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Experiences of Family Caregivers of Children Aged 1–23 Months Who Have Received Pediatric Palliative Care: A Systematic Review With Qualitative Metasynthesis

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ABSTRACT

Introduction: Family caregivers of children receiving pediatric palliative care (PPC) play a crucial role in their care and wellbeing, especially during the early stages of life.

Objective: To explore the experience of family caregivers of children aged 1–23 months who are receiving pediatric palliative care (PPC).

Methods: A systematic review of qualitative studies was conducted using the databases PubMed, Scopus, Web of Science, CINAHL, PsycINFO, and Cuiden. The studies were appraised using the Critical Appraisal Skills Programme tool. The selected studies were synthesized using Noblit and Hare's meta-ethnographic method.

Results: Eleven studies, 169 themes, 36 metaphors and four main themes were identified. Caregivers develop coping strategies related to meaning-making, faith, maintaining hope, and decision-making abilities. They perceive limited time with the child due to structural constraints and the child's deteriorating health, which sometimes prevents them from recognizing their child's identity. Caregivers strive to remain united and rebuild the daily family life they long for, but face challenges related to self-care, maintaining employment, and caring for siblings and their partner. In many cases, they are unsatisfied with the care they receive, attributed to a lack of technical training and understanding of the principles of pediatric palliative care (PPC) by healthcare staff, poor communication skills, and inadequate coordination. Caregivers highlight the role of nurses and the PPC team, advanced care planning, and post-mortem care as positive aspects.

Discussion/Conclusion: Caregivers' experiences reveal coping strategies, active decision-making, constant challenges, healthcare interactions, and a need for improved comprehensive support.

Clinical Relevance: This study underscores the importance of addressing the unique needs of family caregivers of children aged 1–23 months receiving pediatric palliative care (PPC), highlighting their struggles with social isolation, neglected self-care, and disrupted family life. Healthcare providers should prioritize age-specific approaches to PPC, focusing on improving communication, care coordination, and understanding of palliative care principles to better support these caregivers.

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1 | Introduction

Pediatric palliative care (PPC) involves comprehensive care for the child, starting from the diagnosis of a life-limiting illness and continuing regardless of whether curative treatment is received (Improving Palliative Care for the World's Children n.d.).

Approximately 21 million children worldwide require pediatric palliative care (PPC) each year, with the most affected being those with congenital anomalies (25.06%), protein-energy malnutrition (14.12%), meningitis (12.62%), HIV/AIDS (10.23%), cardiovascular diseases (6.18%), cancer (5.69%), and neurological disorders (2.31%) (World Health Organization 2018).

The number of children eligible for pediatric palliative care (PPC) is increasing globally. A recent study projects that there will be 84.2 cases per 10,000 children by 2030, with around 85% of these children suffering from non-oncological diseases (Benini et al. 2022). However, the development of pediatric palliative care (PPC) worldwide remains limited. A study evaluating the state of pediatric palliative care (PPC) in 113 countries concludes that 25.3% provide isolated services, while 10.6% have no recorded activity (Clelland et al. 2020).

Children have specific characteristics and care needs. Those receiving pediatric palliative care (PPC) often do so early, sometimes from birth, and in many cases, palliative care continues throughout their life, becoming embedded in their physical, psychological, and social development (World Health Organization 2018).

The presence of a serious illness in a child affects the entire family unit, leading to changes in daily routines and family dynamics, with parents assuming the primary caregiving role (Improving Palliative Care for the World's Children n.d.).

Family caregivers play a crucial role in pediatric palliative care (PPC) (Chelazzi et al. 2023). They are involved in care, planning, and decision-making, medication management, adapting to functional needs, identifying warning signs and symptoms, obtaining technical aids, and coordinating care (Srivastava and Srivastava 2022).

As care demands increase, the burden on family caregivers grows, leading to overwhelming responsibilities, social isolation, and physical and psychological issues (Srivastava and Srivastava 2022). After the child's death, caregivers may experience complicated grief, physical pain, exhaustion, lack of concentration, difficulty resting, and intrusive thoughts, often requiring professional support (Rud et al. 2023).

Nurse plays an essential role in supporting primary caregivers, not only in the direct management of the child's care but also in their training. It is crucial that the nurse, within their professional role, not only educates the caregiver in technical aspects such as medication administration or symptom control but also provides emotional support, offering tools and strategies to cope with the caregiving situation at home. The nurse's support is key to ensuring that the caregiver can perform their tasks autonomously and safely, providing quality care to both the patient and themselves (Chocarro González et al. 2021). In this regard, the document *International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS* (Benini et al. 2022) establishes as an international standard that, for children to receive 24/7 care at home, caregivers must be adequately trained.

It is therefore necessary to delve deeper into the experiences of family caregivers of children receiving pediatric palliative care (PPC). To date, several reviews have explored the experiences of parents of children receiving home-based pediatric palliative care (PPC) (Tutelman et al. 2021; Winger et al. 2020) and in various settings (Barrett et al. 2023), but none have distinguished by age. This lack of differentiation poses a significant bias, as although some factors may be shared, caring for a neonate receiving pediatric palliative care (PPC) is vastly different from caring for an adolescent. Understanding the specificity of these cases can be useful for the development of the work of the multidisciplinary team that works with the children and their caregivers, specifically the nurse who will accompany them during their adaptation process and learning in caregiving throughout their lives.

This review focused on the lived experiences of informal caregivers of children aged 1–23 months. Children of this age are entirely dependent on their caregivers, with parents acting as primary providers of healthcare, nutrition, stimulation, learning opportunities, and protection—factors essential for healthy brain development (UNICEF 2021; World Health Organization 2020).

Moreover, the metasynthesis approach enables a deeper understanding of the complexity of caregiver experiences in the pediatric palliative care (PPC) context by identifying common patterns and recurring themes, thus enhancing the comprehension of shared caregiver experiences. Additionally, metasyntheses can highlight areas where research is lacking, pointing to the need for future studies and advancing current knowledge on pediatric palliative care (PPC).

2 | Methods

2.1 | Design

This is a systematic review of qualitative studies and interpretative synthesis following the meta-ethnographic approach developed by Noblit and Hare (1988). Meta-ethnography is an inductive method that involves continuous comparisons of the concepts found in various qualitative studies, with the aim of facilitating a critical appraisal of the phenomenon and drawing common conclusions (Noblit and Hare 1988).

2.2 | Study Selection and Critical Appraisal

Original qualitative or mixed-methods studies on the experiences of family caregivers of children aged 1–23 months in pediatric palliative care (PPC), published in English, Spanish, or Portuguese in the past 10 years (2013–2023), were identified. The search was conducted between November and December 2023 in the databases PubMed, Scopus, Web of Science, CINAHL, PsycINFO, and Cuiden. The search terms and equations used for each database are specified in Table 1.

TABLE 1 | Search strategies used in each database.

Database	Search equation	Filters
PubMed	("Palliative Medicine"[Mesh]) OR "Palliative Care"[Mesh] OR "Terminal Care"[Mesh]) AND "Infant"[Mesh] AND "Qualitative Research"[Mesh]	Publication date: Last 10 years (from 2013 to 2023)
Scopus	(TITLE-ABS-KEY("Palliative Medicine") OR TITLE-ABS-KEY("Palliative Care") OR TITLE-ABS-KEY("Terminal Care")) AND TITLE-ABS-KEY("Infant") AND TITLE-ABS-KEY("Qualitative Research")	Publication date: Last 10 years (from 2013 to 2023)
Web of Science	((TS = (Palliative Medicine) OR TS = (palliative care) OR TS = (terminal care)) AND TS = (infant) AND TS = (family) AND TS = (qualitative research)	Publication date: Last 10 years (from 2013 to 2023)
PsycINFO	((Palliative Medicine) OR (palliative care) OR (terminal care)) AND infant AND (qualitative search)	Publication date: Last 10 years (from 2013 to 2023). Language: English, Spanish. Methodology: Qualitative study. Age group: Neonatal (birth-1 month) and infancy (2–23 months).
CINAHL	(palliative care or terminal care) AND infant AND family AND qualitative research	Publication date: Last 10 years (from 2013 to 2023)
Cuiden	[cla = "Cuidados paliativos"] and [cla = "Salud infantil"]	Publication date: Last 10 years (from 2013 to 2023)

Source: Prepared by the authors.

The Rayyan tool (Ouzzani et al. 2016) was used for the article selection process, and the PRISMA model (Moher et al. 2009) was followed. After removing duplicates, a preliminary selection was made based on title analysis, followed by an assessment of the abstract content of each article. Each text was then read in full. This final step was carried out by two researchers independently, with a third researcher resolving any disagreements. Eleven studies out of a total of 429 were selected after successive screenings (Figure 1).

Data extracted and tabulated from the studies included: authors, design, country, sample size, age, illness, population, setting, data collection, and main findings.

The CASPe (Critical Appraisal Skills Programme Español) tool (Critical Appraisal Skills Programme 2018) was used for critical appraisal, consisting of 10 questions related to methodological quality, relevance, and applicability of the findings from the qualitative studies. Two researchers independently conducted the appraisal of the selected studies, with any discrepancies resolved by a third researcher.

2.3 | Synthesis of the Selected Studies

The selected studies were synthesized using Noblit and Hare's seven-stage method (Noblit and Hare 1988). In the first stage, the main theme was identified as the experience of caregivers of children aged 1–23 months receiving pediatric palliative care (PPC). In the second stage, high-quality qualitative or mixed-method studies that met the inclusion criteria were selected.

In the third stage, quotes from informants (first-order constructs) and the descriptions or interpretations made by the authors (second-order constructs) were extracted and imported into Atlas.ti software for review. Key metaphors (second-order constructs) were then identified, and similarities were created between the study findings. The most prevalent metaphors and those including controversial or refutational aspects were identified.

In the fourth and fifth stages, the concepts obtained in the previous stage were grouped into themes and categories (third-order constructs). Finally, a final synthesis was conducted, reconceptualizing the findings into a new interpretation and generating an explanatory model based on the data obtained from each study. The analysis was carried out by three of the authors of this study and subsequently triangulated by the rest of the researchers.

The study was registered in PROSPERO (International Prospective Register of Systematic Reviews) under registration number CRD42024502418.

3 | Results

3.1 | Description of the Studies

The 11 articles were published in English, except for one, which was written in Portuguese (Fiterman Lima et al. 2020). Nine studies employed qualitative methodology, and two used mixed methods (Gilmer et al. 2013; Engler et al. 2019). The studies were conducted in the Netherlands (Falkenburg et al. 2016; Verberne,

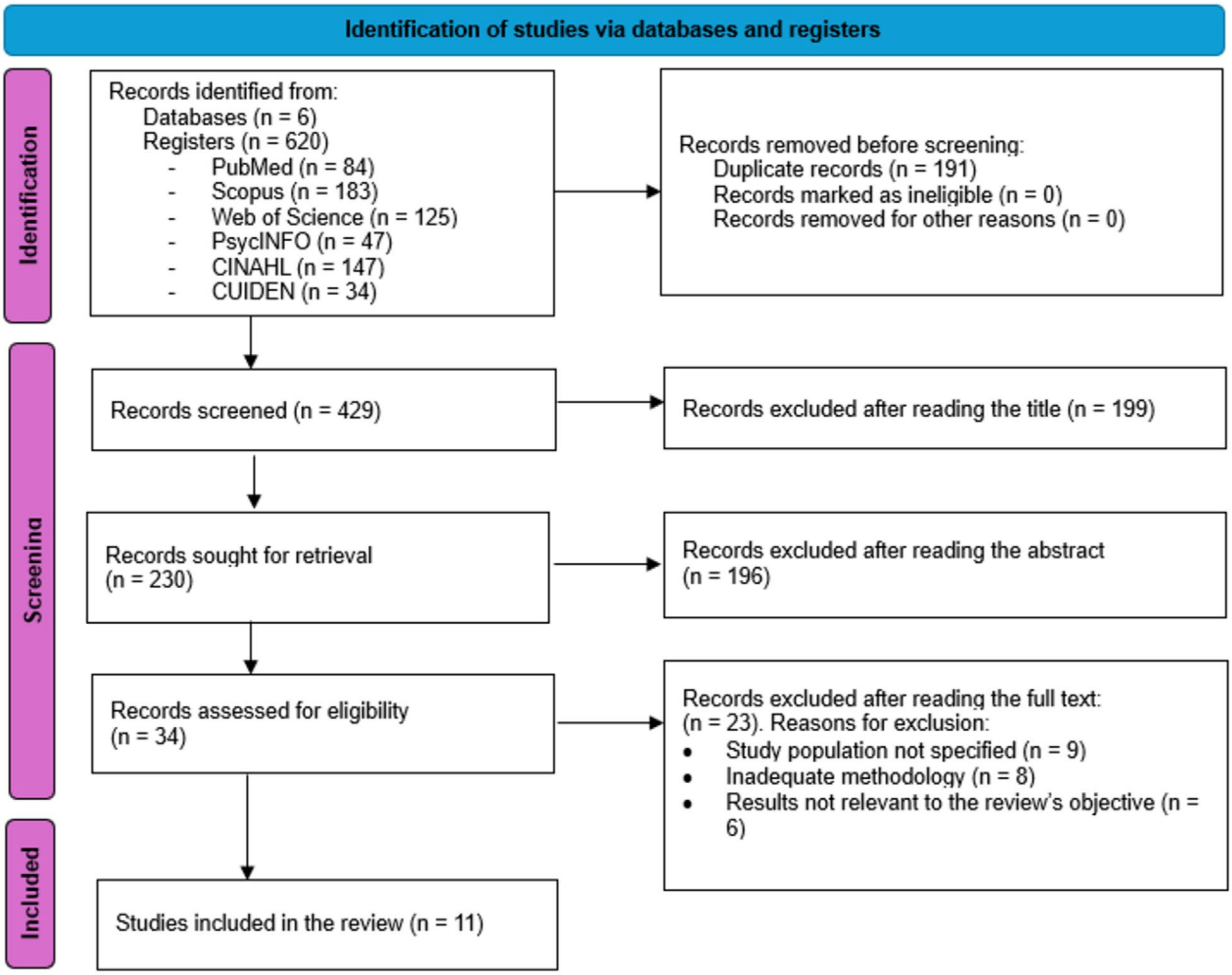

FIGURE 1 | Flow chart of search results. *Source:* Page et al. (2021).

Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019), Ireland (Courtney et al. 2018), Germany (Engler et al. 2019), the United Kingdom (Coombes et al. 2022), Canada (Lord et al. 2020), the United States (Gilmer et al. 2013), Brazil (Fiterman Lima et al. 2020), and South Africa (Plessis et al. 2019).

The age of the children in the studies varied widely, covering a broad range (from 0 to 17 years). Although no articles were identified that focused exclusively on the age range defined in the inclusion criteria, the selected studies included age groups that meet these requirements.

With regard to the children's health conditions, the following were predominant: oncological conditions (Fiterman Lima et al. 2020; Gilmer et al. 2013; Engler et al. 2019; Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022; Lord et al. 2020; Plessis et al. 2019), followed by neurological/neurodegenerative conditions and brain injuries (Fiterman Lima et al. 2020; Engler et al. 2019; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Courtney et al. 2018; Coombes et al. 2022), congenital conditions (Gilmer et al. 2013; Engler et al. 2019; Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022), metabolic disorders (Engler et al. 2019; Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022), respiratory diseases (Engler et al. 2019; Falkenburg et al. 2016; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022), and to a lesser extent, cardiac conditions (Fiterman Lima et al. 2020; Gilmer et al. 2013; Falkenburg et al. 2016; Lord et al. 2020), gastrointestinal diseases (Engler et al. 2019; Coombes et al. 2022), traumatic injuries (Fiterman Lima et al. 2020; Falkenburg et al. 2016), vascular conditions (Falkenburg et al. 2016), neonatal-specific conditions (Gilmer et al. 2013), neuromuscular diseases (Falkenburg et al. 2016), infectious diseases (Gilmer et al. 2013), and renal conditions (Fiterman Lima et al. 2020).

The caregivers who participated in the studies were primarily mothers and fathers, with the maternal figure being predominant. Mothers contributed in all the studies (Fiterman Lima et al. 2020; Gilmer et al. 2013; Engler et al. 2019; Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Courtney et al. 2018; Coombes et al. 2022; Lord et al. 2020; Plessis et al. 2019), and in one study, they were the sole participants (Courtney et al. 2018). Fathers, on the other hand, were present in 9 out of the 11 studies (Fiterman Lima et al. 2020; Gilmer et al. 2013; Engler et al. 2019;

Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022; Lord et al. 2020). In one study, both parents were interviewed together as a couple (Falkenburg et al. 2016). Grandmothers also participated (Fiterman Lima et al. 2020; Plessis et al. 2019), as did the children themselves (Coombes et al. 2022) and their siblings (Coombes et al. 2022). In some studies, healthcare professionals (Fiterman Lima et al. 2020; Coombes et al. 2022) and social care professionals (Coombes et al. 2022) were also involved.

In terms of care settings, pediatric palliative care (PPC) units were prominent (Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019; Coombes et al. 2022), followed by unspecified hospital units (Fiterman Lima et al. 2020; Coombes et al. 2022; Plessis et al. 2019), neonatal intensive care units (Gilmer et al. 2013), pediatric critical care units (Gilmer et al. 2013; Falkenburg et al. 2016), pediatric inpatient wards (Gilmer et al. 2013), home settings (Courtney et al. 2018), complex care or long-term ventilation clinics (Lord et al. 2020), and specialized outpatient palliative care (Engler et al. 2019).

The data were primarily collected through semi-structured interviews (Verberne et al. 2019; Courtney et al. 2018; Coombes et al. 2022; Lord et al. 2020; Plessis et al. 2019), open interviews (Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017), unstructured interviews (Engler et al. 2019; Falkenburg et al. 2016), interviews without further specifications (Fiterman Lima et al. 2020), and in one study, Likert scales were used alongside semi-structured interviews (Gilmer et al. 2013). The specific details of each study are provided in Table S1.

3.2 | Critical Appraisal of the Selected Studies

The evaluated articles were eligible in terms of methodological quality as per the CASPe tool for inclusion in the study (Table 2). Disagreements between two researchers were noted in five of the studies (Fiterman Lima et al. 2020; Gilmer et al. 2013; Falkenburg et al. 2016; Lord et al. 2020; Plessis et al. 2019), requiring the involvement of a third researcher. The sixth CASPe requirement, which relates to the relationship between the researcher and the research objective, was fulfilled in only two articles (Gilmer et al. 2013; Plessis et al. 2019).

3.3 | Synthesis of the Selected Studies

A total of 169 themes were identified and organized into 36 metaphors. The predominant themes were ‘Capacity for decision-making’ (Engler et al. 2019; Falkenburg et al. 2016; Verberne, Kars, et al. 2017; Verberne, Schouten-van Meeteren, et al. 2017; Verberne et al. 2019), ‘Reconstruction of daily life’ (Fiterman Lima et al. 2020; Engler et al. 2019; Verberne, Kars, et al. 2017; Verberne et al. 2019; Courtney et al. 2018), and ‘Faith as support’ (Fiterman Lima et al. 2020; Falkenburg et al. 2016; Verberne et al. 2019; Courtney et al. 2018).

The most significant refutational aspects found in the articles were ‘Unsatisfactory healthcare’ (Engler et al. 2019; Plessis et al. 2019) and

TABLE 2 | Methodological quality appraisal using the CASPe tool.

	Items										Total score (per article)
Author and year	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	
Gilmer et al. (2013)	✓	✓	?	✓	✗	✓	✓	✓	✓	✓	8/10
Courtney et al. (2018)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Lord et al. (2020)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Plessis et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10/10
Falkenburg et al. (2016)	✓	✓	✗	✓	✓	✗	✓	✓	✓	✓	8/10
Fiterman lima et al. (2020)	✓	✓	✓	✓	✓	✗	✓	✓	?	?	7/10
Verberne, Kars, et al. (2017)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Coombes et al. (2022)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Verberne, Schouten-van Meeteren, et al. (2017)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Engler et al. (2019)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Verberne, Kars, et al. (2017)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10
Total score (per item)	11/11	11/11	9/11	11/11	10/11	2/11	11/11	11/11	10/11	10/11	

Note: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research method appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the research question and the method used? 5. Were the data collection techniques appropriate to address the research issue and the method used? 6. Has the relationship between the researcher and the research issue been appropriately reflected upon (reflexivity)? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of results? 10. Can the research results be put into practice? Assessment: ✓ = yes; ✗ = no; ? = can't tell.

Source: Prepared by the authors.

'Satisfactory healthcare' (Gilmer et al. 2013; Falkenburg et al. 2016; Plessis et al. 2019), 'Hopelessness' (Engler et al. 2019; Falkenburg et al. 2016; Verberne et al. 2019) and 'Hope' (Fiterman Lima et al. 2020; Falkenburg et al. 2016; Verberne et al. 2019; Coombes et al. 2022), 'Difficulty staying united' (Falkenburg et al. 2016) and 'Staying united' (Falkenburg et al. 2016), 'Unrecognizable child' (Falkenburg et al. 2016; Lord et al. 2020) and 'Recognizable child' (Falkenburg et al. 2016; Verberne et al. 2019).

In the final synthesis, four main third-order themes were identified regarding the experiences of informal caregivers: 'Individual ability to cope', 'Relationship with the child', 'Informal caregivers and other family members', and 'Informal caregivers and the health system'. Table S2 illustrates the thematic distribution according to each selected article.

3.4 | Individual Ability to Cope

Family caregivers employ coping strategies to adapt to the child's severe health conditions and come to terms with the inevitability of death.

The *acceptance of loss* is described as a painful journey where caregivers recognize the impossibility of recovery and face the final farewell to their children. Caregivers describe this process as endless grief. It involves coming to terms with the gradual loss of *independence*, which contrasts with the normal development of a healthy child, who would naturally progress from complete dependence to full independence. The child's *deteriorating health* helps caregivers gradually embrace the reality of the loss.

> Every moment of loss, as experienced by the individual parent, meant that they had to go through a mourning cycle, again and again. [...] situations when their child was no longer able to attend school [] were experienced as losses and triggered grief.
>
> (Verberne et al. 2019)

> ...but it only got worse. Then I said: 'You may go to grandfather' (i.e., "die").
>
> (Falkenburg et al. 2016)

Caregivers try to find *meaning in their experience*. In some cases, this search leads them to help others facing similar situations. The *willingness to improve care quality* is evident, as they share their experiences with families, patients, and healthcare professionals. *Faith* also stands out as *a source of support*, helping them cope with difficulties and contribute to maintaining hope.

> Families [...] told their stories and were willing to help health care providers understand how they could improve the quality of care.
>
> (Gilmer et al. 2013)

> [...] many parents felt strengthened by their religion or faith [...].
>
> (Verberne et al. 2019)

For caregivers, it is important to *maintain hope* and stay optimistic. This hope is grounded not so much in physical improvement, but in the belief that the child can enjoy a fulfilling and normal life, like anyone else. On the other hand, comparing the sick child's health with that of a healthy child generates *hopelessness*, as it reinforces the idea that the child will never improve or lead a normal life.

> They expressed a desire for their child to live life as fully as possible, to their full potential, experience relationships with others, and have things to hope for and look forward to.
>
> (Coombes et al. 2022)

> OK, she's always going to be a nursing case and always going to be in need of intensive care, forever, and she'll always be in hospital....
>
> (Engler et al. 2019)

Caregivers experience a conflict between the *uncertainty* of how the child's illness will progress and the *fear of losing them*, as they anticipate the pain and sadness that come with such a loss.

> Because it wasn't clear how long that would carry on that way. Do we have our little darling for two months, for two years, for 20 years?
>
> (Engler et al. 2019)

> No início eu não queria, que assim eu não quero que ele morra. [At first, I didn't want to, because I don't want him to die like this].
>
> (Fiterman Lima et al. 2020)

An important aspect of caregivers' ability to cope is their *capacity to make decisions*. They value having control over the illness process above all else, which sometimes leads to an *inability to delegate care to others* or to *question the therapies and treatments* the children undergo. In this regard, the *home* is often the preferred place for the child's care, likely due to the sense of protection that comes from being in a familiar environment.

> As such, parents experienced themselves as being in control of directing the process, which was highly valued.
>
> (Verberne, Schouten-van Meeteren, et al. 2017)

> [Our daughter] is currently recovering from an illness, and we currently do not dare to leave her in other people's care.
>
> (Verberne, Kars, et al. 2017)

Figure 2 provides a schematic overview of the caregivers' ability to cope.

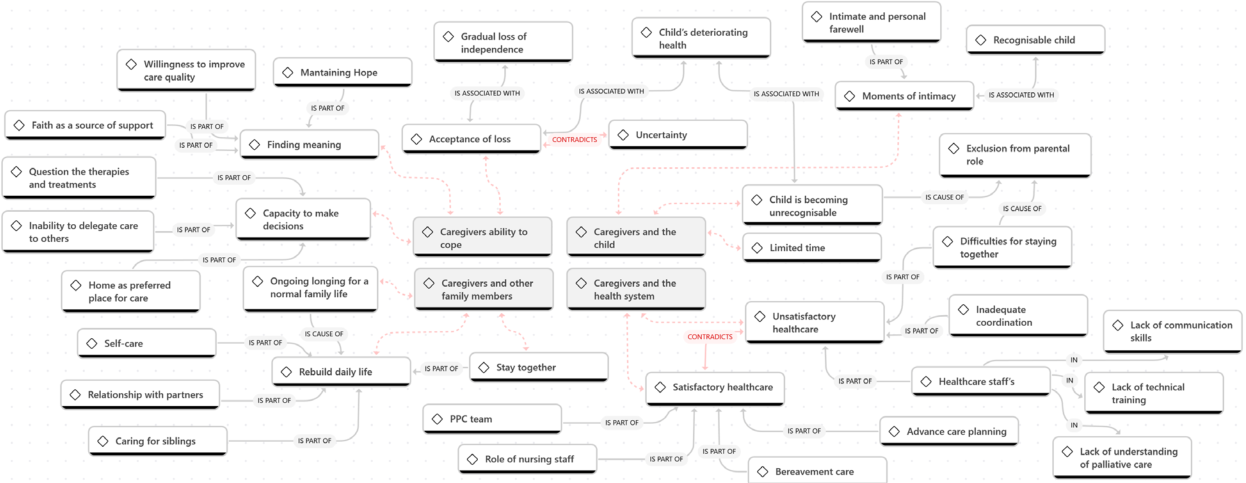

FIGURE 2 | Experiences of family caregivers of children (1–23 months) receiving pediatric palliative care. Interpretative categories in the figure.

3.5 | Relationship With the Child

Caregivers feel that they have *limited time* with their children. Frequent hospital visits and interventions reduce the amount of family time, leading to a longing for a normal daily routine. Additionally, the child's *deteriorating health* often limits their ability to interact with them or even to engage in physical contact.

> They had a strong wish to live as a family, be parents and children, and have a daily routine at home, especially because they felt that their time as a family with their children was limited.
>
> (Engler et al. 2019)

> Then he got worse again and didn't like the touch anymore.
>
> (Falkenburg et al. 2016)

Caregivers notice the physical changes in their child's body caused by the treatments and the progression of the illness. This deterioration can lead to the painful feeling that their *child is becoming unrecognizable*, obscuring their identity and making it harder to maintain a bond. In contrast, one mother describes how physical contact with her daughter helps her feel more connected, allowing her to *recognize her child*.

> And I looked at my husband, and I just teared up and saw that I actually don't know who she is. All I know is her illness.
>
> (Lord et al. 2020)

> When I held her to my chest for the first time, my body started to react! Then I thought: yes this is really my baby.
>
> (Falkenburg et al. 2016)

Sharing *moments of intimacy* strengthens the bond with their children, and this connection is reinforced during critical moments. The time of death is especially important, as *an intimate and personal farewell* with family involvement helps ease the grieving process and strengthens the emotional bond.

> Getting the opportunity to get physically close to their child was of great significance to parents; [...] before, during, and after the child's dying.
>
> (Falkenburg et al. 2016)

> I wanted to bathe him myself. The children helped, they wanted to. They touched him constantly.
>
> (Falkenburg et al. 2016)

Figure 2 provides a schematic overview of the caregivers and the child.

3.6 | Informal Caregivers and Other Family Members

The child's progressive health deterioration affects family relationships and interactions with siblings and the partner, leading to the need to strengthen family bonds and *rebuild daily life*. Caregivers expressed the need to *stay united*, both physically and emotionally. Finding a balance between the demands of caring for the child and the needs of the family is essential. The constant adjustment of the daily routine, right up until the farewell, reflects the *ongoing longing for a normal family life*.

> Family balance is a situation in which all individual family members can keep going, experience wellbeing and are able to develop within their full potential.
>
> (Verberne, Kars, et al. 2017)

> Parents felt also confronted with loss and grief [...] by letting go of the dream of having a carefree family life.
>
> (Verberne et al. 2019)

However, the reorganization can be hindered by constant demands and challenges. In addition to *a lack of self-care*, mothers in particular *give up work*, dedicating themselves to the daily care of their sick children. They also face difficulties in *caring for siblings*, who receive less attention and face emotional challenges. As one father describes, caring for his child creates difficulties in *nurturing the relationship with his partner.* Nevertheless, parents recognize the need to maintain their relationship, ensuring they dedicate time to each other.

> [Parents] reported that they were not able to care for themselves properly by eating and sleeping regularly because they were always on the way to their child.
>
> (Engler et al. 2019)

> [...] Eu larguei de trabalhar desde que ele nasceu [...]. [I stopped working when he was born].
>
> (Fiterman Lima et al. 2020)

> But we do know that it's very important to go out for an evening, to go out to dinner together, to be with each other. But yeah, right now that's not possible.
>
> (Verberne, Kars, et al. 2017)

Figure 2 provides a schematic overview of the caregivers and other family members.

3.7 | Informal Caregivers and the Health System

Caregivers of children receiving pediatric palliative care (PPC) expect to receive appropriate healthcare, but it often falls short of their expectations. *Unsatisfactory healthcare* is described as an additional challenge for caregivers. This lack of support is evident in the absence of care during critical moments, leaving parents with a sense of neglect. Caregivers point to *the healthcare staff's lack of technical training* as a key factor. One study highlights *the lack of understanding of palliative care* among both caregivers and healthcare professionals, who tend to associate it with death and hopelessness.

> [...] we called for help but nobody came./[...] a nurse not knowing how to operate a drip and another's lack of knowledge about basic cardiopulmonary resuscitation.
>
> (Plessis et al. 2019)

> Essa médica da morte veio aqui e falou com a gente, mas aí teve gente que trabalha aqui [...] que avisou pra não aceitar [os cuidados paliativos]. [That death doctor came here and talked to us, but then some of the staff here [...] warned us not to accept palliative care].
>
> (Fiterman Lima et al. 2020)

In some cases, caregivers identify *difficulties in staying united* due to the need for the child to be cared for in intensive care units. The lack of privacy and the strict visiting hours, which limit parents' time with their children, left some caregivers feeling *excluded from their parental role*. In some instances, mothers did not have physical contact with their child from birth until the moment of death.

> Parents felt stressed because there was no room in the hospital for privacy and calm. [...] fixed hours for visiting one's own child are thoughtless and awful.
>
> (Engler et al. 2019)

> I came to the ICU and there you see a large space full with machinery [...]. You have to search for your baby between all machines./[...] their child could not be touched or held, due to "the deterioration of muscles" as parents described it./They held their child close for the first time at the hour of death.
>
> (Falkenburg et al. 2016)

Caregivers point to the *healthcare staff's lack of communication skills* as a negative factor. *Poor communication when delivering bad news* caused great distress for one mother, due to the insensitivity shown by a member of the medical team. Furthermore, a lack of communication can lead to *inadequate coordination*, which can negatively impact mothers' experiences. Another complaint caregivers have about the healthcare system is *being discharged without receiving care instructions*, leaving them to face home care without sufficient training, which affects both the child's care and the caregivers' own wellbeing.

> There was a young assistant doctor who told us: "Yes, when [your daughter] dies it'll be awful. She'll be in pain and gasping for breath" and the like, and I thought to myself, how can he say such things?
>
> (Engler et al. 2019)

> Sometimes they would move [3-month-old son] arbitrarily and not tell us ahead of time.
>
> (Gilmer et al. 2013)

> We hadn't a clue ... [staff] said "right, off you go", and we were like "how do we feed him", and she said "just do as you normally do" ... sure we hadn't a clue.
>
> (Courtney et al. 2018)

In contrast, other caregivers emphasize that *satisfactory healthcare* contributes not only to the well-being of the children but also to the wellbeing of the caregivers themselves. Some caregivers highlight the *role of nursing staff* as a source of support for them.

> The participants appreciated medical and nursing staff's honesty, clinical accuracy, compassion and availability.
>
> (Plessis et al. 2019)

> This experience would not have been bearable without the support of the nursing staff of the NICU.
>
> (Gilmer et al. 2013)

Caregivers recognize *the pediatric palliative care (PPC) team* as a reliable and well-prepared link in addressing the needs of the children. In this regard, they appreciate *advance care planning*, which ensures that care needs are addressed proactively, and the children's care preferences are respected. *Bereavement care* in the palliative context includes ongoing emotional support and participation in farewell rituals. One family, encouraged by the healthcare staff, participated in washing their child's body, creating an intimate moment of farewell.

> Parents described how the health care system and team structure during the child's routine care and acute illnesses provided an important foundation on which ACP [advance care planning] was situated.
>
> (Lord et al. 2020)

> After his death we thought: now what? The nurse said—this was just natural for her: 'My, what would you like? Shall we bathe him nicely, put on nice clothes? What would you like?' That was so nice, to have something to grasp hold of.
>
> (Falkenburg et al. 2016)

Figure 2 provides a schematic overview of the caregivers and the health system.

4 | Discussion

The aim of this study was to explore the experiences of family caregivers of children aged 1–23 months who are receiving pediatric palliative care (PPC). To the best of our knowledge, this is the first systematic review with an interpretative synthesis specifically addressing this objective.

The critical appraisal of the selected studies using the CASPe tool indicates that the methodological quality of the research is generally acceptable. However, only two articles addressed the relationship between the researcher and the research objective. Reflexivity, as highlighted by Dodgson (2019), is a fundamental component in qualitative research to ensure the rigor and credibility of the studies. It is therefore recommended that future research place greater emphasis on this critical aspect.

With regard to the study descriptions, it is notable that oncological conditions are disproportionately represented among the children's health conditions, despite the fact that, according to the Worldwide Hospice Palliative Care Alliance and World Health Organization (2020), oncological conditions constitute only a relatively small proportion of the overall pediatric palliative care (PPC) demand. As noted by Siddiqui et al. (2023), this disparity may be attributable to the fact that 90% of children with cancer reside in low- and middle-income countries, accounting for 84% of the global burden of childhood cancer. In these regions, lower cure rates and higher mortality rates render palliative care essential in the management of pediatric oncology patients.

The maternal figure was predominant in the studies, while the involvement of other significant figures, such as grandparents, was limited. Despite this, grandparents play a crucial role in meeting family needs during the child's illness (Nogueira and Ribeiro 2024; Tatterton and Walshe 2019). Future research should therefore further explore the role of grandparents in various cultural contexts.

Finding meaning, relying on faith, and maintaining hope are crucial coping strategies for family caregivers. Previous reviews (Fisher et al. 2023; Sjuls et al. 2024) have identified faith and spirituality as significant sources of support throughout the child's illness. According to Pravin (2023), spirituality helps families navigate complex situations and make difficult decisions, providing comfort and hope.

Caregivers' ability to make decisions is another key aspect of coping. Healthcare professionals must engage caregivers effectively in the decision-making process, as uncertainty and fear are common emotions among parents (Fisher et al. 2023). The home is perceived as a place where caregivers feel more secure in making decisions. Winger et al. (2020) noted that being at home facilitates daily family life, while emotional support from professionals enhances rest and allows caregivers to share the responsibilities of caring for the sick child.

In this context, caregivers expressed their desire to remain close to their children for as long as possible and highlighted the challenges posed by the child's deteriorating health and structural limitations. This physical and emotional proximity is crucial in fostering a personal bond with the child and in preventing feelings of detachment (Sjuls et al. 2024).

Regarding caregivers' relationships with the rest of the family, informal caregivers strive to rebuild a normal daily life, adapted to the child's health condition. Parents in a study by Kittelsen, Lorentsen et al. (2024) emphasized the importance of maintaining an ordinary life in extraordinary circumstances.

The findings of this review indicate that caregivers, in prioritizing the care of their sick child, often neglect their own self-care, their work (a phenomenon observed only in mothers), and the care of other family members. Kittelsen, Lorentsen et al. (2024) add that parents experienced a decline in their quality of life and a profound emotional impact, characterized by overwhelming feelings of guilt for failing to fulfill their parental roles. In this regard, as also noted in a systematic review by Sjuls et al. (2024), caregivers in this review expressed concern about the limited attention given to the siblings of the sick child. In such situations, siblings may experience anger, jealousy, shame, and guilt towards the sick child (Kittelsen, Castor, et al. 2024). The relationship between parents is also negatively affected. In some cases, the child's condition requires one parent to always be present, resulting in a lack of intimacy between the couple (Sjuls et al. 2024). Fisher et al. (2023) highlight that some relationships become limited to coordinating the child's care, at the expense of other aspects of the relationship. Future studies should explore how to address this neglect of other family members, as it can be highly detrimental to caregivers' emotional well-being.

Caregivers expressed dissatisfaction with the healthcare system, pointing to deficiencies in the technical and communication skills of healthcare professionals. In line with this, Constantinou et al. (2019) reported delays in the provision of care, shortages of technology, supplies, and equipment, as well as poor communication and organization. The systematic review by Fisher et al. (2023) also noted delays in diagnosis, a lack of up-to-date knowledge, and communication issues among healthcare staff. Similarly, Sjuls et al. (2024) described inadequate coordination, communication, and a lack of trust in healthcare professionals.

The findings of this review highlight a lack of palliative care awareness among some caregivers and a lack of knowledge of palliative care principles among certain healthcare professionals. De Clercq et al. (2019) revealed that parents often resist palliative care for their children, associating it with death and hopelessness. Interestingly, some caregivers highly value the involvement of specialized pediatric palliative care (PPC) teams, which they link to advance care planning. These findings are consistent with those of Fields et al. (2023), who emphasize that a palliative care approach allows parents to accept their child's diagnosis while ensuring that all the child's needs are met. This issue requires further exploration, as it has not been included in previous reviews.

This support and accompaniment provided by the nurse results in an improvement in the caregiver's quality of life, as it has been shown that training in pediatric palliative care has a positive impact on the physical and emotional well-being of caregivers. Furthermore, the nurse, as part of the multidisciplinary team, plays an indispensable role in the integration of care at home, ensuring that the primary caregiver can perform their role with confidence and security (Chocarro González et al. 2021).

Finally, caregivers reported positive experiences with post-mortem care for the child and noted its beneficial impact on immediate grief. Schuelke et al. (2021) stress that, after the child's death, healthcare professionals should encourage participation in post-mortem care, as it fosters a sense of belonging and inclusion. These aspects have also not been addressed in previous reviews and should be followed up in future research.

This manuscript explores the experiences of caregivers of children with pediatric palliative care needs, highlighting coping strategies, the impact on self-care, family and partner dynamics, and the relationship with professionals and the healthcare system. These areas are fundamental in nursing care, in communication with the caregiver, and in the resulting impact the findings of this article have on nursing practice, both in critical patient care, in home care, and in the process following the child's death. There is a need to improve the training of nursing professionals in pediatric palliative care, both in techniques, technical knowledge, communication skills, and improved coordination between professionals.

One of the main limitations of this study was that a significant number of studies identified in the initial phases of the review had to be excluded, as the ages of the children receiving pediatric palliative care (PPC) were not specified alongside the interviews conducted with informal caregivers. However, to the best of our knowledge, this is the only systematic review specifically focusing on the experiences of informal caregivers of children aged 1–23 months who have received pediatric palliative care (PPC). The search strategy employed was thorough and rigorous; the methodological quality of the studies was evaluated using a purpose-built assessment tool, and the review followed a predefined meta-ethnographic analysis model.

5 | Conclusions

- Family caregivers of children receiving pediatric palliative care (PPC) adopt coping strategies that include finding meaning in their experiences through sharing them, relying on faith, sustaining hope, and exercising decision-making. The home is particularly valued as the primary setting for care.
- Caregivers frequently perceive that their time with the child is limited, both by structural barriers and by the child's deteriorating health. These factors can lead to feelings of exclusion from their parental role, difficulties in forming emotional connections, and challenges in recognizing their child's identity.
- While caregivers make concerted efforts to stay united and re-establish the family routine they yearn for, they face significant obstacles, particularly with regard to self-care, maintaining employment, and attending to the needs of other family members, including the child's siblings and the caregiver's partner.
- Caregivers often express dissatisfaction with the healthcare they receive, citing the lack of technical expertise, insufficient understanding of pediatric palliative care (PPC) principles, poor communication skills, and inadequate coordination among healthcare professionals. Nevertheless, they acknowledge the essential role played by pediatric palliative care (PPC) nurses and teams, highlighting the importance of advance care planning and the emotional support provided through post-mortem care.

Clinical Resources

The European Pediatric Association (EPA/UNEPSA) focuses on research and the continuous improvement of pediatric care across Europe. It remains a key reference in the field of pediatrics. https://www.epa-unepsa.eu/index.php.

The American Academy of Pediatrics (AAP) is an organization of pediatric professionals providing resources in child health through research, educational programs, and clinical practice guidelines. https://www.aap.org/. The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity and membership body for pediatricians in the UK and worldwide. It plays a key role in postgraduate medical education, professional standards, research, and policy. https://www.rcpch.ac.uk/. The International Children's Palliative Care Network (ICPCN) is a global organization working to improve access to palliative care. https://icpcn.org/.

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Ethics Statement

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The authors have nothing to report.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.