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The experience of families in face of the finiteness of their children in the process of adopting palliative care

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Vivências de familiares diante da finitude da criança no processo de adoção de cuidados paliativos

Experiencias familiares ante la finitud del niño en el proceso de adopción de cuidados paliativos

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ABSTRACT

Objective: To reveal the experience of family members after learning their child would adopt palliative care.

Method: Phenomenological research on Heidegger's perspective. The participants were eleven family members of children who were recommended palliative care in the Pediatric Intensive Care Unit from a university hospital in southern Brazil. The statements were obtained in a semi-structured interview, from January to November/2017, and submitted to Heidegger's theoretical-philosophical analysis. Research approved by the institution's Ethical Committee.

Results: The communication of palliative care triggers the perception of the child's existencial facticity in the Family, revealing reactions explained in the thematic dimensions: "Coping with the finiteness of the child when confronted with the proposal of adopting palliative care" and "The need for compassionate and attentive care".

Final considerations: Phenomenology allows us to understand the parent's existential purpose. An understanding perspective can help interdisciplinary teams to communicate the adoption of palliative care in a sensitive and ethical way, focusing on the best interest of the child.

Keywords: Palliative care. Intensive care units, pediatric. Qualitative research.

RESUMO

Objetivo: Desvelar a vivência de familiares após notícia da adoção de cuidados paliativos para a criança.

Método: Pesquisa fenomenológica na perspectiva de Heidegger. Participaram onze familiares de crianças na Unidade de Terapia Intensiva Pediátrica de hospital universitário do sul do Brasil com indicação de cuidados paliativos. Os depoimentos foram obtidos em entrevista semi-estruturada, de janeiro a novembro/2017, submetidos à análise teórico-filosófica de Heidegger. Pesquisa aprovada pelo Comitê de Ética da instituição.

Resultados: A comunicação de cuidados paliativos desencadeia no familiar a percepção da facticidade existencial da criança, descortinando reações explicitadas nas dimensões temáticas: Enfrentando a finitude da criança diante da proposta de cuidados paliativos e Necessidade de cuidado compassivo e solícito.

Considerações finais: A fenomenologia permitiu compreender o familiar em seu propósito existencial. A perspectiva compreensiva pode auxiliar a equipe interdisciplinar na comunicação da decisão de cuidados paliativos, de modo sensível e ético, focalizando o melhor interesse da criança.

Palavras-chave: Cuidados paliativos. Unidades de terapia intensiva pediátrica. Pesquisa qualitativa.

RESUMEN

Objetivo: Revelar la experiencia de familiares después de descubrir que sus niños serían sometidos a paliativos del niño.

Método: Investigación fenomenológica em la perspectiva de Heidegger. Participaron once familiares de niños internados en Unidad de Cuidados Intensivos Pediátricos de hospital universitario del sur de Brasil con indicación de cuidados paliativos. Los discursos fueron obtenidos en entrevista semiestructurada, de enero a noviembre/2017, y sometidos al análisis teórico-filosófico Heideggeriano. Investigación aprobada por el Comité de Ética de la institución.

Resultados: La comunicación de cuidados paliativos dispara la percepción de la facticidad existencial del niño en la Familia, revelando reacciones explicadas en las dimensiones temáticas: Enfrentando la finitud del niño frente a propuesta de cuidados paliativos y La necesidad de cuidado compasivo y solícito.

Consideraciones finales: La fenomenología permite comprender el propósito existencial de los padres. La perspectiva integral puede ayudar el equipo a comunicar la adopción de cuidados paliativos, de una manera sensible y ética, centrándose en el interés superior del niño.

Palabras clave: Cuidados paliativos. Unidades de cuidado intensivo pediátrico. Investigación cualitativa.

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INTRODUCTION

Generating a child, which philosophical language describes as an act of creation, be it by natural means or adoption, consolidates the feelings of gratitude for the constitution of family, and the need to take responsibility for a new life, which depends on care. A person is not spontaneously generated; their formation takes place through a process of ontogeny. The genesis of this relationship is in the maternal breast, where the being is formed slowly and gradually. This process goes beyond the genetic or somatic meaning of the terms but has a historic and cultural meaning. The process of construction of human history involves a complex set of elements and continuously happen throughout one's life(1).

In the process of constructing an existence, care forms a being and their expression in the world(2). From a Heideggerian perspective, to exist is to be-in-the-world, and the world is the outline of a being, which intimately connects one with the other. In this regard, a being is not a subjectivity closed in itself; it is the expression of an identity that is present in its unique relationship with the world, a shared existence where existing is to be with others. The existential perspective emerges from a mutual interaction between the being and the world. Thus, as this perspective is marked by a being's project or intention, manifested in the actions they take and in the meaning they give to the world and to their relationship with the others(2–3), it gains meaning.

The being is, in its essence, a caring entity, in the construction of its total self and in its process of growth and development, going through the timeline it is given, for which it is responsible, drowned in its facticity, requiring the other both for the understanding of its primordial needs and to achieve its own human evolution. It is an unfinished project of itself as a continuous possibility of becoming, in the perspective of the potential improvement of its existential project(2). The generation of a child involves expectations from the family: that the child is healthy, that their growth can be accompanied by an environment that provides opportunity to develop their potential and talents, that the child will be able to assume their self as a being in the world, formulating their project of life for an authentic existence and finding their space in society.

When a child has a disease, especially a severe, debilitating disease, this can, potentially, disrupt these expectations. A phenomenological perspective enables an understanding according to which, considering the existential facticity of the disease, existential-philosophical questions emerge in the lives of the family, permeating this unique process of human suffering, and triggering a distress which is difficult to be coped with(1,3–5). As the disease advances and chances of a cure decrease, many expectations are destroyed, opening space for fear of the finiteness of the child, and, as a result, hopelessness becomes predominant(4).

Palliative Care is a source of attention targeted at the quality of life of the child and family when it is impossible to achieve a cure. Its principles prioritize relieving the pain and the negative repercussions of the disease, providing multidisciplinary and holistic care, imbued with compassion and empathy towards the diseased being and their family, focusing on interventions in the person and not in the disease, promoting a life as active as possible during the time it lasts, while accepting death as a natural component of existence(6–8). Still, it may be difficult for the family to understand that using Palliative Care is not abandoning the child, but benefits them, generating for the family, instead of comfort, uncertainty and suffering(9).

The meaning of understanding itself and of the act of understanding, as existential phenomena inherent to factual processes of life, is an essential point to provide sensible and empathetic care to the vicissitudes of families concerning the possibility of losing their children. In Heideggerian philosophy, the phenomenon of communication must be understood ontologically. From this perspective, communication, that is, information about something, is essential for existence, it unveils itself in the meeting between beings, in a sort of articulation of "being-one-with-the-other"(2).

The communication enables "the sharing of the co-meeting of the self and of the understanding of the being-with. Communication is never similar to a transport of experience, for example, of opinions and desires, from the interior of a subject for the interior of another"(2). "That-about-what the discourse discourses"(2) has, in essence, a character of meaning, it must make sense and be expressed with meaning so that the result of the language of the discourse, at the times of meeting, can provide the other with an understanding of the world, creating unique dialogic spaces of learning and care(10).

The overwhelming fear of the possibility of the inexorable loss of a child to death raises barriers that are hard to overcome at the time of communicating news that confront the Being with the fragility of the human condition, exposed with such vigor(11). This, however, is inherent to the condition of the need to adopt palliative care, when all therapeutic possibility is exhausted(12).

In face of these considerations, the central thread of this study was the guiding question: How does the family experience receiving, from the team, the news that their children should receive palliative care in the pediatric intensive care unit? Therefore, our goal was to unveil the experience of the families of children in pediatric intensive care, after receiving the news that their children would start undergoing palliative care. Understanding how this experience takes place and the feelings that emanate from it enables health teams to carefully plan this type of approach, to promote care in the form of providing comfort and minimizing trauma from a negative experience.

METHOD

This is an excerpt from an MS dissertation(9) which applied a phenomenological theoretical-philosophical reflection, from the perspective of Martin Heidegger(2), to the reading of the existential changes experienced by families responsible for children in the Pediatric Intensive Care Unit of a teaching hospital in the south of Brazil, who had been recommended palliative care.

Heidegger's existential ontology is characterized by an understanding of the meaning of being through the phenomenological analysis of the different modalities of the presence of the *Being* in the world (the *Dasein*: "being-there", "existence", or "presence"). Through it, the philosopher clarifies that the original feeling of existence is perceived by men in the anguish through which he understands himself as a "being toward death". As the being considers their human condition, he finds himself faced with the contingency of his birth (past) and the inevitability of his death (future). This reflection leads to an authentic feeling of finiteness, the real human condition(2,13).

The information was gathered through qualitative research. Inclusion criteria to participate in the research included: being a relative responsible for the child and having been in a meeting with the health team to communicate the proposal of adopting palliative care. There were no exclusion criteria. The participants of the research were selected by convenience, including eleven members of the families of patients hospitalized in PICU whose clinical situation required the adoption of palliative care. The participants were invited in person, inside the hospital, by the researcher, who, at this time, was an MS student and direct assistance nurse in the unit involved. All invitations were accepted. It was determined that interviews should be carried out less than 48 hours after the team meeting which decided that palliative care should be proposed.

Collection took place from January to November 2017, at the NICU. Semistructured interviews were carried out by the researcher in a private room inside the unit and lasted for a mean of 45 minutes. They were recorded and transcribed by the researcher. Interviews focused on trigger questions for the participants, addressing their knowledge about the disease of the child; what topic was addressed in the conversation with the health team; what the expectations of the child's are about the treatment after that conversation; and what feelings were triggered by the conversation. Data saturation was considered to be the criteria to determine the end of data collection(14), that is, the moment when information became repetitive and redundant.

Because the research team believes that this is a sensitive topic for the relatives, interview transcriptions were not validated by participants for comments and/or corrections, as this could trigger feelings of grief. To respect anonymity, each participant was identified using an alphanumeric code, using the letter F, for family, and numbers indicating the date of the meeting. The interpretation of the results led to the emergence of the thematic dimensions of the study, analyzed in the light of Heideggerian phenomenology(2,15).

The project was submitted to the Research Ethics Committee of the institution and approved under CAEE nº. 58643816.4.0000.5327. All ethical requirements were respected according with norms from Resolution 466/2012 and 510/2016 from the Ministry of Health. Participants received information about the objectives of the research were informed that their anonymity was ensured, and that they were free to leave at any moment. Their acceptance was manifested through the signing of the Free and Informed Consent Form.

RESULTS AND DISCUSSION

In the light of the statements from the interviews with the relatives who experienced the meeting for the proposal of palliative care to their children, statements which were then submitted to phenomenological interpretation(2,15), we uncovered meanings that enabled an understanding according to which the communication of palliative care triggers, intimately within the Being mother or Being father, family caregiver, the perception of the existential facticity of the child. Considering the challenging, non-transferable reality, the Being is launched into a situation that simply exists, and cannot be in another way(2). From this moment on, in their existential trajectory of suffering, several unique reactions are unveiled, which will be addressed later and were categorized in two thematic dimensions: "Coping with the finiteness of the child when confronted with the proposal of adopting palliative care" and "The need for compassionate and attentive care". Below, the thematic dimensions that clarify the existential facticity of experiencing the decision process for the palliative care of a child.

Coping with the finiteness of the child when confronted with the proposal of adopting palliative care

Receiving the proposal of providing palliative care to the child triggers, in the relative that experiences this existential facticity a rupture, that is, a rethinking of the references of their existence. Understanding one's condition of existence requires the Being to accept potential relations with the world as a being who only is as a being-in-the-world (*Dasein*)(2). *Dasein*, or being-there(2) — a Heideggerian construction that characterizes human existence — is being thrown in a world conceived as the consciousness of the being in the present, past, and future(15).

Experiencing a proposal for palliative care means, for the family caregiver, traversing the temporal dimension of consciousness which is made concrete by the act of attributing meaning to past experiences (living with the child), through a present experience (receiving the news about the palliative care), which is understood as the becoming of an existential project of future already in course (the possibility of the finitude of the child)(15). This possibility requires the Being to confront the finiteness of Being, strengthening an existential movement that resides in preoccupation. Preoccupation is the existential element that moves Being, being understood by existential ontology as care(2). Therefore, the family caregiver, from the perspective of preoccupation-care, sees in this existential facticity the child as a "coming-to-be what he can be in his free being for his most proper possibilities"(15) (in the project), but with an abrupt interruption of their existence(2,15).

Considering the unassailable property of being for the death of the child, peculiarities ensued, feelings and perceptions made explicit by: anguish and intense sadness, feelings of emptiness and solitude, and, oxymoronically, an attitude of acceptance. These feelings show themselves at a time that redirects the being in the timing of his existence, a unique time of this happenstance(2), in the perspective of facing the possibility of death of the child. This temporal dimension, which characterizes the inherent process of coping, experienced by the relative, presents a non-transferable pathway that, since one cannot retreat from it, is constantly evolving, in the process of transcendence from Being(2).

The process of coping that takes place is not always easy or spontaneous, requiring time and facilitating conditions(15). This unfolds, leading to the emergence of Anguish due to the possibility of losing one's child:

> [...] *What can I say... I couldn't believe, you know? I had some hope still, but my boy wasn't getting any better. He gets worse and worse. Every day, every week... And its very hard for me to accept... I... I don't know what's going to become of me... How can I go back home without him... I don't know. Right now I can't tell you* [crying]. *But for me it's being very hard to lose him... Deep down I know that I don't want to see it, but I know he won't stay long. And I don't want him to suffer.* (F211117)

> [...] *There's nothing to say* [...] *She's my first child, she was fine* [...] *I feel destroyed, because we put them into the world to care for them. I stopped working, I stopped studying to be with her, so I wouldn't put her in a nursery, so no one else would care, only I would care* [...] *I hope, but I don't know why, I'm already seeing scenes of a coffin, a funeral, her with the little outfit I got her. It's crazy* [crying]. (F200417)

> [...] *I mean... his disease, his birth, all that's surrounding B., it all forced me to go through things I wasn't prepared to deal with. Everything, everything, everything... I was ready to receive a child, change the diapers, have fun with her, present her to the family... I actually had this whole romantic novel in my head, but I was given a drama.* (F170217)

Maternity is conceived as a significant form of existence, that depends on the existence of another being, personified in the child. In the natural order, on expects the child to have a long life. His premature death leads to distress, is an inversion in the natural course to which families are unprepared(16). Therefore, unique attitudes are revealed in this process, such as the possibility of keeping up hope – or denying the possibility of loss – or accepting that loss will take place. From a Heideggerian perspective, death is unveiled as a loss – the loss experienced by those who stay – since it is impossible to experience the death of the other(2,15).

The state of profound sadness and despondency was perceivable in the statements of some relatives interviewed. In their reports, organic manifestations, such as lack of appetite and sleeplessness, emerged as a consequence of losing the child.

> [...] *I lost my air, I felt loss, I despaired, I cried a lot, couldn't sleep at night. Her little bed is next to mine, and I'd look at her little bed and it seems I was already seeing her there...*

> *she who wouldn't go back to her little bed. I cried a lot, I wasn't even eating.* (F040717)
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> [...] *It's really bad, because I had a child that played, that wanted to stay with me all the time, wanted affection... and now seeing him like this – he can only open his eyes and even so he doesn't look at us, doesn't search for us, he stays still – it's very difficult for us!* [...] *It was strange, because the possibility of losing him became more evident, it became clearer* [...] *we understand perfectly what is happening, but you stay there, your hopes go up, because if you don't nurture this hope, you can't live.* (F041017)

Philosophically, a person is a "structure", which means someone constituted, dynamically, by the elements that integrate each of these systems: organic and psychic. Favoring the restructuring of the Being is the true meaning of care(1). Mothers have trouble projecting a future after the death of a child establishes itself in the world of life, since all dreams of the mother regarding the future of the child and the possibility of new experiences die with the child, leading to the breaking of a promise, a harsh blow from destiny to the mother. The feeling of anguish emerges from this lack of perspective for a future(16–17). Therefore, one can understand why the adoption of palliative care can generate, in some relatives, the beginning of the process of experiencing grief.

> [...] *I have the feeling that he isn't there anymore, it's like we have already lost him, that I'm caring for his little body in his memory* [crying], *and no longer caring as if the was there, I feel as if he was with me as in his spirit is present and in my lap as he used to be* [crying], *but no longer there in his little body. Because if I start to think that he's there, in his body, it makes it seem he's locked there, he can't even look anymore, you know, not even a little look... I prefer thinking he left it already, but he's around us, caring, preparing us for the moment he really has to go* [crying]. (F041017).

Some authors(4,16–17) define grief as the reaction of an individual to the loss of a significant bond, caused by death; the greatest the bond between the bereaved and the being lost, the greatest the intensity of care(4). Mothers define their bond with their children as extraordinary, something that cannot be compared with other normal bonds in human relations. So, to them, losing a child is a sign of the loss of a part of themselves(16–17). When the health team proposes the adoption of palliative care, requiring the mothers to confront the finiteness of their child, it is understandable that this triggers deep anguish, perhaps the greatest anguish ever experienced by these mothers, due to the strength of the bond between them and their children.

The perception of emptiness and solitude shows itself as a dimension inherent to the irreversible nature of the phenomenon that anticipates that which was experienced:

> [...] *after I left he meeting here I spent the whole day feeling empty, a feeling of... You know, it's like feeling the pain beforehand in the case of my mother, we felt too, because you know he's in a stage of his little life that is coming to an end, you know he's suffering, you know the way he looks, you see the pain there, you want to avoid it, but you don't want to lose him... You are used, there's that bond, you don't want to lose it... And it's a difficult choice, after all, because it's the life of a human being you see as yours, but... we have to survive, and we have to go on.* (F160217)
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> [...] *I feel even more alone because you have to be in multiple places at once... to go to the visits. I don't go anymore, but it's very hard. I think it's harder because he's locked up, he's not here, because he calls me crying saying he wished to be here seeing her, and my mom can't come either because they won't accept more leaves at her work... so I'm completely alone.* (F200417)
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> [...] *I was really desperate at the time... I cried a lot! Much more than before, because I was suffering by myself! I accepted talking to her without him here, but I was alone, my mother was here. I didn't want here to see me like that because it's even worse... You feel guilty because they are suffering. So I went and called him, I said they had no hope for the baby, that they wouldn't give him more medicine to treat him, just to relieve the pain... So he was sad too, asked me to be calm, to stay close to my mother.* (F061017)

This feeling can be justified, especially, due to how much the relative is identified with his role as caregiver. Taking responsibility for the care of a child with a chronic disease with special needs leads to deep existential changes, leading to the need of dedicating oneself exclusively to the care of the children, forgetting oneself. As the caregiver is thrown in this new challenging moment, they find themselves losing their identity and the meaning of their life(16). The feeling of loneliness emerges with varying intensity, since being in the world means being-with-others, and in the weakness that shakes the being in the world of the family there is anguish, due to the possibility of the finiteness of the child being, and the difficulties sharing experiences of this nature[1–2].

The manifestation of loneliness is also associated with how much relatives miss the presence of other family members, friends, or others that can provide them with affection, so they can divide their fears and anguish about the possibility of losing the child. This is a reality of the population attended in university hospitals associated with the Single Health System: this population is often formed by low-income or socially vulnerable persons, who live many kilometers away from the hospital. Also, the, hospitalization of these children tends to be long-lasting, making it difficult to take turns with other caregivers, and for other members of the family to visit[9].

It is really important that, as we plan the meeting to propose the adoption of palliative care for the child, the team should consider the existential vulnerability of relatives, considering their needs for support from the rest of the family. The availability of therapeutic groups of relatives is also an efficient strategy to reduce the feeling of loneliness of relatives that are going through troubled periods of fear and anguish. Being able to express feelings and perceptions, listening to the reports of other relatives who are experiencing similar situations, and receiving support from other relatives and team members increases the strength of coping strategies and the formation of new bonds of friendship and support[9]. Still, we must consider that the absence of the *being-there* child in the world of the life of the family is the main trigger of the feeling of loneliness, which emerges in the existential facticity of finiteness. From a Heideggerian standpoint, the presence is a condition of the world, it is an opening of the world. It is not a topographic space, but reflects and understands the several different ways in which people relate, live, and behave[2]. An existential understanding of the meaning of presence as the meaning of life can help the health team to adopt a form of attentive care to re-signify the life of the family, based on the provision of support and of a space where experience can be shared and feelings can be expressed[10].

Feelings of anger and revolt were also revealed in the statements of the interviewees. When questioned about how they felt after meeting the team, some relatives declared very negative feelings, that their convictions were not respected. Although their children had been given clear recommendations for the adoption of palliative care, the parents could not understand how and why this therapeutic choice would be beneficial to their children.

> [...] *very angry! I felt really betrayed! I thought they didn't respect my moment, didn't respect what I'm going through* [...] *she trying to push these palliative care 'down my throat'* [...] *she said I didn't understand what palliative care is, maybe I never will, I don't have the obligation to understand.* (F011017)
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> [...] *What I felt was very bad... We, mothers, we know. But so far, they didn't... They won't convince me. They try to get in my... how can I explain? I'm my... in my emotion, there and then, OK, I felt... we cry at the time, but then you have to be strong enough to continue. This is what I feel. I told them they have to and should do all procedures with B. until his life ends, until his last.* (F141117)

Respecting the position of the parents is very delicate, since the desire of protecting the child is in conflict with the perception that the child may die. As a result, the team must try and access the culture, the principles of life, religiousness, and spirituality of family, including their cognitive and social capabilities, to consider the possibility of involving them in the decision process. Therefore, making choices based on the values, beliefs, and interests of the family of the child is one of the greatest challenges for the team[18–19].

For the family to participate in the decision process, they must fully understand the information that is provided by the health team[18]. For that to take place, health workers involved in intensive care must develop communicative abilities in such a way as to provide support to the decision making process of the families, allowing relatives to express their doubts, viewpoints, fears, and expectations[20].

A study showed that, in family meetings aimed at making decisions, family satisfaction is higher when the team spends more time listening than talking[21]. Communication is an essential element of the act o care. It is essential for existence, and can promote the meeting between beings in a species of articulation of the understanding being-one-with-another[2].

Accurate communication is even more pungent when, within the proposal of palliative care, there is a suggestion of limited vital support to the child. This situation has ethical and legal support, as it aims to avoid dysthanasia, that is, the prolongation of the process of death of the child[22]. This was proposed in one of the situations that formed this study, leading to a state of shock for the relative, who could not react at all during the meeting. After some days after the meeting spent elaborating, during the interview, the relative managed to express their position regarding the proposal of palliative care for the child:

> [...] *I felt really bad* [...] *the family will fight till the last minute with me. We'll fight, we'll fight for him* [...] *I don't think it's right! How can you not try?* [...] *I want them* [health workers] *to give me solutions! I'll only rest the day I see that they* [health workers] *did everything, everything, everything.* (F141117)

Making continuous attempts to understand the family shows the transcendence of care on the part of the interdisciplinary team. Providing space and time for the family to elaborate the information given is an expression of sensible and ethical care. Respecting the unique time of each person in their process of understanding, especially considering subjects with the potential of generating insecurity, anger, and anguish, is a human and compassionate attitude, targeted at those who suffer too much when confronted with the frail human condition(10).

The perplexity of the relatives was shown by discourses filled with inconformity, aimed to show how displeased they felt as they received the proposal that their children should start undergoing palliative care. Situations such as this require the team to prepare an adaptable plan with multiple interdisciplinary approaches, selected according with the broad knowledge of the profile of each family in its uniqueness. Receiving news about the imminent death of a child is a factor that triggers despair in the life of parents due to the several changes they will go through: their dreams and hopes, their illusion of immortality, leaving the impression that they failed in their mission as parents(16–17,23). From an existential standpoint, despair is a result of the consciousness of the finiteness an meaninglessness of human existence(15).

It becomes essential to embrace the family in a process of listening and provision of support to their needs, generating a dialogic space that includes a progressive, attentive, compassionate, and patient approach to the subject, making it clear that the health team has the child in its best interests and wants the maximum possible benefits to them, not abandonment(7,18–19).

When the family perceives that the proposal of palliative care from the team is the maximum possible benefit for the child, it makes it possible to unveil feelings of serenity and acceptance in regards to the proposal. These feelings were expressed by relatives of children with complex chronic conditions caused by genetic diseases with no possible cure and very negative prognosis, who had been experiencing the suffering of their children for longer.

> [...] *So everything I'm experiencing again with B., he forces me to act in such a way that I am forced to learn. So death, to me, is not such a terrible situation, an the end. In the case of B. it's the end of suffering, not only his, but mine and my wife's.* [...] *The treatment that was done so far, I believed in it and I still believe, I have hope. But I understand that it won't be curative, definitive. So death, in B.'s case, will give him some rest. In the future, very soon, I'll have him whole again, all this that he was missing will be completed and he won't have these problems anymore. It's hard to know... What tortures me is when this will happen, how long this will take... That's what tortures me, but it's the solution. And I, I'm not saying I'm happy with all that... definitely no. But I understand and I accept... that's it.* (F170217)

> [...] *I, actually, was a bit tense* [...] *But the conversation was much better than I thought. I thought I'd get nervous, but no, I was fine, after that talk I felt in peace, because I've always made a point, as I said, not to make him suffer any longer than necessary. I was always really afraid of going to a hospital, especially a teaching hospital, where they want to invest because the students need to learn and things like that, I was really afraid I'd get to a hospital and no one understood this, because it's a medical decision, not my decision, the doctor has all the power when the child is here, and I've always been really afraid of that. And I thought this conversation was very important, because it's the reaching of a deal: the family wanting the same thing the doctor wants.* [...] *I know they don't want her to suffer either, no one wants her to be hanging there like a Christmas three with a bunch of stuff hanging from her, no.* (F300317)

This acceptance is a movement of possible restructuring of the being, which allows for the emergence of new ways to see the world and understand the entities and relations that link them, specifically te bond of love with the being-there of the child, in the becoming of existence in the attitude of transcendence, according to which men tends to something beyond himself(2). Thus, there is a manifestation of the meaning of transmuting the pain and suffering experienced by the child in the possibility of existing without suffering, perceiving in the childes finiteness the release of the child Being to be free(1).

From the perspective of the transcendence of the being, relatives notice that providing invasive care that prolong the lives of their children can only lead to a life of suffering within the world of the hospital. Since they closely followed the entire trajectory of the health of the child up to that point, suffering with them all consequences of their disease, they manage to understand that the proposal of palliative care is beneficial, not negative to the child. In an extreme act of love, manifested in the action of letting go, they perceive, with serenity, the possibility of the death of the child. Serenity, as used here, indicates the revelation of an attitude of acceptance based on the desire to free the suffering of a child.

This feeling has a profound connection with the manifestation of an attitude that was also revealed in the interpretation of the statements: some relatives immediately seek support in their faith or spirituality, be it in pleas where they ask the entity they believe in for a miracle or to save the child from an early death, or in attempts to find a meaning for that situation where they perceive themselves as impotent and need to gather strength to overcome this painful experience:

> [...] *I want her with me, but I want her well, healthy, no pain, no nothing. And then I started thinking about that every day, I'd kneel down, pray, and I go to church a lot, too, I seek her a lot, I talk to God a lot, my belief is only in God, I have no other... until, thank God, I'm seeing a result. God is giving me an answer.* (F040717)
>
> [...] *I don't believe he's ill enough to die, that doesn't get into my had! You understand? I believe in God a lot, I have a lot of faith in God, that God will do a miracle, I don't know... What I asked God was: let His will be realized, but I don't want to see my son suffering on an ICU bed... I don't want that! So may the lord take him! So taking him Lord! Because we, we get more and more attached! I talked to God, I was honest. If You want to take him, take him! Don't leave me here in this anguish.* (F141117)

Spirituality is a dynamic perspective that is intrinsic to the human being, and through it he searches for meaning, goals, and transcendence, which involves a relationship with oneself, with other beings, nature, and everything he sees as sacred(24). In times of pain, anguish, and suffering – as the awareness of an incurable, potentially fatal disease -, an internal spiritual fight is naturally going to occur, and to cope with it, the being uses strategies of spiritual coping. Health workers are clearly unprepared to evaluate reactions and address spiritual questions with relatives and families(25). Still, there are guidelines according to which spiritual issues should be considered in health care, in order to empower professionals to evaluate cultural and spiritual practices and beliefs of patients and their families in the context of their reactions to the diseas and to treatment(24).

The health team must be attentive and understand the families' process of search for spiritual support, since, if the management of this situation is not respectful and careful, it can lead to a loss of trust between family and team, transforming this therapeutic relationship in a litigious one, bringing suffering and discomfort to all those involved. When the family asks divine powers for a miracle, they may be manifesting denial in regard to the news about the impossibility of care, because, when the team informs them that they have no power to save the child, the only resort they find is to resort to a higher divine power who, in their view, has this power, because they still cannot accept finiteness.

When the family manifests this type of attitude, it is advisable not to insist in limiting vital support, giving them time to elaborate and reflect about what was discussed and presented, so they can understand the proposal without the influence of the defensive attitude of denying the impossibility of a cure. As the relative understands that the miracle they are asking for is not happening, that, during this period, their children is suffering, it becomes possible to address the study in new ways again. As they accept the inevitable death of the child, the family can seek different forms of support in faith and spirituality.

> [...] *In B's case, it's the end of suffering, not only his, but mine and my wife's. And also, this isn't definitive, it's a "see you later", because I cling to the hope of resurrection.* (F170217)
>
> [...] *I despaired. But then I started thinking, thinking that if she was going to suffer here with me, let God take her, if it's her time, let God take her, but let him give me shelter too, don't let me suffer.* (F040717)
>
> [...] *And I don't want him to suffer either. I told them that I can't be selfish, and if God wants to take him, it's because he won't suffer there. I don't want him to suffer here. I, seeing him suffer there on a bed, just so he can stay with me, no... no way! I don't want that! I want him to, if God wants him to stay with me, I want him to be well. I want to go out of the hospital with him, otherwise, I don't want it! That's it. Everyone... everyone was a little distressed because of this... That you can't do anything for the child, you know? Not being able to say anything else... We're kind of hopeless, you know? And so, from now on, we'll leave that to god. God will decide about B's life.* (F211117)

Other studies also found the experience of spirituality as one of the elements that form mothers' experience of grief, a way to find meaning in the death of one's own children and to keep hope that they continue alive in a better dimension, with no suffering[23,25]. In this type of manifestation, parents don't fight against death, but see it as a divine design to end the suffering of their child.

The need for compassionate and attentive care

Dealing with the death of a child, as we have demonstrated, is an extremely painful experience, possibly the greatest anguish in the life of a parent/tutor. In this situation, the need for affection, compassion, understanding, and solidarity from the team found its place during intersubjective moments of care. It can be noticed in the reports below:

> [...] *in palliative care they'll care for us too, care so that we are well, I understood that Dr. Y wanted to say, she can't dress up a thing that doesn't... try to improve a thing... but it hurts they way they say it, because as much as he's there, in that situation, he's still my child! He's still a child like any other!* [...] *Dr. X, who I think she's an angel, because she explained everything and then she asked: Why don't we go home, why don't we rest a bit, and go there see the baby, and she always cares, you know? She explains to us what's happening, what isn't... She told us she knows this isn't life's natural order and things like this shouldn't happen, but they do... And so it was very different. And yesterday they let us stay with the baby until late.* [...] *You know, I can't say anything bad about the nursing team, you know? Everyone is doing their best to relief all this suffering, you know? (...) everyone is trying to make it easier, and I feel it! I feel much better being here.* (F061017)
>
> [...] *I could see that they are not changing shifts in front of us anymore, and they always tell the story... One technician to the others.... They just say what's the medication and then exchange information outside. I noticed that too... that no one is saying anything else for us. They just say: "Ah, I'll start that antibiotic" – but they don't say the things that can hurt us anymore.* [...] *We heard the story and every time we have to repeat or hear it again, it's like we're reliving what happened that day.* (F041017)

These statements show, implicitly, that relatives value highly the attention and affection they receive from the team not only regarding their children, but also regarding themselves, as they notice the attempt of the health team members to mitigate the situation using small gestures, such as the use of soft words, careful voice tones, active listening, and even touches in moments of suffering. These attitudes, through which the team shows their compassion and empathy, are essential when communicating with relatives, who complain about the lack thereof from certain team members:

> [...] *you're are more responsible for care, and you care for us, even us parents – because the nurse was the only one who worried about what I was feeling, who touched me, who told me it would be better that way, she was the only one! Dr. X. stood still like this... I saw he was uncomfortable, but he wouldn't say anything.* (F061017)

Studies highlight the fragility of the family at a time when they are learning of their loss and show the importance of this compassionate and empathetic attitude in all members of the health team(21,26). When parents see that health workers are genuinely worried about the wellbeing of their child, which they show through touch, affective words, guidance, and proposals based on situations that emerge through treatment, they manage to establish a relationship of profound trust in the team, which helps them keep calm when confronted with the options available. One of the mothers states this like so:

> [...] *I felt more at peace. I know they[health team] don't want her to suffer either, everyone wants what's good for her, and so I felt more at home.* (F300317)

It is important for the family to see that the team sees the child as unique being, not as another one of so many cases routinely attended, and for them to understand that the suggestion to refer the child to palliative care results from a careful examination of reality (which explored all possibilities) and from genuine affection and concern for the child's wellbeing, all being done in the child's best interest. That is, what is best for the child in terms of having the best possible quality of life, free from pain and suffering(20).

The concept of best interest of the child refers to an essential principle, according to which any decision made regarding the health of the child should be made so its benefits outweigh potential damage, focusing on the child and their wellbeing(20). Being and acting in Pediatrics should be informed by the development of a compassionate attitude, which does not need to be activated exclusively in certain moments, but be an integral part of routine care(9). The interpersonal dimension is one of the most important dimensions of human conditions, and is intrinsically connected to the unique possibility that unveils itself in the transcendental sphere of care(1).

Understanding the statements shows situations where the proposal of palliative care was embraced favorably by relatives, showing an authentic existence as a being-in-the-world, as the suffering caused by the finiteness of the child is embraced. Therefore, feelings of relief were manifested as parents perceived that their desires regarding the life of the child were understood, and their options were not judged:

> [...] *I was happy because I felt safe that everyone* [health workers] *was understanding me, that we were in the same page, that made me really happy* (F300317).
>
> [...] *Kind of, more or less, you know? Because ever since he was born he's in a hospital, he's never been home... So, that's how he is. I and my husband, we are... because we have another child too, and so...* [...] *It was more of a relief, because, in this case, he's been suffering, and we were seeing that he was suffering a log, so, for us, we already knew that's what was going to come to, you know? At some point they had said something about it.* (F180517)

These statements are from parents who, due to the neurological commitment generated by the severity of their primary disease, showed little-to-no abilities to communicate or have any affective interaction with the parents. Therefore, the parents already had mature thoughts about not prolonging the lives of their children with invasive measures, as, due to the current clinical state of the child, they could understand that their life was nothing but suffering. For them, their children could only stop suffering by losing their lives. This led to the emergence of an existential question that can be expressed as: How can a society that still discusses the morality of aspects related with the right to life accept parents that desire the death of their children?

When the team revealed the proposal of palliative care, these relatives could express relief, since the proposal of the team was exactly what they wanted for the child. This helped them be free from the weight of social judgment regarding their desire to abbreviate the suffering of the child(9).

In the existential facticity where suffering has an implacable predominance in the life of the *being-there-child-with-chronic-disease*, parents and health team can start to share the intersubjective adoption of the modality of palliative care, whose goal is to focus on the quality of life of the days left, without abbreviating them or prolonging them(6–8). Thus, the transcendental care of attentive care is unveiled, that is, the "being-with-the-others in daily life stays within the two extremes of attentiveness – the one that jumps on the other to dominate them, and the one who jumps in front of the other and frees them [...] 'attentiveness' is guided by consideration and patience"(15).

FINAL CONSIDERATIONS

A phenomenological reading of the existential facticity of relatives of children undergoing intensive pediatric care, who received news about the recommendation of palliative care for their children, allowed us to understand the range of feelings and perceptions that emerge when the parents are confronted with the perspective of experiencing the finiteness of the child and the repercussions of the child's absence, from an existential perspective. This reveals a trajectory in which confronting the finiteness of the child, in its many different nuances, becomes a possibility in face of this non-transferable, challenging situation.

The child usually represents, for their family, the continuity of their own lives. Through the child, future projects give support to the constitution of care as an indicative of presence and attentiveness, a genuine preoccupation with this Being conceived to grow and develop, to gain a meaningful life. For caregivers, the pain and suffering that accompanies this unique existential moment is revealed. At this time, feelings and perceptions emerge that acquire the meaning of anguish and depression, emptiness and solitude, anger or revolt, and they seek support in spirituality/religiosity, or evenn in an attitude of acceptance, which forms the thematic dimension "Coping with the finiteness of the child when confronted with the proposal of adopting palliative care". Still, other types of family reactions could be noted, such as the need for affection, understanding, and compassion, that formed the thematic dimension "The need for compassionate and attentive care".

The experience of existing to deal with the end of the life of a child brings adversities that manifest in the form of an intense fragility when confronted with the vulnerable character of human condition. The interdisciplinary intensive care team must adopt an empathetic attitude, based on the principles of embracing and providing authentic care, an understanding response to the existential conditions found in this trajectory of suffering.

The perspective from existential phenomenology can help walking hand-in-hand with the family of the child in palliative care in their existential purpose; and becoming concerned with the reading of the existential changes as one understands the health, disease, and finiteness as existential dimensions that surround the being-in-the-world of the family that goes through this facticity. An understanding perspective can help the interdisciplinary team to communicate the decision of providing palliative care, including analyzing, understanding, and providing sensible care, overcoming distances as the authenticity of the being that cares and the being that is cared for emerge, in the construction of a new pathway, replete with meaning for both, focused on the best interest of the child.

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