

## SYSTEMATIC REVIEW ARTICLE

# The experience of parents accompanying their children in pediatric palliative care: Scoping review


*A experiência dos pais que acompanham os filhos em cuidados paliativos pediátricos: Scoping review*

*La experiencia de los padres que acompañan a sus hijos en cuidados paliativos pediátricos: Scoping review*

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## Abstract

**Background:** Parents accompanying their children with complex chronic diseases until death experience an extreme and complex situation, which renders them vulnerable. It is a situation experienced individually and with specific needs.

**Objective:** To explore and map the available scientific evidence on parents' experiences accompanying their children with complex chronic diseases until death in pediatric palliative care settings.

**Review method:** A scoping review was prepared according to the methodology of the Joanna Briggs Institute. Two researchers conducted the articles' analysis and extraction and the data synthesis.

**Presentation and interpretation of the results:** Eight studies were identified. They were published between 2016 and 2020, and none was conducted in Portugal. The studies allowed observing that parents' "Fighting Spirit," associated with their "Suffering" and "Hope," is only broken by their children's death and that parents report the need for "Support in Grief."

**Conclusion:** The eight studies present results describing parents' experiences. Further studies are recommended to understand the specificity of these parents' experiences in this context.

**Keywords:** palliative care; experience; parents; review

## Resumo

**Contexto:** Os pais que acompanham os filhos com doença crónica complexa até à sua morte experienciam uma situação limite e complexa com vulnerabilidades e que é vivida de forma individual e com necessidades específicas.

**Objetivo:** Explorar e mapear a evidência científica disponível sobre a experiência dos pais que acompanharam os filhos com doença crónica complexa até à sua morte, num contexto de cuidados paliativos pediátricos.

**Metodo de revisão:** Foi elaborada uma *scoping review*, segundo a metodologia proposta pelo *Joanna Briggs Institute*. A análise dos artigos, extração e síntese dos dados foi feita por dois revisores.

**Apresentação e interpretação dos resultados:** Foram identificados oito estudos, publicados entre 2016 e 2020, nenhum realizado em Portugal. O Espírito de Luta associado a sentimentos de Sofrimento e de Esperança é experienciado pelos pais, sendo quebrado pela morte da criança. É referenciada a necessidade de Apoio no Luto.

**Conclusão:** Oito estudos incluídos apresentam resultados que caracterizam a experiência dos pais. Mais estudos devem ser realizados para compreender a especificidade da experiência destes pais neste contexto.

**Palavras-chave:** cuidados paliativos; experiência; pais; revisão

## Resumen

**Contexto:** Los padres que acompañan a sus hijos con una enfermedad crónica compleja hasta su muerte viven una situación limitante y compleja con vulnerabilidades, y que se vive de forma individual y con necesidades específicas.

**Objetivo:** Explorar y mapear la evidencia científica disponible sobre la experiencia de los padres que acompañaron a sus hijos con enfermedades crónicas complejas hasta su muerte en un entorno de cuidados paliativos pediátricos.

**Método de revisión:** Se elaboró una revisión de alcance (*scoping review*), según la metodología propuesta por el *Joanna Briggs Institute*. El análisis de los artículos, la extracción y la síntesis de los datos lo llevaron a cabo dos revisores.

**Presentación e interpretación de los resultados:** Se identificaron ocho estudios, publicados entre 2016 y 2020, ninguno de ellos realizado en Portugal. Los padres experimentan el Espíritu de Lucha asociado a los sentimientos de Sufrimiento y Esperanza, que se rompe con la muerte del hijo. También se mencionó la necesidad de Apoyo al Duelo.

**Conclusión:** Ocho estudios incluidos presentan resultados que caracterizan la experiencia de los padres. Deberían realizarse más estudios para comprender la especificidad de la experiencia de estos padres en este contexto.

**Palabras clave:** cuidados paliativos; experiencia; padres; revisión



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## Introduction

In recent decades scientific and technological development has led to the evolution of the health area, changing the profile of patients and diseases. Undeniable progress has also occurred in child health and pediatrics, enabling more developed and differentiated care while allowing some children with complex chronic diseases (CCDs) to live longer (Barbosa et al., 2016; Capelas et al., 2019; Lacerda & Gomes, 2017).

CCD is understood as any life-limiting condition that can last at least 12 months (unless death occurs), severely affecting one or more organs, and for which there is no hope of a cure. It demands specialized, long-term, interdisciplinary pediatric health care and probably some period of hospitalization in a tertiary care center (Feudtner et al., 2000; Feudtner et al., 2014).

Currently, palliative care (PC) is no longer on the opposite side of curative care. Integrating the two models, curative and palliative, can provide a better quality of life for children with CCDs and their families needing differentiated and multidisciplinary health care (Lacerda & Gomes, 2017). Pediatric palliative care (PPC) is an inter- and multidisciplinary intervention model involving individualized, child-focused, family-oriented care. It respects the child's and family's beliefs and values. The model is built on a good relationship with the healthcare team and aimed at improving the quality of life of sick children, their families, and caregivers and extending after the child's death, i.e., during parental and family bereavement (Barbosa et al., 2016; Himelstein, 2006; International Association for Hospice and Palliative Care, 2018).

The impact of a CCD diagnosis on parents cannot be measured. Parents face the challenges of the complexity of the disease and the near-death condition of their children, sparing no effort to help them celebrate life and fill their memories with resilience, hope, and positive relationships (David et al., 2016; Dutta et al., 2020; Melin-Johansson et al., 2014; Verberne et al., 2019).

Children with CCDs, often dependent on technology for survival, demand differentiated, continuous, and expensive health care, usually provided by parents and supported by health care professionals. These respect and recognize parents' role as caregivers, and value their concerns about their sick children's well-being, ensuring they are treated as unique individuals rather than someone with a disease (Black et al., 2016; David et al., 2016; Melin-Johansson et al., 2014).

Parents who accompany and care for their children live with CCDs permanently, coping with difficult situations, such as making decisions about treatments, and dealing with the surprises and disappointments associated with hope and hopelessness regarding their children's future. Simultaneously, these parents experience dual feelings, as they need to manage their emotional state and also support their sick child, a responsibility that extends to the rest of the family (Black et al., 2016; Björk et al., 2016; David et al., 2016; Melin-Johansson et al., 2014; Verberne et al., 2019).

Mothers are the primary caregivers, delivering complex

child-centered care. As they are often unable to fulfill other family responsibilities, mothers have to sometimes rely on the support of their immediate family to maintain their quality of life and that of their children, with an inevitable change in the family dynamics (Black et al., 2016; Melin-Johansson et al., 2014; Verberne et al., 2019). Despite the relevance of the experience of accompanying one's child with CCD until death, some authors (Collins et al., 2016; Dutta et al., 2020; Melin-Johansson et al., 2014; Verberne et al., 2019) mention the need for further studies on the phenomenon. These must recognize these parents' needs and understand the uniqueness of their experience, valuing their role as parents and caregivers. An initial search on the Joanna Briggs Institute (JBI) Evidence Synthesis, the Cochrane Database of Systematic Reviews (CDSR), and PubMed revealed that there were currently no scoping reviews in progress on parents' experiences accompanying their children with CCDs until death.

Thus, the decision was made to prepare a scoping review, guided by the JBI (2020) methodology and aimed at systematically exploring and mapping the evidence available in the literature on parents' experiences accompanying their children with CCDs until death in a PPC setting. More specifically, this review aims to answer the following question: How is the experience of parents accompanying their children with CCDs until death in a PPC setting?

## Systematic review method

This scoping review followed the JBI methodology, with the PCC (participants, concept, and context) method being used with the following inclusion criteria:

### Inclusion criteria

#### *Participants*

Parents (mother and/or father) who accompanied their children (0-18 years old) with CCDs until death in PPC.

#### *Concept*

All studies consider parents' experiences accompanying their children with CCD until death in PPC.

#### *Context*

Hospital and/or home-based PC setting.

#### *Study design*

This scoping review included quantitative, qualitative, mixed-method studies, and literature reviews. Master's theses and/or doctoral dissertations were also considered, given their importance in the grey literature research review.

## Search strategy

The search strategy included studies written in English, Spanish and Portuguese, published and unpublished between March 2013 and 2021. This period was selected because an integrative literature review was identified



using the exact requirements of this scoping review in the initial search. The search for this integrative literature review was conducted in January and February 2013, with no time limit (Melin-Johansson et al., 2014).

The databases searched were MEDLINE (via PubMed), CINAHL Complete (via EBSCO), Scopus, and the Cochrane Library. The RCAAP - Open Access Scientific Repositories of Portugal was used to search for unpublished studies (master's theses and doctoral dissertations).

This review used a three-step search strategy: Initial search limited to MEDLINE (via PubMed) and CINAHL (via EBSCO) databases to analyze and group the most commonly used words in articles' titles and abstracts. A second search using identified keywords and index terms was carried out in the included databases. Third and finally, the references of all identified articles and studies were reviewed to search for and include additional studies. The search results were exported to Mendeley® reference management software, and duplicate articles were removed. Next, the searched articles were screened considering their relevance to the review based on the information from reading the title and abstract. The full texts of studies meeting the inclusion criteria were retrieved and read following the review process.

Two reviewers independently examined the selected studies' full texts during all stages to verify that all of them met the previously defined inclusion criteria. A third

reviewer was used for final decisions in cases where there were differences.

#### **Data extraction**

The data extraction process provides a logical and descriptive summary of the results that align with the objectives and questions of scoping reviews (Peters et al., 2020). The data extraction of eligible studies was performed by two independent reviewers using an instrument designed by the authors for this purpose and considering the review's objective and question.

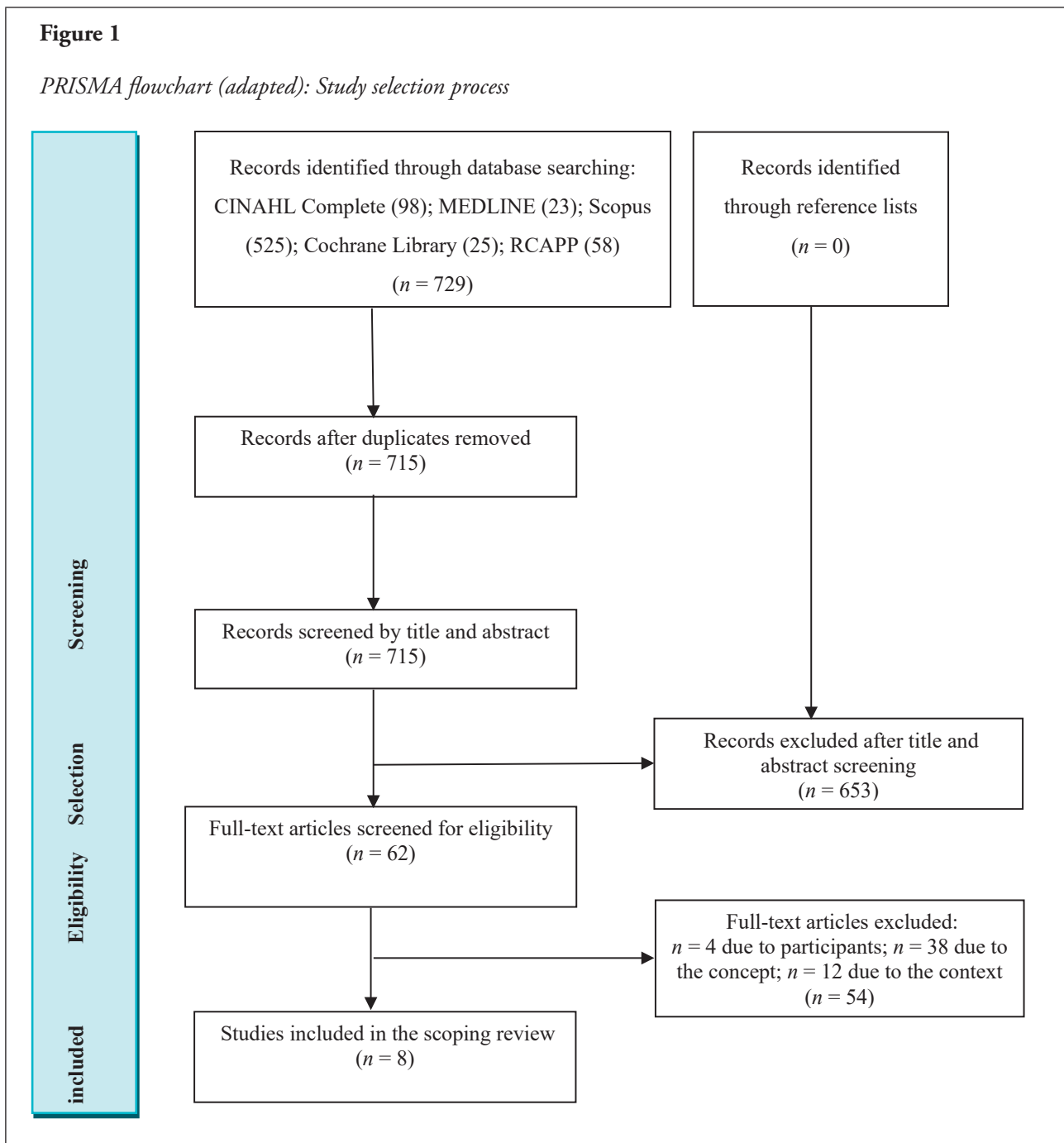
#### **Presentation of results**

Scoping reviews' results can be presented as charts, figures, and/or tables to map the data extracted from the included articles according to the previously defined objectives (Peters et al., 2020).

From the initially identified 729 references in the search, 14 were excluded because they were duplicates. After the screening by title and abstract, 653 were excluded from the remaining 715. After the studies' full texts were read, 54 were excluded from the remaining 62 for not meeting the inclusion criteria. Finally, eight studies describing the experiences of parents who accompanied their children with CCDs until death in PPC settings were included (Figure 1).

**Figure 1**

PRISMA flowchart (adapted): Study selection process



The eight included studies came from different world regions and were published between 2016 and 2020. Two are European (Björk et al., 2016; Zimmermann et al., 2016), two Asian (Dutta et al., 2020; Wang et al., 2019), one Australian (Collins et al., 2016), and three are from North America (Lord et al., 2020; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Sedig, Spruit, Paul, Cousino, Pituch, et al., 2020).

All studies considered the participants as caregivers, a role coincident with being parents (Björk et al., 2016; Collins et al., 2016; Dutta et al., 2020; Lord et al., 2020; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Sedig, Spruit, Paul, Cousino, Pituch, et al., 2020; Wang et al., 2019; Zimmermann et al., 2016;).

Regarding methodology, two are quantitative studies (Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Zimmermann et al., 2016), and the remaining six are qualitative, of which three are phenomenological research studies (Björk et al., 2016; Collins et al., 2016; Wang et al., 2019).

Although all the studies presented the PPC setting, some were conducted exclusively with parents of children with cancer (Björk et al., 2016; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Wang et al., 2019).

In all studies, the period for data collection/interviewing the bereaved parents was never less than six months after their children's death. The characteristics of the included studies are presented in Table 1.

**Table 1***Description of the included studies*

Authors	Title	Year	Country	Methodology	Participants
Dutta et al. (2020)	“Trauma to Transformation: the lived experience of bereaved parents of children with chronic life-threatening illnesses in Singapore”	2020	Singapore	Qualitative	31 parents
Sedig, Spruit, Paul, Cousino, McCaffery, et al.(2020)	“Supporting Pediatric Patients and Their Families at the End of Life: Perspectives From Bereaved Parents”	2020	United States of America	Quantitative	28 parents
Lord et al.(2020)	“Assessment of Bereaved Caregiver Experiences of Advance Care Planning for Children With Medical Complexity”	2020	Canada	Qualitative	13 parents (12 mothers and one father)
Sedig, Spruit, Paul, Cousino, Pituch et al.(2020)	“Experiences at the End of Life From the Perspective of Bereaved Parents: Results of a Qualitative Focus Group Study”	2020	United States of America	Qualitative	12 parents
Wang et al. (2019)	“The experience of parents living with a child with cancer at the end of life”	2019	Taiwan	Qualitative	Ten parents (six mothers and four fathers)
Collins et al. (2016)	“Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study”	2016	Australia	Qualitative	14 parents
Björk et al.(2016)	“Like being covered in a wet and dark blanket – Parents’ lived experiences of losing a child to cancer”	2016	Sweden	Quantitative	Six parents (three mothers and three fathers)
Zimmermann et al. (2016)	“When parents face the death of their child: a nationwide cross-sectional survey of parental perspectives on their child’s end-of-life care”	2016	Switzerland	Quantitative	124 families of children

**Interpretation of results**

Table 2 describes the experiences of parents who lost their children with CCDs in PPC settings in the eight studies included in this scoping review. Parents’ experiences are characterized by their *fighting spirit* throughout the process of their children’s incurable disease, accompanied by struggles, hope, and suffering (Björk et al., 2016; Wang et al., 2019; Dutta et al., 2020)

Regarding their experience, parents also report difficulties in adapting to PPC settings, as they associate PPC with the end of their fighting spirit and giving up on their child (Björk et al., 2016; Wang et al., 2019).

Parents value shared decision-making throughout their children’s CCD process (Collins et al., 2016; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Zimmermann et al., 2016).

Parents consider interventions supporting the complex needs of the whole family are required, particularly regarding care coordination, as these constitute an opportunity to improve end-of-life care and associated quality of life (Collins et al., 2016; Sedig, Spruit, Paul, Cousino, Mc-

Caffery, et al., 2020; Zimmermann et al., 2016).

The experiences of parents accompanying and caring for their children are marked by the multiple and successive losses they go through during the disease process (Lord et al., 2020; Sedig, Spruit, Paul, Cousino, Pituch, et al., 2020), and the negative impact on their health and well-being associated with their physical and social isolation and withdrawal from the labor market (Collins et al., 2016).

The child’s death is an impactful and traumatizing event for parents, who perceive it as an irreversible loss (Dutta et al., 2020; Lord et al., 2020). Nevertheless, they also view it as a manner of maintaining their parenthood and an end to their suffering (Björk et al., 2016; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Wang et al., 2019).

Parents also mention that having more support for their Bereavement process would have been helpful (Collins et al., 2016; Sedig, Spruit, Paul, Cousino, McCaffery, et al., 2020; Zimmermann et al., 2016;). In the narrative of their bereavement experience, parents report that they found a new perspective on life and personal growth

through helping others and also meaning in the loss of their child (Dutta et al., 2020). Moreover, this review's results demonstrate that parents value a compassionate PPC approach and consider that their needs should be met based on the understanding of

their experience of accompanying their child until death. The review found no studies in Portugal on this theme, a gap that future research should address. Table 2 shows the answers to this review's research question per study.

**Table 2**

*Answers to the review's research question per study*

Study	Parents' experiences
Dutta et al. (2020)	In their narratives, parents associate caring for a child with a life-threatening CCD with "batting a dragon." In their grieving process, parents resorted to rituals/ behaviors to overcome the loss and mention the possibility of personal growth through the positive results of their experience in the care and illness process due to their inclusion in the care system as caregivers. They describe their children's death as a void that can never be filled. Despite their child's absence, parents consider it necessary to "maintain the everlasting bonds" with their parenthood. They discovered a new perspective on life and personal growth through helping others and finding meaning in the loss of their child by attending support groups that bring them closer to other parents with similar experiences. During their children's end-of-life hospitalization, parents mention the need to feel health care professionals' compassion during care delivery as a demonstration of respect for their children.
Sedig, Spruit, Paul, Cousino, McCaffery, et al.(2020)	Most bereaved parents (61%) wish to have had shared decision-making in their children's illness process. The association between acceptance of death and parental perception of actual decision-making is aligned with the desired decision-making. Parents report the need to have bereavement support. Only 22% of parents resorted to the available support services (psychological and psychiatric consultations), but participants consider that using support services can be helpful in their grieving process.
Lord et al.(2020)	Parents as caregivers emphasize the multiple and successive losses experienced throughout their children's disease process. They highlight the impact of the moment of death and that the health care team should value parents' experience in caring for their children throughout the disease process.
Sedig, Spruit, Paul, Cousino, Pituch et al.(2020)	The themes most highlighted by parents are the recognition of the communication qualities of the providers, their loss of control in the hospital environment, the challenges associated with the transition of care to hospice services, and end-of-life care coordination within the health care team. Parents mention the need for interventions that support the complex demands of a family receiving end-of-life care, particularly regarding care coordination as an opportunity to improve end-of-life care.
Wang et al. (2019)	The two major themes identified in the parents' narratives are 1) Fighting spirit and 2) Acceptance of their children's death. The "Fighting Spirit" involves parents' immersion in the struggle and suffering, including conflicts and arguments, witnessing their children's suffering, and denying their children's presence in PPC because they expect a miracle. In the "Acceptance of death" parents report the end of suffering, living in the moment, discussing death, and letting go. Parents demonstrate difficulties adapting to a PC setting because they misperceive it as giving up on their children. Religion and beliefs also play significant roles throughout the entire process of their children's incurable cancer.
Collins et al. (2016)	Parents relate their experiences to physical and social isolation, exclusion from the workforce, pervasive grief, and associated impacts on their health and well-being. Limited professional and diminished social support results in parents' full ownership of care responsibility. Nevertheless, parents embrace their role as caregivers. Parents highlight the need to seek physical and emotional support beyond what is available and call for implementing planned support services and other social initiatives to alleviate the impacts on caregivers' health and quality of life.
Björket al.(2016)	The parents' experiences are characterized by not understanding their children's incurability, parenthood after death, and adapting to life in the absence of their child. Parents' experiences throughout their children's illness include their fighting spirit and feelings of Hope (for a miracle) and Suffering. Parents feel that death is the end of suffering and acceptance of their children's end of life. PPC is mentioned as determining in parents' grieving process. Parents assimilate the lived experience of their children's illness process into their new life by maintaining their memory and alleviating the sadness of their loss. When adapting to life without their children, parents demonstrate a change of priorities, devaluing material issues and exhibiting new perspectives in life.
Zimmermann et al. (2016)	The parents' experiences are described as positive and/or negative, associated with their quality of life, and linked to themes such as communication, care satisfaction, support for the family unit, shared decision-making, alleviation of suffering and other symptoms, continuity of care coordination, and bereavement support.

## Conclusion

This scoping review aims to explore and map the available scientific evidence on parents' experiences accompanying their children with CCDs until death in PPC settings. This review has limitations. The studies included were published only in English, Portuguese and Spanish, and including articles in other languages could have added value to this review. Also, an extended search of other databases could have been significant in identifying other relevant results.

Eight studies from various regions of the world were identified, with no Portuguese studies being found.

Parents value a compassionate PPC approach that involves health professionals who genuinely understand and address their concerns and losses through child- and family-focused action plans. It is crucial to implement interventions that support the complex needs of parents during end-of-life care, particularly regarding care coordination.

Throughout the illness process, the parents' fighting spirit, associated with their struggle, suffering, and hope, was only broken by their children's death, described as an irreversible loss. Parents also express the need for support throughout the process, particularly in grief.

Further studies should be conducted to understand the specificity and uniqueness of these parents' experiences in this context.

### Author contributions

Conceptualization: Correia, M. E., Botelho, M. A., Magão, T. M.

Data curation: Correia, M. E.

Supervision: Botelho, M. A., Magão, T. M.

Visualization: Correia, M. E., Botelho, M. A., Magão, T. M.

Validation: Botelho, M. A., Magão, T. M.

Writing—original draft: Correia, M. E.

Writing—review and editing: Botelho, M. A., Magão, T. M.

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