DOI: https://doi.org/10.36517/rmufc.v66e93359.2026

REVIEW ARTICLE

Paradox of innocence: understanding of death in childhood for children, their parents and health professionals

Paradoxo da inocência: compreensão da morte na infância para a criança, seus pais e os profissionais da saúde

Marcelo Lucas de Lima Prado[1].

Arthur Nascimento e Melo[1].

Victor Aleixo Lopes[1].

Anna Valeska Procópio de Moura Mendonça[1].

1 Universidade Federal de Sergipe (UFS), Aracaju, Sergipe, Brasil.

ABSTRACT

Objective: The aim of this study was to obtain an overview of the scientific literature available on the representation of death in childhood for children, their parents and health professionals. **Methodology:** An integrative review was carried out. PubMed, MedLine, Web Of Science, PsycINFO and SciELO databases were searched for articles from 2013 to 2023. **Results:** The articles highlight the importance of a multidisciplinary team to deal with the child's death process and the parents' grief. Furthermore, from the parents' perspective, the need for professional support, stabilization of frequent communication with the child and the fact that they have different ways of dealing with grief are emphasized. Furthermore, it is shown that the child's view of death varies with the cultural environment, age and emotional aspects. **Conclusions:** It became clear that it is important to look at the process beyond the health sector and to balance different ways of dealing with illness or even bereavement, as well as the need for more research involving these factors in different locations in order to further refine strategies for dealing with the impact of death in childhood.

Keywords: Adaptation, Psychological. Attitude to Death. Bereavement.

RESUMO

Objetivo: O objetivo deste estudo foi obter uma visão geral da literatura científica disponível sobre a representação da morte na infância para as crianças, seus pais e profissionais de saúde. **Metodologia:** Foi realizada uma revisão integrativa. Foram pesquisados artigos nas bases de dados PubMed, MedLine, Web Of Science, PsycINFO e SciELO, no período de 2013 a 2023. **Resultados:** Os artigos destacam a importância de uma equipe multiprofissional para lidar com o processo de morte da criança e o luto dos pais. Além disso, na visão dos pais, enfatiza-se a necessidade do apoio profissional, da estabilização da comunicação frequente com a criança e que eles têm diferentes formas de lidar com o luto. Além disso, mostra-se que a visão da criança acerca da morte varia com o ambiente cultural, idade e aspectos sentimentais. **Conclusão:** Ficou clara a importância de olhar o processo para além do setor saúde e equilibrar as diferentes formas de lidar com a doença ou mesmo com o luto, bem como a necessidade de mais pesquisas envolvendo esses fatores em diferentes localidades, a fim de aperfeiçoar ainda mais as estratégias para lidar com o impacto da morte na infância.

Palavras-chave: Adaptação Psicológica. Atitude Frente a Morte. Luto.

Corresponding author: Victor Aleixo Lopes, Avenida Marcelo Deda Chagas, sem número, Rosa Elze, São Cristovão, Sergipe, Brasil. CEP: 49107-230. E-mail: victoraleixol@gmail.com.

Conflict of interest: The authors have no conflicts of interest to declare.
Received: 02 May 2024; Revised: 18 Ago 2024; Accepted: 11 Set 2025.

INTRODUCTION

The concept of what it means to be a child has always been difficult to define. For the purposes of the National Policy for Comprehensive Child Health Care (PNAISC), the Brazilian Ministry of Health follows the World Health Organization's (WHO) concept of children: people aged between zero and 9 years, in other words, from zero to 10 years or 120 months.[1]

From a socio-historical point of view, from the 17th century onwards, the first real conception of the child emerged among the ruling classes. Adults then began to worry about the child as a dependent and weak being.[2] In the 18th century, from the idea that the child was born as a blank slate, put forward by John Locke, and that they were beings of pure and naive nature, disseminated by Rousseau, the social emergence of the child was observed.[3] Therefore, it can be seen that from these centuries onwards, the idea of what it is to be a child began to be constructed.

On the other side of the human life process is death, which, like childhood, receives different views depending on the historical and cultural context. For modern Western man, death reveals a concept of failure, something shameful that must be overcome at a cost. And when experience brings the reality that this desire has not been achieved, it is hidden and denied.[4]

From the intersection of this contradiction between the beginning of life, childhood, and the end of it, death, the paradox of childhood is born, characterized by death in childhood and the challenges it generates: on the part of the health professionals who deal with terminally ill children, their parents and the way the children themselves see finitude.

Addressing this paradox is essential, not only because it highlights a particularly vulnerable and sensitive phase of life but also because it sheds light on the social, cultural, and emotional dimensions of healthcare. Investigating these representations deepens our understanding of how death in childhood influences clinical practices, parental coping strategies, and the broader societal perception of childhood and mortality. Furthermore, this study seeks to address a significant gap in the literature by integrating the perspectives of children, parents, and health professionals, which are often examined in isolation. By studying the relationship between these perspectives, the research provides a more comprehensive perspective for understanding and improving pediatric palliative care practices.

As far as professionals are concerned, since the child's moment of finitude often takes place in hospital environments, they are required to have the technical-scientific knowledge and emotional preparation to help family members cope with this moment.[5] As for parents, they experience a sense of loss from the child's initial diagnosis, through the progressive worsening of the child's condition and, finally, in the child's death.[6] And from the children's point of view, it is known that understanding death is a complex process, depending on emotional, socio-familial and cultural factors.[7]

So how do health professionals represent the death of children in their care processes? How do the children themselves, as patients, represent death? And for the parents of these children, how do they also represent this experience? In order to answer these questions, the current study was carried out with the aim of making an integrative analysis of the representation of death for children in their treatment process, their parents and professionals.

MATERIAL AND METHODS

The current study uses an integrative review as an instrument, the purpose of which is to gather and synthesize scientific knowledge that has already been produced so that its evidence can be evaluated for incorporation into practice.[8]

The construction of an integrative review follows six phases. The first is the development of the guiding question - this determines which studies will be included. The second is the literature search or sampling, establishing criteria for the selection of materials. The third is data collection, including subjects, methodology, sample size, measurement of variables, method of analysis and underlying concepts used. The fourth is the critical analysis of the studies involved, in order to weigh up the rigor and characteristics of each study. The fifth stage is to discuss the results, comparing them with the theoretical framework. The sixth stage is to present the integrative review, which should be clear and complete.[9]

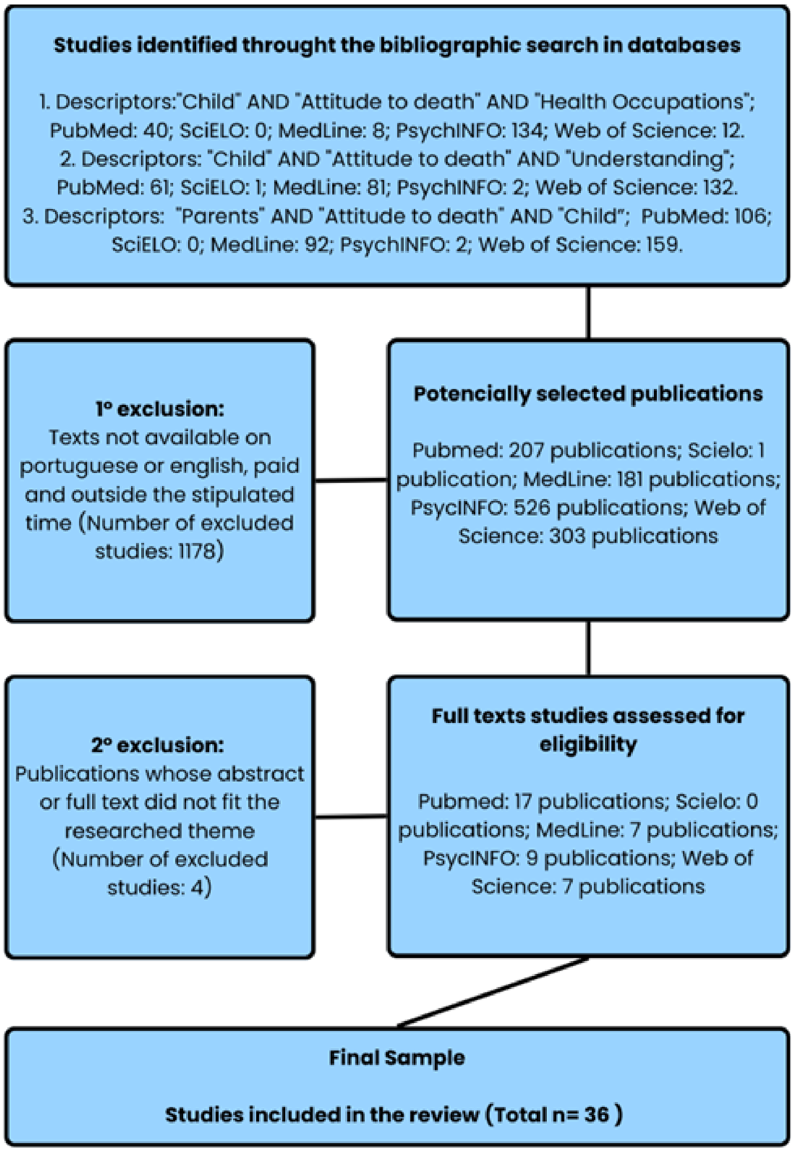
PubMed, MedLine, Web Of Science, PsycINFO and SciELO databases were searched for articles from 2013 to 2023. A set of descriptors was defined to guide the search for professionals' views on the death of children, a set of descriptors to address how parents deal with the death of a child and a set of descriptors to address the child's view of death. For the question "How do professionals deal with the death of child patients?", a search was carried out using the descriptors "Child" AND "Attitude to death" AND "Health Occupations". For "How do parents cope with the death of a child?", the descriptors "Parents" AND "Attitude to death" AND "Child" were used. And for the question "How do children view death?", the descriptors "Child" AND "Attitude to death" AND "Understanding" were used. The three questions and their respective descriptors were used in the searches carried out in PubMed, MedLine, Web Of Science, PsycINFO and SciELO.

The articles were selected independently by at least two authors after reading the title, abstract and full text, with disagreements resolved by consensus. The inclusion criteria were articles published between 2013 and 2023 in the aforementioned databases, written in English or Portuguese, full-text and free of charge, addressing death in childhood and its impacts.

The temporal cut was chosen to ensure the inclusion of recent studies, reflecting the most current practices, advances and developments in the field. In reference to the publication language, preference was given to the wide availability of relevant scientific publications in these languages and to the accessibility of the texts for the researchers involved, seeking to mitigate linguistic biases through the wide coverage of relevant databases. The exclusion criteria were articles that do not align with the object of study, studies that did not answer the research questions and duplicates. After searching and applying the filters, the search process was organized into a flowchart according to PRISMA, shown in Figure 1.

The data was extracted in a standardized way by one author and reviewed by two others. The information extracted refers to the following factors: title of the article, author, year of publication, which view the article takes, whether of the child, the professionals or the parents, type of study, research design, objectives, main results and conclusion. The data was analyzed separately for the different views of parents, children and professionals, by each of the authors. In this sense, the characteristics of each study were assessed, such as the definition of quantitative or qualitative research, the relationship between the topic and the scenario of death in childhood and the main outcomes. The texts were carefully read and, from them, two tables were made: the first contained the databases, the filters used and the results available; the second was a table containing the selected articles and the information collected from them.

Figure 1. Flowchart of the article selection process according to PRISMA.



RESULTS

A total of 389 articles published in the last 10 years, written in English or Portuguese and available in open access were found. Of these, 24 articles were selected for the study.

In the PubMed database, using the descriptors “Child” AND “Attitude to death” AND “Health Occupations”, considering the filters already mentioned, 40 results were found, after which 7 articles remained. Using the descriptors “Child” AND “Attitude to death” AND “Understanding”, 61 results were found, of which 4 remained after analysis. Using the descriptors “Parents” AND “Attitude to death” AND “Child”, 106 results were found, of which 6 articles were selected after analysis.

In the MedLine database, using the descriptors “Child” AND “Attitude to death” AND “Health Occupations”, considering the filters already mentioned, 8 results were found, after which 0 articles remained. Using the descriptors “Child” AND “Attitude to death” AND “Understanding”, 81 results were found, of which 6 remained after analysis. Using the descriptors “Parents” AND “Attitude to death” AND “Child”, 92 results were found, of which 1 article was selected after analysis.

In the Web of Science database, using the descriptors “Child” AND “Attitude to death” AND “Health Occupations”, considering the filters already mentioned, 12 results were found, after which 0 articles remained. Using the descriptors “Child” AND “Attitude to death” AND “Understanding”, 132 results were found, of which 1 remained after analysis. Using the descriptors “Parents” AND “Attitude to death” AND “Child”, 159 results were found, of which 2 articles were selected after analysis.

In the PsycINFO database, the following descriptors were used in the advanced search: “Child” AND “Attitude to death” AND “Health Occupations.” Initially, 2 results appeared. After applying the filter for free and complete texts, no texts were available. To research the question “how children perceive and deal with death,” the terms “Child” AND “Attitude to death” AND “Understanding” were used. Initially, 134 results were found. Applying the filters, 1 article was selected. To research the question “how parents deal with the death of children,” the descriptors “Parents” AND “Attitude to death” AND “Child” were used. Initially, 390 results were obtained. With the filters, 2 articles were selected.

In the SciELO database, using the descriptors “Child” AND “Attitude to death” AND “Health Occupations”, considering the filters already mentioned, 0 results were found. Using the descriptors “Child” AND “Attitude to death” AND “Understanding”, 1 article was found, of which none remained after analysis. Using the descriptors “Parents” AND “Attitude to death” AND “Child”, none results were found.

In Table 1, in order to facilitate the study, the articles had to be categorized. They were divided into three groups: A, with a view to parents, B, with a view to children and C, with a view to health professionals.

In Table 2, articles with a common theme were grouped together. The study design and the main results achieved by these articles were then highlighted.

Table 1. Selected articles, with authors, identification and date of publication.

Identification	Article	Author	Date published
A1[10]	Parental coping in the context of having a child who is facing death: A theoretical framework	Darlington et al.	2017
A2[11]	Parents’ acceptance and regret about end of life care for children who died due to malignancy	Kunal Das, Tanvi Khanna[1], Anshika Arora, Nitika Agrawal[1]	2019
A3[12]	When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with	Kochen et al.	2020
A4[13]	Death Rituals Reported by White, Black, and Hispanic Parents Following the ICU Death of an Infant or Child	Brooten et al.	2017
A5[14]	Helping parents prepare for their child’s end of life: A retrospective survey of cancer-bereaved parents	Wiener et al.	2021
A6[15]	When parents face the death of their child: a nationwide cross-sectional survey of parental perspectives on their child’s end-oflife care	Zimmermann et al.	2016

Continue.

Continuation.

Table 1. Selected articles, with authors, identification and date of publication.

Identification	Article	Author	Date published
A7[16]	O tratamento do câncer infantojuvenil: desvelando as vivências dos pais	Benedetti et al.	2014
A8[17]	Parent Spirituality, Grief, and Mental Health at 1 and 3 Months After Their Infant's/Child's Death in an Intensive Care Unit	Hawthorne et al.	2016
A9[18]	Perceptions of the parents of deceased children and of healthcare providers about end-of-life communication and breaking bad news at a tertiary care public hospital in India: A qualitative exploratory study	Das MK et al.	2021
A10[19]	Parental experiences with a paediatric palliative care team: A qualitative study	Verberne et al.	2017
A11[20]	No impact of previous evidence advocating openness to talk to children about their imminent death	Kreicbergs U, Pohlkamp L, Sveen J	2021
B1[21]	Dynamic and heterogeneous effects of sibling death on children's outcomes	Fletcher J et al.	2018
B2[22]	Exploring Children's Understanding of Death: Through Drawings and the Death Concept Questionnaire	Bonoti F, Leondari A, Mastora A	2013
B3[23]	Embracing Death: Mexican Parent and Child Perspectives on Death	Gutiérrez et al.	2020
B4[24]	A Sociocultural Approach to Children's Perceptions of Death and Loss	Yang S, Park S	2017
B5[25]	Compreensão Emocional da Morte Pelas Crianças em Idade Pré-escolar: Uma Dimensão Esquecida	Silva FM, Lopes AF, Carneiro V, Campelo Á.	2020
B6[26]	Understanding death with limited experience in life: dying children's and adolescents' understanding of their own terminal illness and death	Bates AT, Kearney JA	2015
B7[27]	Developmental Understanding of Death and Grief Among Children During COVID-19 Pandemic: Application of Bronfenbrenner's Bioecological Model	Chachar AS, Younus S, Ali W	2021
B8[28]	Care and support when a baby is stillborn: A systematic review and an interpretive meta- synthesis of qualitative studies in high-income countries	Persson M et al.	2023
C1[29]	The conceptual understanding of pediatric palliative care: a Swiss healthcare perspective	Clercq et al.	2019
C2[30]	Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor	Szymczak et al.	2018
C3[31]	Resiliência e morte: o profissional de enfermagem frente ao cuidado de crianças e adolescentes no processo de finitude da vida	Santos RA dos, Moreira MCN.	2014
C4[32]	Novice Nurses' Experiences With Palliative and End-of-Life Communication	Hendricks-Ferguson et al.	2015

Continue.

Conclusion.

Table 1. Selected articles, with authors, identification and date of publication.

Identification	Article	Author	Date published
C5[33]	Important situations that capture moral distress in pediatric oncology	af Sandeberg et al.	2020
C6[34]	Cuidados paliativos em oncologia pediátrica: percepções, saberes e práticas na perspectiva da equipe multiprofissional	Silva AF, Issi HB, Motta MGC, Botene DZA	2015
C7[35]	Stories of paediatric palliative care: a qualitative study exploring health care professionals' understanding of the concept	Riiser et al.	2022
C8[36]	Discussing Death as a Possible Outcome of PICU Care	Gilleland JC, Parshuram CS	2018

Table 2. Selected articles, divided by objective, with research design and main results.

Articles	Study design	Objectives	Main results
A1[10]; A3[12]	Literature review	To provide a theoretical overview of parental coping in conditions of psychological problems related to the proximity of the death of a child and a basis for bereavement interventions centered on parents by health professionals.	Necessity of balance different ways of dealing with grief, such as direct approach, avoidance and personal and third-party coping. Some intervention components stood out: recognizing parenthood and the child's life; establishing memories; follow-up contact; education and information and remembrance activities.
A2[11]	Questionnaire	Analyze the choices made in the end-of-life plans of pediatric cancer patients	None of the families consulted the child about their wishes regarding the end-of-life plan. Only 30% of families chose hospital-based terminal care. Parents of children in hospice care were 54% satisfied with the reduction in symptoms due to medication administered in the hospice. A total of 46% of families regretted their decisions in retrospect, especially those who decided to keep the children in hospital.
A4[13]	Interviews	Examining the rituals of black, white and Hispanic parents after the death of children in the ICU	Three themes emerged: Immediately after the death - shock and stress, need to help with preparations, decisions about burial or cremation), when and where to hold wakes, funerals/burials. Wakes and funerals - who prepares the child's body, appropriate attire, who can attend - variations according to the child's age, parents' choice, culture, religion, country. After the burial/cremation - being with the family, special celebrations.
A5[14]	Questionnaire	Provides tips on communication and end-of-life guidance for parents	In this research, approximately 40% of the parents felt ill-equipped to handle both the medical issues their child was dealing with and how to cater to their child's emotional needs; fewer than 10% felt very equipped for either. Parents were more inclined to feel ill-equipped when they sensed high distress.

Continue.

Continuation.

Table 2. Selected articles, divided by objective, with research design and main results.

Articles	**Study design**	**Objectives**	**Main results**
A6[15]; A7[16]	Questionnaire; Interview	To assess the perspectives and experiences of parents bereaved by the death of a child in the neonatal period due to various health problems/parents facing the treatment of children or adolescents with cancer.	A6 revealed positive parents' assessment of the services offered to terminally ill patients and their families, despite the difficulties faced by these individuals. A7 showed that during and after treatment, parents experienced fear of the unknown and uncertainty about their children's future, as well as the indifference of local health service professionals, which increased parents' uncertainty and insecurity.
A8[17]	Interview	To test the relationship between spiritual/religious coping strategies and bereavement, mental health and personal growth for mothers and fathers 1 and 3 months after the birth of a baby/child who died in a NICU/PICU.	The bereaved who engaged more in spiritual practices experienced fewer symptoms of grief and better mental health (less depression and post-traumatic stress), although this did not apply to post-traumatic stress in fathers. The participation in religious activities was notably linked to enhanced personal development for mothers, but this was not the case for fathers.
A9[18]	Interview	Focuses on the perceptions and experiences of the parents of deceased children and HCPs regarding the end-of-life communication including death declaration to inform the clinical practices.	Most parents reported that the resident physicians' approach was insensitive and sometimes inappropriate or negative. However, the senior physicians' approach was empathetic and positive. Parents of children in palliative care suffer unimaginable psychological stress and require a great deal of compassionate professional support. The physicians were emotionally affected by the death of their patients, but were limited by their high workload, infrastructure limitations, and lack of communication training. Parents indicated that the resident physicians were to blame for their child's condition (delay in seeking medical care). No physician or nurse reported having received formal communication training. They had to learn on the job or from senior physicians. The physician's cold and neutral approach may be perceived as evasive, cold, and unempathetic by the family and may be counterproductive when the family needs empathy. Physicians may feel helpless, ineffective, and helpless in times of crisis and may resort to blocking behaviors to immunize themselves against potential distress.
A10[19]	Interview	To obtain insight into the support provided by a new paediatric palliative care team from the parents' perspective.	Parents feel supported by the paediatric palliative care team and increasingly valued the team over time. Parents highly valued the process-related aspects such as providing one reliable point of contact, continuity throughout the palliative trajectory and coordination of care; practical support; and the team members' sensitive and reliable attitude. The parents' understanding of the additional value of the paediatric palliative care team increases the likelihood of parents' acceptance of the team in an early stage of the palliative trajectory.
A11[20]	Literature review	To review previous studies on communication about death between parents and children	The number of parents that have regrets during bereavement can be reduced by sensitive communication throughout the illness trajectory.

Continue.

Continuation.

Table 2. Selected articles, divided by objective, with research design and main results.

Articles	**Study design**	**Objectives**	**Main results**
B1[21]; B4[24]; B5[25]	Analysis of drawings; Interview; Databases	Indicates how children identify the emotional aspect of death and the impact of the death of someone close to the child.	Most of the children used realistic expressions to narrate the death and expressed thoughts about life after death. Children mentioned fear, anxiety, sadness, depression, loneliness, anguish and pity. Emotional resources in the home environment decrease significantly after the death of a sibling.
B2[22]; B3[23]; B6[26]	Questionnaire; Analysis of drawings; Interview; Literature discussion	Indicates that children have different views of what death encompasses according to age	The 7-year-olds primarily illustrated biological aspects, while the two older groups incorporated some elements of psychology and metaphysics. However, the 9- and 11-year-olds mainly portrayed biological aspects. The majority of children showed at least a basic understanding of the biological purpose. 18 four-year-olds, 18 five-year-olds, and 17 six-year-olds exhibited a solid grasp of this sub-concept from a biological perspective.
B7[27]	Literature review	To explore the developmental understanding of the process of death and grief by applying the conceptual framework of Bronfenbrenner's theory. Understanding mutual interaction between a child and various ecological systems determines how children perceive death and process grief can facilitate effective communication that has significant implications.	Children may not have the skills needed to manage their grief constructively to identify, normalize, and express their reactions to loss in their lives. Children's ability to comprehend death and grief depends on their developmental stage, life experiences, individual temperament, parental communication patterns, and support from their environment. Health care professionals working with bereaved children should consider children's views of death in their communications during clinical encounters. They can help children to rework their understandings of death as they progress developmentally. The author states that reasons for fearing death include loss of self, fear of the unknown, pain, suffering, and leaving family members in distress.
B8[28]	Systematic review	To identify important aspects of care and support for parents, siblings, and healthcare professionals in high-income countries from the diagnosis of stillbirth throughout the birth and postpartum period.	Personification implied that the baby was considered unique, even when the medically correct term would be a deceased fetus. By engaging in this personification, siblings could understand that a little brother or sister was born without signs of life. Existential issues were marked by a whirlwind of emotions, where parents oscillated between hope and despair, life and death. Siblings of the stillborn baby also experienced chaos and uncertainty, with thoughts about life and death becoming tangible. The synthesis revealed that these existential thoughts about the meaning of life and what mattered in life and death prompted questions about the siblings' future. Simultaneously, siblings might miss the opportunity to discuss their existential concerns as their parents were consumed by grief. Siblings experienced similar stigma, feeling isolated in their grief, and sometimes feeling odd or misunderstood among their peers. Additionally, they could feel lonely within the family, as their parents were more absent due to their grief.

Continue.

Conclusion.

Table 2. Selected articles, divided by objective, with research design and main results.

Articles	Study design	Objectives	Main results
C1[29]; C2[30]; C4[32]	Interviews	Health professionals' understanding of the concept of pediatric palliative care and the relationships between professionals	The nurses recognized that they don't always have the same medical information as the doctors, which can create disagreements. They believed that families understand "palliative" as "death", and once that language is used, the conversation goes off the rails, feeling that they did not have effective communication skills to discuss palliative care topics with children, families and other health professionals.
C3[31]; C5[33]; C6[34]	Questionnaire; Interviews	To analyze the resilience of the team caring for children and adolescents with chronic illnesses.	Healthcare workers sometimes inadvertently convey hopelessness to dying children and adolescents during routine visits and struggle with parents who choose not to discuss treatment and death with their child.
C7[35]; C8[36]	Entrevista; Reflexão e Experiência pessoal	Indicates practical considerations related to discussions about the death or possible death of a seriously ill child.	The professionals addressed the importance of providing parents with timely information so that they can absorb and understand why their child is dying. A talk from an available member of the ICU team or with a non-ICU but historically involved healthcare professional can help the family understand the situation acutely, communicate with the family and shape short-term expectations before a more formal conversation.

DISCUSSION

Initially, it is noticed through the analysis of the selected articles that death has a great impact on various people who have some degree of proximity to it. However, the way of seeing it varies according to the culture in which the individual is inserted. In Western society, until the 18th century, a "good death" meant dying surrounded by loved ones, in a domestic environment. However, from that century, with the advance of rationalism, people began to die in hospitals, separating the dead from the living.[37]

It is necessary to create an appropriate environment for the discussion of grief, as people tend to resist, requiring an invitation or direct question to start the discussion. In this context, the individual in mourning can present a wide variety of feelings, including sadness, denial, anger and even the absence of reaction. It is noted that the influence of death is not limited to family members, but extends to health professionals, generating dilemmas, which worsen when the patient is a child.[38]

Thus, articles C1, C2 and C4 highlight the need for different health professionals to interact with each other, share information and, beyond the team, know how to communicate with the child's family, clarifying concepts such as palliative care. These studies coincide with previous literature, which establishes that when caring for the young public, palliative care needs to be composed of a multidisciplinary team in order to meet the demands of patients and their families.[39]

Both C1 and C2 clarify that the concept of palliative care is often associated with death and dying, perhaps due to a difficulty of the professional to initiate and establish direct communication with the parents and the child, according to C4. In addition, this reports, on the part of professionals, the feeling of being alone in the face of the questions of parents and children, once again reiterating the need for an integrative team in care.

Likewise, article C4 gives relevance to the need for communication between professionals, with the use of routine follow-ups and discussion of patient developments. This statement communicates with article C3, which emphasizes the difficulty for the professional to have to deal with the figure of the child and death, associated with the emotional wear and tear of the professional due to constant exposure to work activity. In this sense, a greater approximation between professionals would make the process of caring for the child less difficult, which would result in better treatment.

In the context of the child's illness, C7 and C8 comment that it is important for professionals to know how to talk to parents and help them understand the situation. In the meantime, C3, C5 and C6 bring up the consequences of not having the preparation that the situation requires: the professional can generate problems for the patient and family members, such as the intensification of the feeling of hopelessness and the lack of knowledge of how to guide parents to communicate with children about the finitude of life. Consequently, the palliative care process is hindered, which can prolong suffering and mourning.

The parents' point of view confirms the importance of an appropriate professional approach during the process of illness and loss. They tend to present greater grief or difficulty in dealing with loss when they do not receive adequate support.[40] In a study conducted by A5, 40% of the participating parents responded that they did not feel prepared to deal with the medical problems that the child faces and their emotional needs. Furthermore, in the research by A6, conducted with parents in the terminal care sector, the continuation and coordination of care was the area that received the most criticism, despite the general satisfaction of the parents with the care. Corroborating with A6, A7 studied the experience of parents with children facing cancer, revealing the fear of the unknown and the uncertainty of the future that these parents feel, which are aggravated by the indifference of local health professionals. In this sense, A9 and 10 show that a well-trained, sensitive team that is involved in the child's case can facilitate the process in view of the psychological stress that parents and family members face. Furthermore, it was shown that more experienced professionals convey more appropriate communication in the situation.[18] Concurrently, A4 and A8 highlight that the way parents deal with the finitude of their children's lives does not depend solely on what happens within hospitals, variations occur in the way of facing death according to culture, age, religion and involvement with spiritual activities, factors that indicate the need to manage the struggle process beyond the health sector, that is, with a holistic view.

Likewise, regarding the attempt to deal with the death of their children, A1 highlights that parents can adopt different strategies: denial of the loss of the child, starting to have self-centered behavior in themselves or in the family, such as planning trips with the sick child while he/she can still enjoy it. A11 showed another difficulty that parents face when communicating with their sick children about impending death, showing that clear communication was better accepted by grieving parents than those who did not address the topic. While the reviews by A3 and A1 demonstrate that health professionals are fundamental to help parents go through the grieving process, using mechanisms such as recognition of life between parents and children, establishment of memories, contacts, passing on information to parents and remembrance activities.

In the process of illness, the family experiences pain and difficult situations involving exams, hospitalizations, consultations, and treatments, which affect the physical and mental well-being of the members.[41] Thus, it is interesting to note the discussion in A2 about the best place to carry out the treatment: while some parents opted for home treatment, others opted for the hospital. Among the dissatisfactions with the hospital, the uncontrollable pain of the child, the fear of the hospital environment, and the desire to return home stood out, while the home environment had dissatisfactions related to pain and lack of support from the health team.

In general, the feeling that parents experience in the face of the loss of a child is indescribable. Some report an incomparable pain, the feeling of guilt amid the impotence to cure the child, and even a difference in the way the father or mother faces death, given that the man is tied to the role of providing material well-being for the child and must be strong, while the mother is responsible for providing affection.[42]

Lastly, it was evidenced that the child's view of loss differs from others in various aspects, due to the construction and development of consciousness and personality. Therefore, the analysis of the child's view of death becomes more complex, since part of the concepts and experiences that could clarify the idea of loss were not experienced by the child, which, evidently, can vary according to the emotional, sociocultural, and family influences that the child experiences at different periods of childhood.[37]

From this perspective, B6 showed the understanding of children and adolescents about death in four main points: universality, when the child understands that all living things die; irreversibility, the understanding that there is no reversal of death; non-functionality, the understanding that the body's functions cease in death; and causality, the knowledge that death has a cause.[26,43] The analysis of the child's understanding based on these four points allows for a more precise direction of the impact of death on the individual's life, as shown in B4.[35]

In this context, B2, B3, and B6 investigated the factors related to how children see death, indicating that most children have a biological view of it, but there are also traces of a metaphysical and psychological view varying between ages. B3 states that a greater biological knowledge about the end of life reduces the fear of this process and can facilitate reasoning about death. B7 showed that a child's reaction to death depends on their stage of life and their experiences, in addition to the factors surrounding them, such as school and interaction with health professionals, who are responsible for providing good communication and addressing the child's understanding of death for a good recovery. This is corroborated through interviews and analysis of drawings made by children, highlighted by B2, B4, and B5, which allow the perception that, for them, deaths are generally associated with external and realistic causes, such as accidents and violent causes, and as a state, a scene in a coffin, for example, demonstrating a character of causality and irreversibility at the end of life.

In addition, an emotional, metaphysical, and psychological load was described in some analyses. B2 brings, in the description of the children's drawings, death associated with emotions and feelings of sadness, anxiety, stress, and loneliness, and even with the religious and metaphysical perspective. Finally, B1, B3 and B5 bring the conclusion that the expression of this type of painful sensation in the face of the loss of close people is natural, even though the local culture treats death in a more present way.

Given the above, it is evident that greater knowledge about the understanding of children in different phases of childhood and in different sociocultural environments can improve assistance to problems eventually caused by loss. B6 showed that strategies for professionals such as communication skills training, directed learning, and dramatizations can help in situations like these. B8, in a systematic review, it was shown that principles such as personification, respectful attitude and respect for existential issues can honor the departure of a dead child and facilitate the grieving process. Finally, the article showed the need for increased communication from parents to children on the subject, adapting to the level of understanding and maturity of the child, with discussion in an honest and concrete way, in addition, of course, to the essential intense family support.[20,26]

From a clinical perspective, the study underscores the importance of institutionalizing family-centered care approaches, where families are actively involved in care planning and emotional support strategies. Such steps not only build trust between families and health teams but also ease the emotional weight on everyone, helping improve feelings during the time of loss.

This study had important limitations regarding the unspecificity and subjectivity of the topic and, consequently, the difficulty of generalizing the outcomes in a single approach, given the different methodologies and lines of thought of the articles included. Although the article's results are limited, it provides an overview of the situation faced by the individuals involved in the death of a child and the main needs in this scenario. Future work and research could circumvent these restrictions through a careful methodology, both in the inclusion of the sample and in a comparative and objective analysis of the views of each individual, in order to align the outcomes in an objective line of thought, with the main problems and possible solutions.

It should be noted that the articles included in this review do not address a single, standardized scenario of end-of-life in childhood. The situations reported vary considerably in terms of clinical context (such as chronic illnesses, cancer, palliative care, or sudden death), the structure of healthcare services, and sociocultural environments. This heterogeneity directly impacts the experiences of professionals, parents, and children in the face of death and must be taken into account when interpreting the results. In this way, undue generalization of the findings is avoided, and the need to contextualize the data within their specific realities is emphasized. Recognizing this diversity reinforces the complexity of the topic and the importance of sensitive approaches tailored to different circumstances of childhood finitude.

CONCLUSION

Through this integrative review, it is clear that the process of illness and mourning involving the death of a child has impacts related to health professionals, parents, and the children themselves. Professionals play an important role in dealing with the child as a patient, taking into account that they already have some degree of understanding of what death is, and properly guiding parents to understand the loss and go through the grieving process. In addition, it is noted that the different cultures and environments in which a family is inserted influence this entire moment, and can even make it lighter. Therefore, more research is needed highlighting these factors in different regions of the world in order to establish highlights of the strengths of each culture for dealing with death.

CONFLICT OF INTERESTS

The authors declare that there is no conflict of interests and this paper received no financial support.

REFERENCES

1. Brasil. Ministério da Saúde. Portaria nº 1130, de 5 de agosto de 2015. Institui a Política Nacional de Atenção Integral à Saúde da Criança (PNAISC) no âmbito do Sistema Único de Saúde (SUS) [internet]. Brasília; 2015 [cited 2024 April 15]. Available from: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2015/prt1130_05_08_2015.html.

2. Levin E. A infância em cena - constituição do sujeito e desenvolvimento psicomotor. 3º ed. Petrópolis: Vozes; 1997. 285p.

3. Kuhlmann M Junior. Uma história da infância: da idade média à época contemporânea no ocidente. Cad Pesqui. 2005;35(125):239–42.

4. Combinato DS, Queiroz MS. Morte: uma visão psicossocial. Estud psicol (Natal). 2006;11(2):209–16.

5. Kovácz MJ. O sofrimento da equipe de saúde no contexto hospitalar: cuidando do cuidador profissional. Mundo Saúde. 2010;34(4):420–9.

6. Kars MC, Grypdonck MH, Korte-Verhoef MC, Kamps WA, Meijer-van den Bergh EM, Verkerk MA, et al. Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. Support Care Cancer. 2011;19(1):27-35.

7. Downing J, Knapp C, Muckaden MA, Fowler-Kerry S, Marston J; ICPCN Scientific Committee. Priorities for global research into children's palliative care: results of an International Delphi Study. BMC Palliat Care. 2015;14:36.

8. Silveira RC, Galvão CM. O cuidado de enfermagem e o cateter de Hickman: a busca de evidências. Acta paul enferm. 2005;18(3):276–84.

9. Souza MT, Silva MD, Carvalho R de. Integrative review: what is it? How to do it?. Einstein. 2010;8(1):102–6.

10. Darlington AE, Korones DN, Norton SA. Parental coping in the context of having a child who is facing death: A theoretical framework. Palliat Support Care. 2018;16(4):432–441; doi: 10.1017/S1478951517000463.

11. Das K, Khanna T, Arora A, Agrawal N. Parents' acceptance and regret about end of life care for children who died due to malignancy. Support Care Cancer. 2020;28(1):303–8.

12. Kochen EM, Jenken F, Boelen PA, Deben LMA, Fahner JC, van den Hoogen A, et al. When a child dies: A systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. BMC Palliat Care. 2020;19(1):28.

13. Brooten D, Youngblut JM, Charles D, Roche R, Hidalgo I, Malkawi F. Death Rituals Reported by White, Black, and Hispanic Parents Following the ICU Death of an Infant or Child. J Pediatr Nurs. 2016;31(2):132–140.

14. Wiener L, Tager J, Mack J, Battles H, Bedoya SZ, Gerhardt CA. Helping parents prepare for their child's end of life: A retrospective survey of cancer-bereaved parents. Pediatr Blood Cancer. 2020;67(2):e27993.

15. Zimmermann K, Bergstraesser E, Engberg S, Ramelet AS, Marfurt-Russenberger K, Von der Weid N, et al. When parents face the death of their child: A nationwide cross-sectional survey of parental perspectives on their child's end-of life care. BMC Palliat Care. 2016;15:30. Erratum in: BMC Palliat Care. 2017;16(1):16.

16. Benedetti GM, Garanhani ML, Sales CA. The treatment of childhood cancer: unveiling the experience of parents. Rev Lat Am Enfermagem. 2014;22(3):425–431.

17. Hawthorne DM, Youngblut JM, Brooten D. Parent Spirituality, Grief, and Mental Health at 1 and 3 Months After Their Infant's/Child's Death in an Intensive Care Unit. J Pediatr Nurs. 2016;31(1):73–80.

18. Das MK, Arora NK, Chellani HK, Debata PK, Meena KR, Rasaily R, et al. Perceptions of the parents of deceased children and of healthcare providers about end-of-life communication and breaking bad news at a tertiary care public hospital in India: A qualitative exploratory study. PLoS ONE. 2021; 16(3): e0248661.

19. Verberne LM, Schouten-van Meeteren AY, Bosman DK, Colenbrander DA, Jagt CT, Grootenhuis MA, et al. Parental experiences with a paediatric palliative care team: A qualitative study. Palliat Med. 2017;31(10):956-963.

20. Kreicbergs U, Pohlkamp L, Sveen J. No impact of previous evidence advocating openness to talk to children about their imminent death. Acta Paediatr. 2021;110(5):1671-1672.

21. Fletcher J, Vidal-Fernandez M, Wolfe B. Dynamic and heterogeneous effects of sibling death on children's outcomes. Proc Natl Acad Sci U S A. 2018;115(1):115–120.

22. Bonoti F, Leondari A, Mastora A. Exploring Children's Understanding of Death: Through Drawings and the Death Concept Questionnaire. Death Stud. 2013;37(1):47–60.

23. Gutiérrez IT, Menendez D, Jiang MJ, Hernandez IG, Miller P, Rosengren KS. Embracing Death: Mexican Parent and Child Perspectives on Death. Child Dev. 2020;91(2):e491–e511.

24. Yang S, Park S. A Sociocultural Approach to Children's Perceptions of Death and Loss. Omega (Westport). 2017;76(1):53–77.

25. Silva FM, Lopes AF, Carneiro V, Campelo Á. Preschool children's emotional understanding of death: A forgotten dimension. Acta Med Port. 2020;33(10):649–656.

26. Bates AT, Kearney JA. Understanding death with limited experience in life: Dying children's and adolescents' understanding of their own terminal illness and death. Curr Opin Support Palliat Care. 2015;9(1):40–45.

27. Chachar AS, Younus S, Ali W. Developmental Understanding of Death and Grief Among Children During COVID-19 Pandemic: Application of Bronfenbrenner's Bioecological Model. Front Psychiatry. 2021;12:654584.

28. Persson M, Hildingsson I, Hultcrantz M, Kärrman Fredriksson M, Peira N, Silverstein RA, et al. Care and support when a baby is stillborn: A systematic review and an interpretive meta-synthesis of qualitative studies in high- income countries. PLoS ONE. 2023;18(8): e0289617.

29. De Clercq E, Rost M, Rakic M, Ansari M, Brazzola P, Wangmo T, et al. The conceptual understanding of pediatric palliative care: A Swiss healthcare perspective. BMC Palliat Care. 2019;18(1):55.

30. Szymczak JE, Schall T, Hill DL, Walter JK, Parikh S, DiDomenico C, et al. Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor. J Pain Symptom Manage. 2018;55(5):1260–1268.

31. Santos RA, Moreira MC. Resilience and death: The nursing professional in the care of children and adolescents with life-limiting illnesses. Cien Saude Colet. 2014;19(12):4869–4878.

32. Hendricks-Ferguson VL, Sawin KJ, Montgomery K, Dupree C, Phillips-Salimi CR, Carr B, et al. Novice Nurses' Experiences With Palliative and End-of-Life Communication. J Pediatr Oncol Nurs. 2015;32(4):240–252.

33. Af Sandeberg M, Bartholdson C, Pergert P. Important situations that capture moral distress in paediatric oncology. BMC Med Ethics. 2020;21(1):6.

34. Silva AF, Issi HB, Motta Mda G, Botene DZ. Palliative care in paediatric oncology: perceptions, expertise and practices from the perspective of the multidisciplinary team. Rev Gaucha Enferm. 2015;36(2):56–62.

35. Riiser K, Holmen H, Winger A, Steindal SA, Castor C, Kvarme LG, et al. Stories of paediatric palliative care: a qualitative study exploring

health care professionals' understanding of the concept. BMC Palliat Care. 2022;21(1):187.

36. Gilleland JC, Parshuram CS. Discussing Death as a Possible Outcome of PICU Care. Pediatr Crit Care Med. 2018;19(8S Suppl 2):S4-S9.

37. Diniz AS. A iconografia do medo: imagem, imaginário e memória da cólera no século XIX. 1º ed. In: Koury MGP, org. Imagem e memória: ensaios em antropologia visual. Rio de Janeiro: Garamond; 2001. 113-50p.

38. Mughal S, Azhar Y, Mahon MM, et al. Grief Reaction and Prolonged Grief Disorder. Treasure Island (FL): StatPearls Publishing; 2024 [cited 2024 April 15]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK507832/.

39. Costa TF, Ceolim MF. Nursing in palliative care to children and adolescents with cancer: integrative literature review. Rev Gaucha Enferm. 2010;31(4):776–84.

40. Champion MJ, Kilcullen M. Complicated Grief Following the Traumatic Loss of a Child: A Systematic Review. Omega (Westport). 2025;91(4):2142-2164.

41. Menezes CN, Passareli PM, Drude FS, Santos MA, Valle ER. Câncer Infantil: Organização Familiar e Doença. Rev. Mal-Estar Subj. 2007;7(1):191-210.

42. Reis CG, Olesiak LR, München MA, Quintana AM, Farias CP. O luto de pais: considerações sobre a perda de um filho criança. Psicol. cienc. prof. 2021;41(spe3):e196821.

43. Kenyon BL. Current Research in Children's Conceptions of Death: A Critical Review. Omega J. Death Dying. 2001;43(1):63–91.

How to cite:
Prado ML, Melo AN, Lopes VA, Mendonça AV. Paradox of innocence: understanding of death in childhood for children, their parents and health professionals. Rev Med UFC. 2026;66:93359.