

Between life and death: case study of a child with an indication for palliative care

Summary

Objective: To promote reflection on the issues related to life and death that emerge from the experiences of family members and professionals in the care of a child with no possibility of disease-modifying treatments and a long period of hospitalization.

Methodology: A single case study of a situation marked by irreversible neurological conditions incompatible with life, and prolonged hospitalization in a University Hospital, offering obstinate care and palliative care. Semi-structured interviews were conducted with professionals and life histories with family members. The statements were classified in an attempt to grasp the nuclei of meaning and from there the empirical categories were extracted.

Results: Constructed report: Pandora, eight years old, victim of drowning when she was one year and six months old. She was hospitalized for approximately six years. Her death, despite being a natural fate, was for many a commotion. The following empirical categories were extracted from the analysis of the interviews: 1) Difficult acceptance of death in childhood, 2) Family reorganization, 3) Indication of palliative care, 4) Vicissitudes of work in the face of death.

Conclusion: This case study showed that the decision making process at the end of life is surrounded by many dilemmas, which make its action in care something that deserves special attention and serious reflection.

Keywords: palliative care at the end of life, paediatrics, death

Volume 7 Issue 1 - 2024

Julia Marinho Rodrigues,¹ Sara Fiterman Lima,² Vanise Barros Rodrigues de Motta,³ Ivana Santos Vale,¹ Luís Victor Moraes de Moura,¹ Zeni Carvalho Lamy²

¹Graduated from the Federal University of Maranhão, Brazil

²PhD and lecturer in the Postgraduate Program in Collective Health at the Federal University of Maranhão, Brazil

³Master's degree and lecturer in medicine at the Federal University of Maranhão, Brazil

Correspondence: Sara Fiterman Lima, Federal University of Maranhão – UFMA, Brazil, Tel +55(98)996087040, Email sara.fiterma@ufma.br

Received: March 06, 2024 | **Published:** March 14, 2024

Introduction

The rise of technological medicine, combined with improved social and health conditions from the second half of the 20th century onwards, changed the prognosis of countless diseases and increased the life expectancy of the population.¹ Faced with the emergence of new resources such as resuscitation protocols, parenteral nutrition, mechanical ventilation and Intensive Care Units, the search for a cure for different diagnoses ended up becoming the main objective of care in health services.^{2,3} Throughout this transition, death ceased to be an event experienced at home, in front of the family, and became institutionalized. A distant relationship was built up with dying and, in the face of its occurrence, a feeling of failure emerged on the part of the professionals.^{3,4} As a result, we have seen the exaggerated prolongation of death through useless treatments which, in order to save the lives of patients with reserved prognoses, have ended up subjecting them to more suffering. In opposition to these behaviors of therapeutic obstinacy, the need has emerged to identify what would be a scientifically appropriate and ethical approach, and to redefine the limits for medical action, including questions such as when to invest in treatments and when to stop them.^{5,6}

In pediatrics, children and adolescents today survive clinical situations that were once fatal, but on many occasions this survival is accompanied by incurable conditions that threaten life and demand special attention.^{7,8} In these situations, even when there are no possibilities for disease-modifying treatments, unnecessary procedures are used that prolong the hospitalization time of these children and have a major physical, psychological, social, economic and spiritual impact on the patient, their family and the care team. In view of these situations, the World Health Organization (WHO) has defined pediatric palliative care (PPC) since 1998 as active and

total care provided to children when a life-limiting or life-threatening condition is diagnosed, in an approach focused on their body, mind and spirit, as well as family support, and should be present regardless of whether or not the child receives treatment for the disease.⁹ Given this concept, we can see that PPCs are fundamental to guaranteeing humanized, qualified treatment geared towards the needs of children and their families. However, for various reasons, this care is still offered in an incipient manner. The aim of this case study is to promote reflection on the issues related to life and death that emerge from the experiences of family members and professionals in the care of a child with no possibility of disease-modifying treatments and a long period of hospitalization.

Methodology

This is a unique case study of a situation marked by irreversible neurological conditions incompatible with life, and prolonged hospitalization in a University Hospital, offering obstinate care and palliative care. The single case study was chosen because, according to Yin, it is suitable for investigating contemporary phenomena.¹⁰ Two family members (the child's father and paternal grandmother) and eight professionals (doctors, nurses, psychologists, physiotherapists and social workers) were interviewed for the case study, which took place between February and May 2019. Topical life history interviews were conducted with family members and semi-structured interviews with professionals. The trigger question for the life story was "Talk about what has happened to Pandora since she suffered the accident". A semi-structured script was drawn up for the semi-structured interviews. The interviews were recorded and later transcribed, and the data obtained was interpreted using the thematic content analysis technique.¹¹ The research was approved by the Research Ethics Committee (CEP) of the University Hospital of the Federal University

of Maranhão, CAAE No. 4886.7.0000.5086. To ensure anonymity and confidentiality of information, the participants were identified by names taken from Greek mythology: Pandora, the child; Prometheus the father and Gaia the paternal grandmother. The professionals were named after Greek gods.

Results/Discussion

Case presentation

Pandora, eight years old, female, from São Luís, Maranhão. Her first child was born by normal birth at full term. She showed growth and development compatible with her age until she was one year and six months old, when she drowned in a bucket in a pond at her home while trying to catch a ball. The mother was attending prenatal care and the father was at work, the child was being cared for by neighbours. She took a long time to be rescued by neighbours and family members and was taken to an emergency unit, where she went into cardiopulmonary arrest (CPR) and was revived by the team on duty. Her vital signs returned, but she suffered severe neurological sequelae. She remained in this unit for about a week and was then referred to a referral hospital, with a diagnosis of hypoxic-ischemic encephalopathy after CA. She was hospitalized for seven years and six months, initially in the Pediatric Intensive Care Unit and later in a ward. She had irreversible and non-progressive conditions secondary to anoxic brain damage. She remained in a comatose state, with continuous ventilatory assistance, dysphagia, psychomotor impairment, spasticity, assessed with Lansky: 0, i.e., nonresponsive. During this period, she had several complications such as cardiorespiratory arrests and infections and always received advanced life support measures. In this way, she was kept on mechanical ventilation, gastrostomy feeding (GTT), Ventral Venous Catheter (CVC), administration of vasoactive drugs, courses of antibiotic therapy, and other resuscitation measures when necessary, measures considered to be distanasic. There were many professional efforts to keep her alive.

At the beginning of her hospitalization, she was accompanied by her mother, who was pregnant with her second child at the time, and her father. Her paternal grandmother and two aunts were also present. After the birth of her sister, her father became her main caregiver. After two years in hospital, the mother left the family and moved to another state, completely withdrawing from her daughter's care. Visits from the paternal grandmother and aunts, which were initially constant, became scarcer and the father became the sole caregiver, abandoning his chores to live in the hospital, considering the requirement for a companion. Although several attempts were made to include *Pandora* in palliative care, the family was resistant, as her father and paternal grandmother showed expectations of a cure, linked to divine intervention, and projected the future for when she woke up and could return home. Her body grew up restricted to bed, and despite the interventions of the multi-professional team, she had significant deformities caused by being restricted to bed (anatomical changes in the bones of the upper and lower limbs, plantar drop, latero-lateral widening of the chest, abdomen and face). She was already showing signs of puberty, such as increased hair and breast growth. Throughout her hospitalization, she never showed any reactions, and there was a consensus among the team that the neurological damage was too severe to allow any response. She was therefore recognized as a patient with no therapeutic possibilities for a cure. Her inclusion in Palliative Care, even after many attempts, only took place four months before her death, when she was entitled to a reduction in invasive interventions, not to receive futile treatments and not to be resuscitated.

Presentation of categories

The following empirical categories emerged from the analysis: The difficult acceptance of death in childhood; Family reorganization; The Indication of Palliative Care; Vicissitudes of work in the face of death.

The difficult acceptance of death in childhood

The knowledge of finitude as part of a natural cycle of life was present, albeit indirectly, in all the professionals' statements. At the same time, the reports showed difficulties in recognizing this possibility in their daily work:

"we have to begin to understand that there is an end" [Hera].

"so even though we knew that the end of that story was inevitable, we didn't expect it to be tomorrow or the day after" [Athena].

This difficulty in recognizing and offering care during the dying process generates personal conflict over the quality of care offered.¹² The biomedical model of care has imposed on some professionals the obligation to adopt obstinate measures to deal with clinical situations, under the belief that they have the function of curing and restoring health to everyone.^{13,14} When they spoke of *Pandora*, the professionals recognized the absence of curative possibilities, but part of the team did not recognize the possibility of death as something present at that moment:

"It's a child with no prospect of getting better." [Aphrodite].

"The team used to say: "Oh, Pandora's still going to bury a lot of people" and "there are people who are going and Pandora's still going to be there."" [Athena].

This unconscious defensive mechanism involves the decision to postpone attention to an impulse or conflict, which in this case is the death of the child.¹⁵ This defense may be associated with the difficulty of accepting the child's death. In addition, terminality is more complex in childhood, the definition of irreversibility is a more arduous process and takes longer when compared to adults.¹⁶ The failure to recognize death as a concrete possibility for the outcome of this case made the subject taboo among the team members, who somehow recognized that it was this reaction, with its consequent communication obstacles, that made it difficult for the family to accept:

"We didn't talk about Pandora's death here. It was forbidden. It was taboo." [Aphrodite].

When they admitted the possibility of death, the difficulty of facing this moment was also present, either because they were afraid of the reactions of family members or because they were afraid of facing the child's own finitude:

"The father argued with the staff... nurses, technicians... the staff were already a little afraid of him. So much so that when she died, the whole team was afraid of his reaction." [Hermes].

"God answered my prayers. I didn't take part in that moment [death]" [Athena].

A study carried out on end-of-life care in Japan showed that a lack of formal education on end-of-life care, concerns about the legal ramifications of interrupting treatment, a lack of social acceptance and hesitation to discuss death and end-of-life care directly influence the actions of the team in the face of a possible death.¹⁷ The possibility of death was a difficult reality for the family, and so the father and paternal grandmother, in their interviews, reported that during almost the entire seven years of *Pandora*'s hospitalization, they hoped for a cure:

“The only thing that leaves me here is the love I feel for her and the hope that God will wake her up. Although the doctors, medicine doesn't believe in it, I believe in it very much, very much in God.” [Prometheus].

“We're looking at her case, it's delicate. So she can go at any time or wake up at any time.” [Gaia].

A child should not continue disease-directed therapy to maintain flexibility, especially when the disease significantly affects their quality of life.¹⁸ The knowledge of death and its presence in the daily lives of the family members and professionals involved in this case was based on a religious/spiritual condition, in which the individual beliefs of the family members recognized death as inevitable, but believed in the possibility of divine intervention.

Family reorganization

Throughout the life cycle, the family system goes through various losses, requiring reorganization, restructuring and re planning. Faced with the threat or even death or illness, this adjustment is one of the most difficult transitions in life, especially when it is related to the loss of a child.¹⁹ Pandora's family went through this process. However, unlike what is reported in various studies,^{20,21} on paternal abandonment in situations where children fall ill, in this case the mother was the abandoner, and the father became the main caregiver, as already mentioned. The lack of people to share the child's care with created a work overload:

“My mother stays with my other daughter. My brother is married and has children. My sister, who is also married and has children, doesn't have time, so it's just me and God for now.” [Prometheus].

“It's Prometheus who stays the longest. He stays the most. I only come sometimes, two or three times a week. That's because I live far away and her sister stays with me.” [Gaia].

“[Child] Abandoned, right? In quotes, by her mother. So the father took care of the child and the grandmother eventually, there was a little sister who visited her from time to time” [Athena].

Macedo et al, reflect on the importance of relieving this burden through activities that involve the whole team with the aim of offering support to deal with the challenges of care, welcoming and guaranteeing solutions to the physical and psychological problems of this caregiver.²² Prometheus' tiring daily routine inside the hospital was also identified by the team:

“I used to call him a hero because, in reality, he was the only one in his family, he was the only one who looked after the child. The child had no grandparents, no mother, no uncles, no siblings. He was the only one who looked after the child.” [Apollo].

The professionals also reported an improvement in Prometheus' quality of life after the palliative care team's intervention, which made him reflect on his own needs and the importance of maintaining his mental health well:

“Then we said: “Prometheus, how are you?”, and he said: “No, look, I really needed it, I was really bad, I was about to freak out in here, and I'm also in a relationship with someone else, I was really tired, I was about to have an outburst in here, I'm feeling better”. [Aphrodite].

It is part of the line of care for children in complex clinical conditions and their families to promote actions to welcome the family network into the hospitalization environment, considering that these families are exposed to vulnerability factors, such as: changes in routine,

stress, difficulty in interpreting alternative communication needs, which can lead to neglect and intra-family violence.²² The change in routine associated with the stress of prolonged hospitalization may have motivated Prometheus to resist and demand treatment, as reported by some professionals:

“[...] we had a lot of problems with him, the team had a lot of problems with him, in terms of care, because when we went to see him, sometimes he didn't want to be seen.” [Hermes]. [Hermes].

During a long hospital stay with a child with a chronic condition, the family member faces a relentless quest to fulfil what they see as their duty: to protect and spare the child from suffering. In addition to the possibility of feeling guilty about the child's condition.²³

The indication for palliative care

During the analysis of the speeches, we observed a lack of knowledge and skill on the part of the professionals in relation to palliative care:

“[...] They put her on medication, even though she was in palliative care. I don't even know if it was right or not, but they medicated whenever they needed to, but even central access was done, even though she was in palliative care.” [Hermes].

The term palliative care raises a lot of doubts among family members and even staff about whether it should be used or accepted, as it suggests a false idea of terminality. End-of-life care is part of the palliative care group, but it encompasses much more than that.²⁴ Even after accepting palliative care, it was possible to identify disagreements between team members about how to approach possible outcomes with family members:

“And the palliative didn't, I actually told him that his daughter was going to die, that she should have already died, and he went crazy, and there were some in the team who didn't agree, because the people here love her; but there were others who were relieved, because someone said what they were supposed to say to him.” [Artemis].

According to Sá,²⁵ since it is not possible for the child to even give their consent to the conduct adopted and the decision about their future, it is necessary for the health team and family to be in the greatest possible harmony, in complete harmony, without communication it is impossible to make decisions together and for this communication to be effective it is necessary for professionals to know about the term palliative care. Similarly, there were disagreements over decisions regarding the child's future:

“When it's time for the child to desaturate, Prometheus yells at the team, he demands the doctor, and then she goes to resuscitate, she goes up, so it's because he didn't agree [with palliative care], in fact.” [Artemis]. [Artemis].

Most health professionals around the world have little or no knowledge of the principles and practices of palliative care. Due to this gap in training, the behaviour of therapeutic obstinacy is still common.¹³ Pediatricians' lack of knowledge about this different type of care can delay or even make it impossible for the family to make a decision and then, if possible, home care, if this is the final decision.¹³ Acceptance seemed to be questioned by some professionals, even though the palliative care team had been called in:

“There were benefits for children in palliative care, but I think the most difficult thing is to get the pediatric medical team to provide this kind of care.” [Artemis].

For Quill and Abernethy,²⁶ due to the lack of sufficient specialists in palliative care, it is necessary for each medical specialty to plan basic expectations about primary skills in the area, with the aim of managing symptoms, listening, supporting and guiding family members. The change in the team's attitude came about after the palliative care team began to monitor the case:

"[...] before this palliative care team started working, we didn't talk about children dying here. It was forbidden. It was taboo. Prometheus was even given hope that one day the child would get up from that bed" [Aphrodite].

After the change in attitude, it was possible to identify reports from professionals about the importance of this intervention in the final outcome:

"From what little I know about palliative care, I think they have the ability to change this. To change everyone's thinking. The father, who is very difficult, and even the staff." [Artemis].

"I think the family kind of prepared themselves, although when we talked about it, it was very difficult, but we said: 'there is a possibility, people. Let's prepare for that possibility too, shall we?'" [Aphrodite].

For the family members, the meetings with the palliative care team gave them a different perspective on the child's clinical condition. Prometheus reports that the intervention was accepted to treat symptoms and relieve suffering, but that he didn't feel comfortable talking about the reserved prognosis:

"I think she's going to wake up and go home with me. She [the palliative care doctor] kept saying she wasn't going to wake up and I said okay. But because she told me that she'll feel less pain during this treatment, and said that I'd be able to go out more, I agreed." [He promised].

Boldrini,¹³ when studying the subject, reflects on the possibility of patients and family members refusing palliative care if they don't feel comfortable talking about the prognosis. However, it is important to emphasize that this care should at least be available for the family to choose. High-quality pediatric palliative care for children with serious illnesses is now an expected standard of medicine. However, even in resource-rich settings, there are still significant barriers to achieving optimal care related to the lack of formal education, cost-related issues, the emotional impact of caring for a dying child and, most importantly, the lack of interdisciplinary pediatric palliative care teams with sufficient professionals.¹⁸

Vicissitudes of work in the face of death

When a child falls ill, the fantasy built up by the parents breaks down. The fantasy that their love and adequate care are enough to protect them from destructive events. Death doesn't seem to be "allowed" to be part of childhood, the initial phase of life.¹⁹ Due to Prometheus' defense mechanism, in which he tried to remove the inevitable from his consciousness, the team reports that they expected a reaction of anger and aggression, which did not occur:

"It was surprising because they said he didn't fight, he didn't shout, he didn't do anything. He was very calm, quiet, he cried, but he didn't show any anger." [Hermes].

Some family members remain in a process of denial and non-acceptance of the clinical condition, in order to distance themselves from contact with the pain of the inevitable: death, and may react to it more intensely.¹⁹ As mentioned above, the intervention of the palliative care team made it possible to work on grief in advance.

Despite the team's involvement with Pandora and her father, aftercare only took place to resolve funeral issues:

"Unfortunately I had no further contact [with the family after the death]." [Hera]. "So our approach to bereavement, how do we do it? There's that impact of the news, you hope to calm the situation down a bit. It's usually the psychologist, the doctor, sometimes they also call in the Social Service to give support, but we stay there, usually taking the family to a more private space. We have this difficulty here." [Aphrodite].

Supporting the family after the death of their child is one of the actions of palliative care that has received little attention,⁵ but studies report the need for this approach.^{27,28} Prometheus' care was recognized by a professional who said he was dissatisfied at not having had the opportunity to thank him:

"I didn't have the opportunity to thank him either, because one way or another, despite the negative things that also happened, for me, the father staying with his daughter the way he did, was something that deserved to be recognized." [Athena].

After so many years of living together, professionals have become partners and collaborators in care, establishing bonds and needing welcome and palliation during illness and after death.²⁹ In the close relationship between professionals, children and family members, there are teachings that express the representations of terminality as changes in the meaning of life and learning.³⁰ Some professionals reported the suffering and feelings experienced by the care team itself after the child's death:

"I think the team suffered and I won't deny that I helped some of the team, I helped in the sense of welcoming and listening, people really cried at Pandora's death." [Hera]. *"Seeing the room empty is strange, it's a strange feeling. It was sad. If I'd been on duty, I would have felt it even more, and it would have been sadder."* [Athena].

After the death of the child, special attention should also be paid to the care team involved in the case. It is advisable to hold a meeting so that everyone can share their feelings and criticisms about the care and treatment offered. This meeting helps the team to deal with their grief.⁵ According to Genezine et al,¹⁹ death is always considered an unwanted enemy that cannot be part of childhood, causing indignation for everyone involved, family members, staff and society in general.

Conclusion

The case presented highlights the many layers of challenges faced by patients, families and health teams in the context of end-of-life care, especially in pediatrics. There is a difficulty in accepting death in childhood, both by health professionals and family members, making it a taboo subject, difficult to approach and accept. Family reorganization emerges as a dynamic and often painful process, which requires an expanded support network that is attentive to the needs not only of the patient, but also of the main caregivers, illustrating the emotional, social and economic burden that serious illnesses impose on families. In conclusion, this study reaffirms the essentiality of pediatric palliative care as an integral part of the health care spectrum. It reflects on the need for an approach that recognizes the complexity of end-of-life care, patient dignity and support for family members and health professionals. It is hoped that the lessons learned from Pandora's journey will inspire continued reflection and improvements in palliative care practice, ensuring that every child and family facing similar circumstances receives the support, compassion and dignity they deserve at the end of life.

Acknowledgments

None.

Conflicts of interest

The authors declare that there are no conflicts of interest.

References

- Martino AR. *What should we know about pediatric palliative care in children?* In AEPap edn. Pediatrics Update Course 2012. Madrid: Exlibris Ediciones; 2012. pp. 28592.
- Foucault M. *The birth of the clinic*. 7edn. Rio de Janeiro: Forense Universitária; 2013.
- Dantas MMF, Amazonas MCLA. The illness experience: palliative care given the impossibility of healing. *Rev Esc Enferm USP*. 2016;50:46–52.
- Rubio AV, Souza JL. Pediatric and perinatal palliative care. *Pediatrics*. 2019;144(6):e20193146.
- Piva JP, Garcia PCR, Lago PM. Dilemmas and difficulties involving end-of-life decisions and palliative care in children. *Rev Bras Ter Intensiv*. 2011;23(1):78–86.
- Iglesias SBO, Krebs VLJ. Palliative care in pediatrics and neonatology. *Pediatrics*. 2012;(53):12–14.
- Valadares MTM, Mota JAC, Oliveira BM. Palliative care in pediatrics: a review. *Rev Bioé*. 2013;21(3):486–493.
- Menezes RA, Barbosa PC. The construction of the “good death” in different stages of life: reflections on the palliative ideology for adults and children. *Cien Saude Colet*. 2013;18(9):2653–2662.
- World Health Organization. WHO definition of palliative care for Children. 2019.
- Yin RK. *Case Study: planning and methods*. Bookman; 2015.
- Minayo MCS. *The challenge of knowledge: qualitative research in health*. 12th edn. Hucitec, São Paulo, 2006.
- Souza LF, Misko MD, Silva L, et al. Dignified death of the child: perception of nurses in an oncology unit. *Rev Esc Enferm USP*. 2013;47(1):30–37.
- Boldrini B. Introduction In: Rubio AV, Souza JL. *Palliative care: pediatric and perinatal*. Rio de Janeiro: Atheneu; 2019.
- Bushatsky M. *Patients without therapeutic possibilities: perceptions of caregivers, students and health professionals in the face of finitude and palliative care*. Recife: Federal University of Pernambuco; 2010.
- Volpi JH. *Defense mechanisms article from the body psychology specialization course*. Curitiba; Reichian Center, 2008.
- Lago PM, Garros D, Piva JP. Terminal ill children and end-of-life practices in the pediatric intensive care Units. *Revista Brasileira de Terapia Intensiva*. 2007;19(3):359–363.
- Makino J, Fujitani S, Twohig B, et al. End-of-life considerations in the ICU in Japan: ethical and legal perspectives. *J Intensive Care*. 2014;2(1):9.
- Friedrichsdorf SJ, Bruera E. Delivering pediatric palliative care: from denial, palliophobia, pallilalia to palliative. *Children*. 2018;5(9):120.
- Genezine D, Pallottino ERCN, Camara CMC. Family support after the loss of a child. In: Rubio AV, Souza JL. *Pediatric and Perinatal Palliative Care*. Atheneu; 2019.
- Fernandes RT, Lamy ZC, Morsch D, et al. Weaving the web of abandonment: beyond the perceptions of mothers of preterm infants. *Ciê Saude Colet*. 2011;16(10):4033–4042.
- Daltro MCSL, Moraes JC, Marsiglia RG. Caregivers of children and adolescents with mental disorders: changes in social, family and sexual life. *Saúde Soc*. 2018;27(2):544–555.
- Macedo EC, Silva LR, Paiva MS, et al. Burden and quality of life of mothers of children and adolescents with chronic illness: an integrative review. *Rev Lat Am Enfermagem*. 2015;23(4):769–777.
- Silva FM, Correa I. Chronic disease in childhood: family experience with hospitalized children. *REME Rev Min Enf*. 2006;10(1):18–23.
- Garros D, Cruz CT. Palliative and end-of-life care in the pediatric intensive care unit. In: Rubio AV, Souza JL. *Pediatric and perinatal palliative care*. Atheneu; 2019.
- Sá FC. Terminality in neonatology: ethical, legal and moral aspects. In: Rubio AV, Souza JL. *Pediatric and perinatal palliative care*. Atheneu; 2019.
- Quill T, Abernethy AP. Generalist plus specialist palliative care - creating a more sustainable Model. *N Engl J Med*. 2013;368(13):1173–1175.
- Nelson JE, Puntillo KA, Pronovost PJ, et al. In their own words: patients and families define high-quality palliative care in the intensive care unit. *Crit Care Med*. 2010;38(3):808–818.
- Halal GMCA. *Parents’ perception of the death of their children in a pediatric intensive care unit*. Porto Alegre: School of Medicine of the Pontifical Catholic University of Rio Grande do Sul; 2010.
- Franco MHP. *Multidisciplinary and interdisciplinary - psychology*. In: Ayer R (org.) *Palliative Care*. São Paulo: CREMESP, 2008;74–76.
- Fernandes FS, Ferraz F, Salvaro GIJ, et al. Social representations of health professionals about terminally ill children and adolescents. *Rev CEFAC*. 2018;20(6):742–752.