look not only at the child, but also at the parents experiencing their child's end of life, providing care to overcome the adversities characteristic of this situation.

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