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Research Article

Family experiencing fear of death in a pediatric intensive care unit: phenomenological study

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Abstract

Background: the pediatric intensive care unit is a stressful environment, where the family experiences an unexpected situation, surrounded by anguish, fear of the unknown and the risk of the child's death.
Objective: to understand the families' experiences during the child's hospitalization in the pediatric intensive care unit.
Methodology: qualitative research with a phenomenological approach, carried out in a teaching hospital. Participants were 13 family members of children who were hospitalized in the pediatric intensive care unit. Data collected through a phenomenological semi-structured interview and interpreted using hermeneutics.
Results: the family experiences the fear of the unknown in the face of the existential vulnerability of being a child during hospitalization, the fear intensifies when the child is hospitalized for the second time. This impact adds to a variety of negative feelings; in coping, the family uses different coping mechanisms such as strengthening the support network, positive thinking, faith, strength and hope.
Conclusion: to face the situation of illness, receiving the prognosis and risk of death of the child, the family suffers a strong impact, the fear of losing the child is evident as the greatest of them, being essential to adapt to the situation and use a coping mechanism.

Keywords: intensive care units; death; family; child

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Introdution

Hospitalization in a Pediatric Intensive Care Unit (PICU) represents for the family a rupture in their way of being-in-the-world, when they encounter the existential facticity of existing as a vulnerable and finite human being. Experiencing the illness and worsening of the clinical condition of the child, makes the family face the risk of finitude, understanding itself as a being released into the world that has no control over the facticities of existence (Heidegger, 2015).

In the Heideggerian perspective what is feared has a threat character (Heidegger, 2015), families fear the worsening of the clinical condition of the child, for its existential vulnerability, its finite existence, the unknown world of PICU and the impotence in front of the child's frailty.

In this context, the importance of humanization in the hospital context is demonstrated; the National Policy of Humanization (NPH) adds discussions from management to health practice, seeking excellence in reception, valuing subjective aspects, historical and sociocultural processes of health and disease. (Paiva & Barros, 2023). So, the family facing the unknown must be welcomed by health professionals with humanized assistance that promotes trust and involvement with the multiprofessional team (Dourado et al., 2022).

In this context, the 'being-there' family of a child admitted to a PICU is a way of being-in-the-world and relates with others according to a predominant mode of being. The 'being-there' is essentially 'being-with', cohabiting and sharing the world with others. Death is feared, since existential analysis precedes the issues of biology, psychology and theology, it is a privileged possibility of presence, in the broadest sense it is a phenomenon of life (Heidegger, 2015) The New York Times.

This study is justified by the relevance in highlighting how the family experiences the moment of hospitalization of a child in PICU and what mechanisms it uses to cope with the situation, contributing to increase the quality of care provided to the child and his family.

It was defined as a research question: What is the experience of families during hospitalization in the Pediatric Intensive Care Unit? And as a goal: to know the experience of families during the hospitalization of the child in the Pediatric Intensive Care Unit.

Background

The birth of a child is accompanied by expectations on the part of the family, for example, that it is healthy, can be accompanied in its growth, with environment and opportunity to develop their potentialities and talents, with possibility to assume as being in the world, to formulate their life project for an authentic existence, finding their space in society (Neis et al., 2022). However, when one has a process of illness followed by a hospitalization this expectation can be broken.

PICU is a stressful environment, with complex care and generating an emotionally committed atmosphere, still allied to several negative feelings, such as fear, uncertainties and doubts, due to the fact that this sector is usually associated with the risk of finitude (Anjos et al., 2019).

According to Heidegger (2015) the human being experiences the past, present and future, concomitantly, in this way, when the family experiences the hospitalization in the present, it is experiencing something different from what was planned in the past, They revive remnants of plans that were not possible to be executed, which demonstrates a temporal intersection. In this context, the family experienced a totally unexpected situation, surrounded by the anguish of fear of the unknown and the risk of death of the child.

The illness and hospitalization of the child is potentially inducing a rupture of expectations. The phenomenological look makes it possible to understand that, before the existential facticity of illness and hospitalization, philosophical-existential questions emerge in the life of the family and permeate this singular process of human suffering, raising concerns difficult to face (Schneider et al., 2020).

The risk of losing a child triggers the thought of the probability of the beginning of moments of distress and despair in front of the idea of finitude. In addition, the anguish of realizing the agony of the child causes the family to want to experience the process of disease rather than their child, so that then the suffering by which the child lived is addressed to them, given the vulnerability inherent to the pediatric condition. The child's suffering; the serious clinical state induces the family members to a state of anxiety and misunderstanding of what is really happening within that context. The first thought is the fear of the child's death, which causes an important commotion (Florêncio & Cerqueira, 2021).

Other feelings are described in the literature before the possibility of finitude of the child as anguish, state of deep sadness, discouragement and anger, as well as some organic manifestations such as inapathy and difficulty to reconcile sleep. Given this, it is noteworthy that the coping process is not always simple or spontaneous, requires time and facilitating conditions (Neis et al., 2022).

During hospitalization, the nurse is the one who stays longer with the patient. To care, in addition to techniques, it is necessary to have emotional balance; however professionals still have difficulty in experiencing the process of dying in pediatrics (Vasconcelos et al., 2020).

Nurses need to be prepared to deal with this situation, therefore, to minimize feelings of guilt, failure and denial of death it is important that they have subsidies and supports within the institution, such as continuing education and therapeutic support, so that the care of the child and support to the family are not harmed (Santos et al. 2020).

Methodology

A qualitative research with a phenomenological-hermeneutical approach; phenomenology is linked to the act of "showing", what is shown is revealed. The show itself is a privileged way of meeting (Heidegger, 2015). Thus, phenomenology aims to bring to light, to make clear something, revealing itself and becoming visible in itself. Therefore, in this study we adopted this reference seeking to make visible the experience of families facing the risk of finitude of the child.

Research conducted in a pediatric hospital after discharge from PICU, in a teaching hospital in the south of Brazil, between June and July 2017.

Thirteen relatives of children who were hospitalized in PICU were participants of the survey, adopting as inclusion criteria: family members of children who discharged from PICU at least one day, having experienced at least seven days of hospitalization in PICU. Relatives of children who evolve to death were excluded; children in palliative care and family members under 18 years old. Thus, 13 participants who met the inclusion and exclusion criteria participated in the survey and two families of children who died were excluded, as well as one family represented by the mother who is under 18 years old.

For the data collection, a phenomenological semi-structured face-to-face interview was conducted, this being a process of interaction and dialogue between researcher and participant, whose objective is that the interviewee can recognize and describe their experience and the meanings given to the lived situations related to the research topic (López, 2014).

Thus, the invitation to participate was personally carried out by the interviewer. Thus, the guests in their entirety accepted to participate, not having refusal during and after the end of the interview, which was guided by the question: How was your experience of the child's hospitalization in PICU?

To ensure the anonymity of participants, we adopted the letter "F" of "FAMILIAR", followed by the number of the interview to identify them.

The study met the checklist of recommendations of the Consolidated Criteria for Qualitative Research Reporting (COREQ) in its elaboration (Tong et al., 2015).

At the time that children are discharged from PICU they are hospitalized in Pediatrics until they have conditions of hospital discharge, so the interviews were conducted on the patient's bedside in the Pediatric Unit by choice of participants, and the participant, the researcher and the child were present. The average duration was 30 minutes. They were recorded in audio by mobile phone and transcribed in full.

For the interpretation of information, we opted for the use of hermeneutics by Paul Ricouer, because it allows the interpretation from an existential point of view, seeking to understand the experience of families facing the risk of the finitude of the child during hospitalization in PICU (Ricouer, 1978) The New York Times. Considering also its existential manifestations of presence as being in the world and being-in-the-world-with-others (Freitag et al., 2020), in this case, being in the world with your child and afraid of his death.

In this context, some steps were followed for the interpretation of information: 1. Search for information: obtaining the reports of the experience of participants through interview; 2. Interpretation of information: a) careful reading of the information to obtain meaning; b) re-reading to identify the units of significance in order to reveal the hidden phenomena in the manifestations; c) summary of the units of meaning, discussing the experience of the participants (Ricouer, 1978).

Thus, two units of meaning emerged: The family experiencing the fear of the unknown in front of the existential vulnerability of being a child hospitalized in PICU; Adaptation of the family in front of the risk of finitude of the child in hospitalization in PICU.

This study respected the ethical precepts of Resolution 466/12 of the National Health Council of the Ministry of Health, which addresses research with human beings. The project was approved by the Ethics Committee of the Faculty of Nursing of the Federal University of Pelotas by CAAE 69933617.7.0000.5316.

Results

The study included 13 participants (12 mothers and 1 father), aged between 18 and 39 years old. On marital status, 5 family members declare themselves as married and 8 as single. In addition, four family members experienced the hospitalization of their child for the 1st time and nine for the second time.

From the interpretation of the analyzed information, the following categories are presented:

The family experiencing the uncertainty of the existential future of being a child and the fear of death.

During the child's admission to PICU, the family faces fear, uncertainty about what is happening and what may happen, causing panic and fear of death.

We do not know how she (child) will be, and they said that she was very bad because we did not know what she had, so we did not know what would happen, it is quite difficult, causes fear. (F1)

At the moment he (child) was with very fast heart, I was already afraid of the heart stop, there every time I was going out, his heart would start, then that machine (monitor) and I was panicking. (F4)

Thinking, in reality, we were not sure if he (child) was going to neither leave there nor [...] for what the doctor told me he would not leave there, it is afraid of the future, death. (F7)

I was afraid of death during his hospitalization (child), I am afraid of death every day because I know that the lung problem is very serious, I fear it will go bad and die. (F10)

When health professionals refer to the family about the severity of the patient, warning them of possible negative prognoses, they raise their hopes leaving them scared, afraid and even in a state of shock.

A shock! we think of the ICU as what the person is already in last case [...] I was very scared because he is too serious, to go to the ICU, so I got there and the doctor said "he is serious, we will try to recover". It’s scary, I was scared. (F13)

The doctor said several things that could happen to him, I honestly thought he would take the guri (child) back in a box (refers to coffin; related to the death of the child), fear. (F8)

When the hospitalization process happens for the second time in PICU, and with more complications than the first, the relatives report feeling more fear, added to the fear of what will happen to their children.

It was difficult the second time she (child) was in PICU, because she had to put a drain, so it was kind of complicated, it was hard! [...] I was more afraid, the doctor thought she would not hold it. (F3)

Coping with the family facing the risk of finitude of the child in hospitalization in the Pediatric Intensive Care Unit.

After the family feel despair and fear in front of unpredictability and the possibility of loss developed coping modes, such as: call their relatives and have a positive thinking, therefore, families refer that 'feels-The 'better' or 'calm down'. This highlights the reorganizations to the sensations presented during the period experienced within PICU.

I was afraid of what could happen to her, in fact it was a despair not knowing what will happen, fear yes! Very, very, very scared! [...] then I would call the house and I felt better, passed a little of that fear, anguish, that we stay for you. (F2)

It’s horrible, I fear for her (child), you do not know what direction to take, just talking with my husband who is at home to feel better; I know that I can tell. (F9)

The family members outline about their support system, people who share their lived world, being their own family (those who wait at home for the recovery of the child); with the act of 'calling home' strengthen their ties. They are listened to and heard by people who share the same feelings and concerns, and thus minimize their anxiety, anguish and fear.

The feeling we have is a probable loss, it can happen, we are exposed to everything, (...) often we feel this shock, but it passes quickly, cannot be thinking bad thing, only positive thought. (F5)

I was afraid of losing my son all the time, the thought was essential, thinking very positive, but also thinking a lot of bad things, because of the way he arrived. Then I was calming down, calming down. (F6)

It is evident in these statements that positive thinking contributes to the coping of the experienced situation, becoming essential while decreasing bad sensations, such as fear of the probable loss of the child.

The family members also reinforce that within the PICU environment they absorb all events, but with strength, hope and faith can reorganize themselves to experience this situation.

We (the mother and father) took all that energy there was (PICU), we were exhausted, but did not let us win because we had faith that she (child) would improve and improved, we are here now (Pediatrics Unit). (F11)

We absorb a lot, absorb the disease of your child, absorb the deaths that happen, this will weaken you; you have to have a lot of strength, hope that everything is right, to be able to strengthen you and adapt. (F12)

About this perspective it is demonstrated how the emotional atmosphere in a PICU is dense, stimulating and severe, propitiating for the family to feel weakened and displaced, amid an unknown environment and inherent events that can completely change their daily life, for example, the death of a child. Although sensitive, the family adapts with the understanding that it needs to have strength and hope in the recovery of the child.

Discussion

The existential itinerary of these families that experience the hospitalization of their child in a PICU is marked by moments of panic and fear of death, because often they do not understand the situation of the child, diagnosis and prognosis, see the child before all the technological initially, they think that the child will not improve.

In this sense, death is revealed as a loss, which only those who remain experience and suffer. Death is the passage from presence to no more presence, while non-being-more-in-the-world (Heidegger, 2015). Thus, experiencing the risk of death of the child is a painful experience for the family.

In this context, a child and family-centered care model, blurring the biological model, can help in understanding the child's condition by the family and, consequently, will decrease doubts, insecurities, uncertainties, helping it in (re)organization of their way of being in the world.

At this juncture, nursing, inserted in the multidisciplinary team, needs to form a network of support and guidance with relatives, respecting their rights in decision-making and care delivery (Tsutumi et al., 2023). Family-centered care recognizes the importance of the family in child care and involves it as an integral part of the health team, valuing its needs, concerns and experiences during the period of hospitalization (Leal & Franco, 2024); thus, minimizing suffering, improving communication and helping to manage stress.

The phenomenon of fear is a mode of disposition, being afraid of something, veils at the same time being and being-in danger, because it, the fear let's see the danger to the point that the presence needs to be reconstituted after it passes (Heidegger, 2015). Fear is a way to be with the child, since the fear is for him, what can happen. So, fear turns to those who fear and not to what is feared.

Corroborating with these findings, the study revealed that mothers experience emotions such as fear, insecurity, impotence and guilt. The mothers experienced a sense of loss of control over the situation, as well as fear for their baby's death, a feeling that has not yet been known (Lima & Smeha, 2019).

In this context, the family is confronted with the unknown, and this causes fear in the human being. The fear is to be-with another and turns into a threat "actually not yet, but at any time yes", weakening the being-in-the-world of occupation, and turns into dread. In the Heideggerian view, fear is caused by anxiety and causes a movement of uneasiness (Heidegger, 2015).

In this premise, the family understands that the child needs to face this situation and feels weakened by this context, their feelings emerge and come into conflict. Death is a constant and close presence in a PICU. Faced with the risk of death of the child, which would be the continuity of its existence, the family is faced with its own finitude.

Having a child in PICU is an experience of suffering, fear, stress, insecurity and impotence, so family lives dense situations and feelings emerge. A study conducted with mothers of children admitted to a Neonatal or Pediatric Intensive Care Unit, revealed that they feel fear of death, impotence in the face of their child's condition and desire to receive more information and participate actively. Thus, it is necessary that the multidisciplinary team perform a family-centered care (Lima & Smeha, 2019).

The participants of this study felt exposed to everything, being shaken, however, the feeling of fear of losing the child was mitigated by the effort to think positively, by talking with other family members, forming a support system, and the improvement of the clinical condition of the child. Thus, they were able to calm down and understand the situation imposed on them.

The family's effort for positive thoughts and anxiety generated by fear of the unknown made possible the confrontation of that moment. In the Heideggerian view, everything that anguish is anguished is defined as being-in-the-world as such, because it is indeterminate, is a threat and does not have the character of something harmful to the threatened, is not only anguish, but an anguish for. However, it enables to be the 'free-being' for freedom of choice (Heidegger, 2015).

Then, through the anguish, the family has the possibility to choose to live helping the child to come-to-be by healing. The strategies used are composed of family support, as well as the way of thinking, since the information, it is perceived that the family absorbs issues from the daily life of a PICU, such as the child's disease, the deaths that occur, and feels powerless before this scenario. However, gain strength, hope that everything will work out, in order to strengthen and adapt. Thus, fear becomes a fortress, believing in a coming-to-be of the son (Heidegger, 2015).

The psychosocial support network becomes fundamental, showing that people may feel displaced and/or lost because they do not know how to face imposed situations, this support network formed by close people such as family and friends can welcome and guide (Busa et al., 2019).

It is important to highlight that the health team, especially nursing, can act as a source of support for these families through active listening, dialogue that welcomes, understanding and dirimenting their doubts and uncertainties, given the complexity that concerns the hospitalization of a child in a PICU. At this juncture, nursing can seek authentic care, caring, helping the family to experience this moment, since care is configured in responsibility and trust with and for the other.

The study aimed to identify and analyze the support systems used by family members for the process of adaptation to the hospitalization of the child in PICU, showed that during hospitalization, the health team forms an important support system for family members, so that the bond is intensified through active listening and reception (Bazzan et al., 2019). These aspects are consistent with a study that identifies that the family members of children treated in a child psychosocial care center form a network of support with professionals, highlighting that the family members feel welcomed which strengthens integral care (Oliveira et al., 2023).

Conclusion

The experience of families of children admitted to a Pediatric Intensive Care Unit reveals fear and uncertainty about what is happening and what may happen with the child causing the family the feeling of panic and fear of death. These feelings are intensified when health professionals refer to the family about the patient's severity, warning them of possible negative prognoses, thus leaving them with may fear of finitude even in a state of shock.

The hospitalization process when it happens for the second time makes the process even more difficult, bringing more fear in front of possible loss of your child. Families develop important coping mechanisms, among them strengthening their family support network, positive thinking about the situation experienced, faith, strength and hope.

The research shows how the nuances of a PPU are overwhelming in the life of the family, which needs tools and resources to make its adaptation process effective. Such resources can be arranged from the health team, with singular care and humanized reception as a strategy of emotional strengthening that brings the family closer to the process of hospitalization.

The family's coping will be influenced/benefited by the bonds of trust with the interdisciplinary team, mainly by nursing, which remains full-time with the child and, in addition to other assignments, is responsible for identifying changes that compromise the child's life.

The limitation of this study is that there can be no generalizations because it is a qualitative research formed by a group of families in a specific context. In addition, the data collection was carried out on the edge of the bed may have interfered with the responses, due to possible distraction of participants.

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