Journal of Integrative Nursing and Palliative Care (JINPC)

Original Article

Volume ٦ | Page 73-82

Supporting Everyday Life: Family Needs in Home-Based Pediatric Palliative Care — A Qualitative Study

Murat Basal[1*], Mikail Erol[2]

[1]*Department of Nursing, Faculty of Health Sciences, Tarsus University, Mersin, Turkey.*
[2]*University of Health Sciences Dr Behcet Uz Child Disease and Surgery Training and Research Hospital, Izmir, Turkey.*

Abstract

Pediatric palliative care seeks to promote the well-being of children living with life-limiting or life-threatening illnesses and to support their families. Providing this care in the home is increasingly recognized as the preferred approach. To deliver effective home-based services, it is crucial to understand families' specific experiences and needs. This study investigated how parents perceive their care and communication needs when receiving pediatric palliative care at home. Using a qualitative exploratory design, five focus group discussions were conducted with 18 parents of children affected by severe or life-limiting conditions. The collected narratives were examined through thematic analysis. The analysis generated four overarching themes: (1) Insufficient awareness within the healthcare system regarding families' everyday needs; (2) The potential of a designated care coordinator to reduce parents' workload and stress; (3) The importance of accessible, continuous communication with healthcare professionals who know the child; and (4) The benefits of a unified health record system that promotes information sharing and gives parents greater confidence and oversight.
Parents caring for seriously ill children face demanding responsibilities while managing fragmented healthcare structures and seeking reliable information. The findings emphasize the necessity of coordinated communication between healthcare providers and families. A dedicated care coordinator and improved systems for information exchange can enhance continuity, accessibility, and parental empowerment in home-based pediatric palliative care.

Keywords: Home-based care, Family experiences, Pediatric palliative care, Communication needs, Care coordination, Qualitative research

Introduction

Globally, an estimated 21 million children are in need of pediatric palliative care (PPC) [1]. In Norway, international prevalence estimates suggest that roughly 8,000 children live with life-limiting and/or life-threatening (LL/LT) conditions and therefore qualify for PPC services [1–3]. The primary goal of PPC is to enhance the quality of life (QoL) for both the child and their family by addressing physical, psychological, social, spiritual, and existential dimensions of care [4]. PPC is recommended for children aged 0–18 years with LL/LT conditions, a diverse group encompassing both oncological and non-oncological diagnoses [1]. Ideally, PPC should begin at the time of diagnosis and continue across the entire course of the illness [1, 2].
Medical and technological advances have prolonged the lives of many children with LL/LT conditions, creating an increasing demand for sustained, multidisciplinary care [1, 2]. These children often experience fluctuating and multifaceted needs that span medical, emotional, and social aspects of life [5–7]. For many, interactions with

Corresponding author: Murat Basal
Address: Department of Nursing, Faculty of Health Sciences, Tarsus University, Mersin, Turkey.
E-mail: ✉ mbasal@gelisim.edu.tr
Received: 16 March 2025; **Revised:** 25 May 2025; **Accepted:** 26 May 2025

How to Cite This Article: Basal M, Erol M. Supporting Everyday Life: Family Needs in Home-Based Pediatric Palliative Care — A Qualitative Study. J Integr Nurs Palliat Care. 202٥;٦:73-82. https://doi.org/10.51847/70qzCeTL8q

healthcare professionals (HCPs) who demonstrate genuine understanding, provide clear and relevant information, and involve them in decision-making are vital to their sense of agency and well-being [7].

Parents, in turn, emphasize the importance of clear communication, access to appropriate home-based support, and practical assistance in balancing their caregiving responsibilities with the needs of siblings and the family as a whole [7, 8]. Effective coordination between primary and specialist healthcare services is crucial for ensuring continuity, quality, and coherence in PPC delivery [9, 10]. Although the structure and organization of PPC differ across and within countries—including the Nordic region [3, 6]—home-based care is widely acknowledged as the preferred model [1]. Nonetheless, the extent and quality of home-based PPC vary significantly, shaped by healthcare system organization, available resources, and individual family circumstances.

In Norway, home-based PPC typically builds upon existing healthcare services, with contributions from both primary and specialist care providers, in alignment with international recommendations [1, 3]. In some cases, families also receive support from pediatric home-hospital programs or hospital-based PPC teams [3]. The level of contact and the scope of support differ: while some families maintain regular communication with home-based teams—sometimes with 24-hour access—others primarily engage with these services during periods of clinical instability or at the end of life, depending on their child's condition [3]. Although remaining at home is not always possible or appropriate, and some families require hospital-based care due to illness severity or complexity [7, 11], home-based care often enables children to stay in a familiar environment and avoid unnecessary hospitalizations [9].

Despite potential emotional and logistical challenges, many parents prefer home-based care, valuing the normality, comfort, and sense of control it provides [6, 7, 12]. The home setting fosters family closeness and allows for a more natural rhythm of daily life [13–15]. However, ensuring high-quality home-based PPC requires a well-coordinated and skilled multidisciplinary team [7, 16]. Existing research consistently points to families' experiences of fragmented care, poor coordination, and communication barriers with HCPs [10, 15].

To strengthen home-based PPC, a comprehensive understanding of families' needs and care conditions is essential [9, 17, 18]. Current evidence remains limited, particularly regarding the perspectives of parents caring for children with diverse LL/LT diagnoses across all phases of the PPC trajectory—not solely during end-of-life care, which has received the greatest research attention [7, 12, 17]. Additionally, few studies have examined the interrelated care and communication needs of children, parents, and siblings. Expanding this knowledge base is vital to inform clinical practice and promote care models that support the entire family unit while recognizing parents as key partners in care delivery [19, 20].

In response to these gaps, the present study explored the care and communication needs of families receiving home-based PPC from the parents' perspective. The specific research question guiding the study was: *How do parents of children with life-limiting and/or life-threatening conditions perceive their care and communication needs in home-based pediatric palliative care?*

Materials and Methods

Design

A qualitative, exploratory approach was adopted to investigate parents' perceptions of care and communication needs within home-based PPC. Focus groups were selected as the primary data collection method to harness the value of group interaction, shared reflection, and collective meaning-making—elements that often elicit insights not captured through individual interviews. While one-on-one interviews typically provide in-depth personal accounts, focus groups are particularly useful for identifying shared experiences, viewpoints, and patterns among participants who face similar circumstances [21].

The study was grounded in a family-centered theoretical framework, emphasizing collaboration with families, recognition of their lived expertise, and the delivery of individualized, holistic care that meets the needs of both the child and the family [1, 19].

This research forms part of the broader *Health Technology in Home-Based Pediatric Palliative Care (CHIP homeTec)* project, which investigates aspects relevant to developing digital tools that enhance communication among children, families, and healthcare providers involved in PPC. The present paper specifically focuses on parents' perspectives regarding care and communication needs, as discussed in a series of focus groups. The study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [22, 23].

Participants

Parents of children with LL/LT conditions were recruited through an open online survey conducted under the CHIP homeTec project. In this survey, respondents could indicate their willingness to participate in follow-up focus groups. Additional participants were recruited through a pilot focus group organized at a specialized habilitation outpatient clinic providing services for children with LL/LT conditions.

Purposeful sampling was employed to include parents of children aged 0–18 years who had an LL/LT condition, resided in Norway, and could communicate in Norwegian during group discussions. No explicit exclusion criteria were applied, as the inclusion criteria inherently limited participation to eligible parents. Interested parents were contacted by LJM via email or phone and received detailed written and oral information about the study before providing informed consent.

A total of 25 parents agreed to participate. Six were later unable to attend due to acute illness—either their own or their child's—or other personal circumstances, and one withdrew for unspecified reasons. The final sample consisted of 18 parents of children aged between 1.5 and 18 years, representing all four Norwegian health regions. The children had diverse medical diagnoses that met international PPC eligibility criteria [1] and represented three of the five recognized LL/LT condition categories **(Table 1)**. Participating families received a range of healthcare services; some had established connections with primary or specialist PPC teams, while others were supported through existing care structures adapted to their individual needs.

Table 1. Demographic characteristics of parents (N = 18) and their ill children (N = 14)

Characteristics of Parents and Children	
Parent Characteristics	**N = 18**
Age of parent, median (range)	40.0 (29–49)
Gender of parents, female, n (%)	15 (83%)
Child Characteristics	**N = 14**
Age of child, median (range)	5.8 (1.5–18.0)
Gender of child, female, n (%)	8 (57%)
Children with siblings, n (%)	11 (79%)
Health Conditions of Children [a]	
Life-threatening conditions	3 (21%)
Conditions where premature death is inevitable	-
Progressive conditions with no curative options	4 (29%)
Irreversible but nonprogressive conditions	5 (36%)
Unborn children with significant health issues	-
Other (combined conditions suitable for PPC)	2 (14%)
Norway Regional Health Authority (RHA) Regions	
Northern Norway RHA	4 (29%)
Central Norway RHA	1 (7%)
Western Norway RHA	7 (50%)
South-Eastern Norway RHA	2 (14%)

Note: PPC refers to Pediatric Palliative Care. The footnote "a" likely indicates that the health conditions are categorized based on specific criteria, but no further details were provided in the original table.

[a]. Categories of LL/LT conditions: (1) Life−threatening conditions for which curative treatment may be feasible but can fail; (2) Conditions in which premature death is inevitable; (3) Progressive conditions without curative treatment options; (4) Irreversible but nonprogressive conditions causing severe disability leading to susceptibility to health complications and the likelihood of premature death; and (5) Unborn children who may not live through birth, infants who may survive for a few hours/days, infants with birth anomalies or for whom intensive care has been appropriately applied but developed an incurable disease (1)

Data collection

An interview guide containing open-ended and follow-up questions was created to stimulate reflection and discussion among participants during the focus groups. The guide was reviewed by a reference panel to ensure clarity, relevance, and appropriateness of the questions. This panel consisted of parent representatives of children with LL/LT conditions, members of relevant user organizations, healthcare professionals (HCPs), and researchers with expertise in pediatric palliative care. A pilot test of the interview guide was conducted, after which minor adjustments were made to question wording and sequence. The final version included questions addressing parents' perspectives on healthcare services, home-based care experiences, and the use of health technology. Additionally, it explored the daily needs of the child, parents, and siblings, and strategies for meeting these needs—reflecting the family-centered theoretical framework underpinning this project [19].

Five focus group sessions, including the pilot, were conducted between December 2023 and March 2024. Each group included between three and five parents. In some cases, both parents participated together; in others, only one parent (either the mother or father) attended. The sessions lasted between 50 and 85 minutes (median duration:

65 minutes) and were conducted without breaks. To ensure participant comfort and minimize associations with clinical settings, in-person focus groups were held in neutral venues such as hotel meeting rooms. Three focus groups took place in person, while two were conducted online using Microsoft Teams with audio and video enabled; however, only the audio recordings were retained for analysis.

All groups were moderated by the first author (LJM), with one of the coauthors (AW or SAS) serving as assistant moderator. At the start of each session, the moderators introduced themselves, presented their professional backgrounds, and explained the aim of the study—to explore families' care and communication needs in home-based PPC. The discussions were audio recorded, and the encrypted files were securely transferred to the Service for Sensitive Data (TSD) for transcription and analysis. Access to the stored material was restricted to the four authors [24].

Analysis

The first author transcribed all focus group recordings verbatim. Data organization and management were performed using NVivo software (QSR International Pty Ltd., Victoria, Australia). The analysis followed a narrative thematic approach, which combines principles of narrative and thematic analysis to identify recurring themes and patterns within participants' accounts [25]. Following Riessman's methodological framework [25], the analysis focused primarily on *what* participants shared rather than *how* they articulated their experiences, with attention given to the meanings and themes underlying their narratives.

Narratives were understood as structured accounts constructed to make sense of lived experiences, shaped by both social context and audience [25]. The transcripts were read multiple times to gain deep familiarity with the material, and analytic notes were written directly on printed copies. An inductive, iterative coding process followed, through which meaningful patterns were identified at the level of sentences, paragraphs, and entire narratives. Initial codes were generated and grouped using NVivo to reflect emerging conceptual patterns.

Subsequently, the research team refined these preliminary codes into broader themes through several cycles of review. Codes were reorganized, merged, or refined to ensure internal coherence and analytical clarity. The authors collaboratively developed, discussed, and finalized the thematic structure and naming of each theme. In the final stage of analysis, representative excerpts from parents' narratives were selected to illustrate the core themes.

The analysis was led by LJM in close collaboration with AW, HH, and SAS. The entire research team engaged in multiple reflective discussions throughout all phases of analysis, critically examining interpretations and incorporating alternative viewpoints—an essential process of reflexivity in qualitative research [26].

Preunderstanding

All members of the research team have professional backgrounds in healthcare. The first author (LJM) is a Ph.D. candidate and pediatric occupational therapist with 15 years of experience in specialized habilitation services for children, including those with LL/LT conditions requiring PPC. This background provided insight into the practical and emotional realities of family caregiving and emphasized the significance of family engagement in care.

Coauthors HH, SAS, and AW are registered nurses with extensive clinical and/or research experience in pediatrics, palliative care, critical illness, and health technology. All authors are active members of the national research network *Children in Palliative Care (CHIP)* and participate in the *CHIP homeTec* project.

To mitigate potential bias, the team engaged in ongoing reflexive dialogue, critically examining how their professional experiences and assumptions might shape data interpretation. Diverse perspectives within the team were actively integrated throughout the analytic process to enhance rigor and trustworthiness.

Ethical considerations

Ethical approval for the study was granted by the Regional Committees for Medical and Health Research Ethics in Norway (Reference No. 251065) and by Sikt – the Norwegian Agency for Shared Services in Education and Research (Reference No. 657413). All participants were provided with detailed written and verbal information outlining the study's purpose, procedures, potential risks, and benefits. Participation was entirely voluntary, and participants were informed of their right to withdraw at any time without consequences. Confidentiality and data protection were emphasized throughout the study.

Prior to participation, digital informed consent was obtained from all parents. In accordance with ethical guidelines and approval conditions, data concerning the duration of the child's illness, receipt of PPC, or similar details were not collected.

Results and Discussion

The thematic analysis generated four overarching themes reflecting parents' perceptions of care and communication needs in home-based PPC **(Table 2)**:

1. The healthcare system lacks a comprehensive understanding of family needs.
2. A dedicated care coordinator can reduce parents' caregiving burden.
3. Direct access to healthcare professionals familiar with the child is essential.
4. A shared health record system improves information flow and gives parents a sense of control and oversight.

Table 2. Examples of the analysis process and theme development

hemes	Codes	Excerpts from Related Stories/Quotes
The healthcare system fails to fully grasp the needs of families	- Addressing parents' own needs while advocating for the child's and family's rights - Handling intricate nursing and caregiving responsibilities - Insufficient recognition of the family's holistic requirements - Siblings require ongoing support	"We actually reached out to Child Protective Services once, to say that we needed help. They gave us someone to talk to, and when we finally got started and began to benefit from it, it was taken away. Because then we got Personal Assistance, and everything was supposed to be fixed. So we kind of lost that person, and then we're left standing a bit on our own … The focus is on what's best for the child, but what's best for the parents is what's best for the child … (Participant 2, FG 2)"
An assigned coordinator can reduce the caregiving burden for parents	- The coordinator does not provide genuine relief from parental responsibilities - Poor collaboration generates extra workload for parents - Effective coordinators offer invaluable assistance - Desire for a coordinator within specialized health services - Better coordinated planning for the child's care	"The first thing I thought of when they said coordinated services, which would make our daily lives a hundred times easier, was if the different departments and doctors could talk to each other and coordinate things when we go to the hospital… But then they only set up one appointment, if they were a bit proactive, they could get several things done at the same time by coordinating it. That would save us an incredible amount of travel days. It's one thing for us parents to travel, but for the kids in all of this who are sick and have their own problems, it's quite a big strain for them with travel, hospitals, and people in white coats and blue gloves. So that's one of the biggest wishes we have for the hospitals, this is priority number one for us … (Participant 2, FG 4)"
A direct hotline to healthcare professionals knowledgeable about the child is crucial	- Need to consult with HCPs in various scenarios - Appreciation for hospital follow-up care - Valuing reliable contact persons - Insufficient expertise about the child in primary healthcare - Inconsistencies in HCP availability and support - Appreciation for HCPs with specialized knowledge of the child's condition - Straightforward and immediate access to HCPs	"For the diabetes, it's been absolutely great, both the system and having an open line to the Children's Ward at the hospital. So if there's ever something urgent, we can call there and get good answers right away. So it's just been, that follow-up has been incredibly … (Participant 2, FG 2)"
A unified health record system can improve information exchange and give parents greater control and visibility	- Efforts to monitor information manually - Absence of accessible information and overview - Streamlined approaches to sharing information - Desire to consolidate all child-related information - Preference for a shared electronic health record centered on the child	"We've mostly acted as the middlemen, passing along what the hospital wants us to communicate to the home care service and the doctor's office. So we've kind of taken responsibility to make sure they get the information, but I wish there was a shared platform where, for example, the health nurse could communicate with the specialist health services about things like which vaccines he should get. Or what kind of follow-up we should provide him moving forward … That you could find the information you need in the same place… (Participant 2, FG 3)"

FG focus group, HCP healthcare personnel

The healthcare system's limited understanding of family needs

Parents described how having a child with a life-limiting or life-threatening (LL/LT) condition profoundly affected every aspect of family life. They expressed that the healthcare system often failed to grasp the full scope of their situation, highlighting an absence of holistic and family-oriented care within the services they encountered. Many parents spoke of a continuous struggle to be recognized and understood by healthcare professionals (HCPs), reporting that their needs were frequently overlooked or inadequately addressed. This lack of understanding often led to frustration, delayed access to care, or, in some cases, complete absence of appropriate services.

Parents emphasized that their needs extended far beyond the medical management of the ill child and called for a more comprehensive, family-centered approach. Such an approach would include elements like access to respite care—allowing brief periods of rest at home—timely provision of essential medical or technical equipment, and adequate financial support or care allowances enabling parents to remain at home to care for their child.

However, families frequently experienced inconsistencies and contradictions in service delivery. When one need was met, another form of assistance could be withdrawn, or new services were provided in ways that did not align with their expectations. For example, one parent shared how access to child protective services was revoked once they received approval for a personal assistant, even though these two forms of support had distinct purposes.

Parents described living in a constant state of negotiation, balancing their caregiving role with the ongoing responsibility of advocating for their child's rights and needs within a fragmented healthcare system. They felt that the system was not equipped to manage the complexity of their child's care needs and that they had to "fight" continuously for appropriate support:

"When our son was diagnosed with this condition, a doctor told us that now we had to be his advocate, roll up our sleeves, and fight for him, because nothing comes on its own. And she was right. You feel like you have to push and push everywhere …" (Participant 1, FG 4)

Many parents expressed a deep desire to simply *be* parents rather than full-time caregivers or administrators of their child's care. Instead, they felt that the numerous responsibilities—managing medical needs, coordinating services, and advocating for care—often turned them into unpaid care managers rather than mothers and fathers. These heavy responsibilities strained their emotional well-being, affected their marital relationships, and, in many cases, made it difficult to maintain paid employment.

A recurring concern was the limited capacity to care for siblings. Parents described feelings of guilt and sadness over being unable to give adequate attention to their other children, who were often "pushed aside" due to the overwhelming focus required by the ill child. They sought emotional and practical support to help siblings cope with the family's circumstances. Parents who had access to sibling support services described them as invaluable, emphasizing the benefits of activities such as counseling sessions, peer groups, and support meetings with other families in similar situations. These opportunities offered siblings a sense of understanding and belonging while helping parents manage their demanding daily lives. However, such services were rarely offered proactively and usually had to be initiated by the parents themselves.

A dedicated coordinator can ease the care burden on parents

Parents consistently highlighted that coordinating their child's care across multiple healthcare services was an overwhelming and time-consuming task that detracted from their role as parents. They described the process of organizing medical appointments, especially across hospital departments and specialties, as stressful and exhausting. The lack of communication and collaboration between hospital departments and between specialist and primary healthcare services frequently led to overlapping or poorly scheduled appointments.

Parents illustrated these coordination challenges with examples of hospital visits scheduled on multiple days within the same week, instead of being grouped together. In some cases, appointments at different hospitals or departments were arranged simultaneously, forcing parents to reorganize schedules themselves. Although parents sometimes managed to consolidate appointments to reduce absences from work or school, this self-coordination required substantial time and effort—energy they wished could instead be devoted to their family and caregiving responsibilities.

While most families had municipal coordinators or child coordinators assigned to their cases, these roles were often described as symbolic rather than functional. Parents felt that the coordinators lacked both the mandate and resources to effectively manage the child's care across different levels of the healthcare system. According to parents, local coordinators had limited authority to engage with hospital-based specialists or influence decision-making processes. As one parent stated:

"We want them to coordinate and keep track at the hospital, but they're not allowed to, and it just stops. And the people at the hospital don't know what the child coordinator is supposed to do; it's just a mess. And that's why we parents end up being the coordinators and doing these things ourselves …" (Participant 1, FG 5)

Parents repeatedly emphasized that reducing the number of hospital visits and consultations would help preserve the child's daily routines and social life. Maintaining normal interactions with friends, family, and school or kindergarten peers was seen as essential for the child's well-being. Consequently, parents strongly advocated for a more integrated and holistic coordination model that would ensure smoother communication between all levels of care.

They proposed the establishment of a system in which care coordinators have both the formal authority and adequate resources to oversee all aspects of the child's care. Such coordinators, parents suggested, should be able to ensure that hospital appointments, follow-ups, and transitions between healthcare services are properly synchronized. This would allow parents to devote more time and emotional energy to caring for their child and family rather than managing the administrative burdens of the healthcare system.

Direct access to familiar healthcare professionals is essential

Parents expressed a strong desire for consistent and direct access to healthcare professionals (HCPs) who knew their child and could respond promptly when urgent issues arose. Many described the time-consuming and stressful process of trying to reach the right person or department when seeking advice or reporting medical concerns. Parents noted that HCPs working in local hospitals or primary care settings often lacked the expertise to manage their child's complex needs, which made obtaining timely help difficult. Challenges included limited knowledge about specialized medication regimens, inadequate ability to recognize and respond to adverse effects, and uncertainty in handling the child's highly individualized care requirements.

"Availability from healthcare personnel. As I mentioned, they are available locally. We have open returns, it's safe … But then, since the local hospital often falls short when it comes to very complex epilepsy, for example. And there I feel like there are gaps that are hard to fill, that you get enough help at the moment you need it … You don't get the same answers locally, or they no longer dare or have to consult. So for us, it's a wish for more availability from the specialist hospital. We know he has his doctor there … But at the same time, you often have to call the switchboard and you don't necessarily get through quickly …" (Participant 1, FG 3)

The parents emphasized that a strong, ongoing connection with the specialist healthcare service was essential. They valued interactions with HCPs who were already familiar with their child's diagnosis and treatment history, as this provided reassurance and allowed for more efficient and meaningful communication. Parents repeatedly highlighted that specialists and hospital-based professionals were better equipped to answer questions, adjust treatments, and offer guidance compared to primary care staff, who often lacked experience with rare or complex pediatric conditions.

Because their children frequently required care from multiple departments and healthcare levels, parents wished for a single point of contact—a healthcare professional responsible for maintaining an overview of the child's care plan and follow-up needs. Parents who had a dedicated pediatrician or another HCP acting in this role described feeling a much greater sense of trust and security, knowing that someone understood their child's medical background and could provide informed advice without delay. The parents' reflections collectively underscored how the absence of easily accessible, knowledgeable professionals placed additional emotional and logistical strain on families already coping with demanding care situations.

A shared health record system promotes information flow and parental control

Parents described the need for reliable, up-to-date, and easily accessible information about their child's health status, treatment, and ongoing care. They explained that they often assumed the role of "information managers," responsible for gathering, organizing, and communicating essential medical details to different healthcare providers. This included maintaining documentation, recording treatment plans, and relaying updates such as medication changes or wound care instructions.

Several parents shared experiences of acting as intermediaries between hospitals or healthcare teams during emergencies, emphasizing the importance of having quick access to accurate medical records. In crisis situations—such as respiratory arrests or severe epileptic seizures—parents found it vital to provide ambulance staff or emergency physicians with concise and correct medical information. As one parent explained, they could not expect every doctor to review extensive medical summaries spanning several years, making a well-structured overview indispensable.

Parents also described how fragmented electronic health record (EHR) systems made coordination more difficult. They noted inconsistencies between the EHRs used by hospitals and those used by municipal healthcare services, leading to poor communication across service levels.

"I think we have a few too many platforms that don't work very well … If everything was gathered in one place, instead of documenting in so many places, it might work better … I think that's a bit hard to achieve in a country as long as ours. But of course, if everyone used the same system across Norway and things were the same everywhere, that would be nice. That you could go to a national service and they find what they need, or if you move, you don't have to start over …" (Participant 3, FG 4)

Parents strongly advocated for the implementation of a unified EHR system that would integrate all relevant health information across different healthcare settings. They believed that such a system would not only reduce the administrative burden placed on families but also ensure that every professional involved in the child's care had access to accurate and up-to-date information. A shared record would streamline communication, reduce the risk of errors, and provide parents with a clearer overview of their child's medical history and current treatment.

Moreover, parents highlighted that centralized access to the child's health information would simplify various practical and bureaucratic processes—such as applying for welfare benefits or home care support—since relevant medical documentation would be readily available. Ultimately, parents viewed a national shared EHR system as a crucial step toward improving continuity of care, facilitating collaboration between healthcare levels, and empowering families to feel more in control of their child's health management.

This study identified a clear need among parents for more accessible and direct communication with healthcare professionals (HCPs) within specialist pediatric services. Parents regarded these HCPs as vital sources of support and reliable information; however, they experienced current communication channels as fragmented and inconsistent, generating frustration and uncertainty. Effective communication is a cornerstone of family-centered care [19], and previous research confirms that families prioritize availability and clear communication as essential for collaborative relationships with healthcare services [7].

Parents in our study emphasized the value of having dedicated contacts within specialist services, such as assigned doctors, familiar HCPs, or coordinators, who could provide consistent, continuous guidance. In contrast, parents often perceived municipal healthcare staff as lacking sufficient experience and expertise to manage their child's complex needs effectively, a finding supported by prior studies [15]. This perceived gap sometimes led families to seek guidance directly from specialist services rather than relying on primary care [27, 28].

Specialist services were consistently seen as more reliable for answering questions and discussing the child's condition in depth. Parents highlighted the importance of being able to identify the appropriate professional to contact, as well as the need for HCPs who demonstrate empathy, actively listen, acknowledge parental perspectives, and communicate in an open and supportive manner [9, 29, 30]. Despite this, parents reported substantial variability in the functionality of their designated contacts and uncertainty regarding their entitlement to a consistent point of contact within specialist services. They also noted the considerable effort required to collect and share relevant information about their child with different HCPs.

A shared electronic health record (EHR) emerged as a potential solution to address fragmented care and support seamless information exchange between parents, HCPs, and other professionals. Such a system could provide access to comprehensive health data, daily care reports, and advance care plans, thereby enhancing preparedness for both routine and urgent home visits. Previous studies corroborate the importance of timely and accurate information exchange for delivering high-quality care to children with complex needs [31, 32]. Inefficient communication systems and healthcare platforms that do not facilitate information sharing can disrupt interactions between parents, HCPs, educational staff, and personal assistants [32]. Additionally, HCPs may face challenges in staying updated on a child's condition prior to home visits due to multiple professionals being involved and the unpredictable trajectory of the child's illness [31, 33]. A shared EHR could bridge these gaps, supporting more coordinated, cohesive, and proactive care [33].

The findings emphasize the importance of enhancing care coordination, improving communication systems, and adopting a holistic approach that includes sibling support. Strengthening the competencies and mandates of care coordinators, along with implementing shared EHRs, may promote comprehensive, family-centered care. By fostering genuine collaboration between families, HCPs, and healthcare systems, these strategies can help ensure that the principles of pediatric palliative care are upheld and ultimately improve care quality for children with LL/LT conditions and their families.

Strengths and limitations

This study included parents of children with diverse LL/LT conditions from all Norwegian health regions, capturing a wide range of experiences and care needs. Notably, three fathers participated, which strengthens the study by including perspectives that are often underrepresented in pediatric palliative care research [34, 35]. Their participation provided unique insights into both emotional and practical challenges, offering a more nuanced understanding of family needs. However, the sample included too few fathers to analyze potential differences between mothers' and fathers' experiences.

The participants' varied backgrounds, geographic locations, and differing levels of access to healthcare services, combined with their willingness to share detailed experiences, suggest that the sample size provided sufficient information power for the study's focused research aim [36]. Some focus groups included couples participating together, which may have influenced group dynamics. While this could introduce uneven power distribution, it also appeared to create a supportive environment where participants felt safe to share experiences. Dependability was reinforced by using a consistent moderator and structured interview guide across all sessions. Transferability was strengthened by providing detailed descriptions of the study context, sampling, data collection, and analysis, along with rich illustrative quotations. These measures allow other researchers and practitioners to assess the applicability of findings to their own settings.

A limitation of the study is the absence of detailed information about the children's specific health conditions, which restricts contextualization of parental reflections. Pediatric palliative care shares characteristics with complex care, emphasizing comprehensive, long-term support. A family-centered approach is essential in this context, ensuring interventions are coordinated, holistic, and responsive to the needs of both children and their families [19].

The authors' clinical backgrounds enabled insightful probing and enhanced the depth of the data collected. However, this expertise may also have introduced preconceptions or led to overlooked aspects during interviews and analysis. To mitigate such bias, the research team engaged in ongoing reflexive practices, critically examining assumptions and decisions throughout the study, thereby increasing transparency and dependability.

Conclusion

Parents of children with life-limiting or life-threatening (LL/LT) conditions face demanding and multifaceted caregiving responsibilities, emphasizing the critical need for a dedicated coordinator to oversee and streamline interactions across the various levels of healthcare services involved in their child's care. Additionally, parents highlighted that a shared electronic health record (EHR) system could facilitate more efficient information exchange and provide timely access to essential details regarding their child's medical history and ongoing care. Implementing such comprehensive support structures has the potential to reduce parental burden and ensure that the entire family receives the assistance necessary to maintain daily life and well-being. These findings also underscore the importance of designing improved information-sharing systems to enhance the overall experience and effectiveness of home-based pediatric palliative care.

Future research should explore care models and healthcare system strategies that promote more accessible communication with healthcare professionals and better coordination of services within pediatric palliative care. Further studies should also incorporate the perspectives of both the child receiving care and their siblings to achieve a more complete understanding of family needs within the context of home-based care.

Acknowledgments: None.

Conflict of interest: None.

Financial support: None.

Ethics statement: None.

References

1. Benini F, Papadatou D, Bernadá M, Craig F, De Zen L, Downing J, et al. International standards for pediatric palliative care: from impacct to GO-PPaCS. J Pain Symptom Manag. 2022;63(5):e529–43.
2. Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. Palliat Med. 2021;35(9):1641–51.
3. Winger A, Holmen H, Birgisdóttir D, Lykke C, Lövgren M, Neergaard MA, et al. Children with palliative care needs the landscape of the Nordic countries. BMC Palliat Care. 2024;23(1):118.
4. Hain RDW, Rapoport A, Meiring M, Goldman A. Oxford textbook of palliative care for children. Third edition. ed. New York: Oxford University Press; 2021.
5. Boyden JY, Ersek M, Widger KA, Shea JA, Feudtner C. The home-based experiences of palliative and hospice care for children and caregivers (EXPERIENCE) measure: evaluation of psychometric properties. J Pain Symptom Manage. 2024;68(4):e287-302.
6. Malcolm C, Knighting K, Taylor C. Home-Based end of life care for children and their Families - A systematic scoping review and narrative synthesis. J Pediatr Nurs. 2020;55:126–33.
7. Winger A, Kvarme LG, Løyland B, Kristiansen C, Helseth S, Ravn IH. Family experiences with palliative care for children at home: a systematic literature review. BMC Palliat Care. 2020;19(1):165.
8. Noyes M, Delaney A, Lang M, Maybury M, Moloney S, Bradford N. Preparing for death while investing in life: a narrative inquiry and case report of homebased paediatric palliative, end-of-life, and after-death care. Children (Basel). 2023;10(11):1777. doi:10.3390/children10111777
9. Gill FJ, Hashem Z, Stegmann R, Aoun SM. The support needs of parent caregivers of children with a life-limiting illness and approaches used to meet their needs: a scoping review. Palliat Med. 2021;35(1):76–96.
10. Verberne LM, Kars MC, Schouten-van Meeteren AYN, van den Bergh EMM, Bosman DK, Colenbrander DA, et al. Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study. Eur J Pediatr. 2019;178(7):1075–85.
11. Malcolm C, Knighting K. A realist evaluation of a home-based end of life care service for children and families: what works, for whom, how, in what circumstances and why? BMC Palliat Care. 2022;21(1):31.
12. Noyes M, Herbert A, Moloney S, Irving H, Bradford N. Location of end-of-life care of children with cancer: a systematic review of parent experiences. Pediatr Blood Cancer. 2022;69(6):e29621.
13. Castor C, Landgren K, Hansson H, Kristensson Hallström I. A possibility for strengthening family life and health: family members' lived experience when a sick child receives home care in Sweden. Health Soc Care Community. 2018;26(2):224–31.
14. Kittelsen TB, Lorentsen VB, Castor C, Lee A, Kvarme LG, Winger A. It's about living a normal life: parents' quality of life when their child has a life-threatening or life-limiting condition - a qualitative study. BMC Palliat Care. 2024;23(1):92.

15. Rud SA, Skagestad E, Aasebø Hauken M. Parents' experiences of paediatric palliative care in the community healthcare system: a qualitative study. Palliat Care Soc Pract. 2023;17:26323524231193036.
16. Donovan LA, Slater PJ, Delaney AM, Baggio SJ, Herbert AR. Building capability in paediatric palliative care and enhancing education through the voice of parents: the quality of care collaborative Australia. Palliat Care Soc Pract. 2022;16:26323524221128835.
17. Holmen H, Riiser K, Winger A. Home-based pediatric palliative care and electronic health: systematic mixed methods review. J Med Internet Res. 2020;22(2):e16248.
18. Miller KA, Baird J, Lira J, Herrera Eguizabal J, Fei S, Kysh L, et al. The use of telemedicine for Home-Based palliative care for children with serious illness: a scoping review. J Pain Symptom Manage. 2021;62(3):619–36.
19. Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Arch Phys Med Rehabil. 2008;89(8):1618-24.
20. Broden EG, Boyden JY, Keller S, James R, Mooney-Doyle K. Who. What, where, and how? The state of family science in pediatric palliative care. J Pain Symptom Manage. 2024;68(4):e254–79.
21. Brinkmann S, Kvale S. Doing interviews. London: SAGE Publications Ltd; 2018.
22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
23. Lincoln YS, Guba EG. Naturalistic inquiry. Newberry Park: SAGE Publications Inc; 1985.
24. University of Oslo. Services for sensitive data (TSD) Oslo: University of Oslo. Available from: https://www.uio.no/english/services/it/research/sensitive-dat a/index.html. Cited 2025 21.01.25.
25. Riessman CK. Narrative methods for the human sciences. Los Angeles: Sage; 2008.
26. Braun V, Clarke V. Thematic analysis: a practical guide. Los Angeles, California: SAGE; 2022.
27. Leary JC, Krcmar R, Yoon GH, Freund KM, LeClair AM. Parent perspectives during hospital readmissions for children with medical complexity: a qualitative study. Hosp Pediatr. 2020;10(3):222–9.
28. Kerr AM, Harrington NG, Scott AM. Communication and the appraisal of uncertainty: exploring parents' communication with credible authorities in the context of chronic childhood illness. Health Commun. 2019;34(2):201–11. doi:10.1080/10410236.2017.1399508
29. Williams LJ, Waller K, Chenoweth RP, Ersig AL. Stakeholder perspectives: communication, care coordination, and transitions in care for children with medical complexity. J Spec Pediatr Nurs. 2021;26(1):e12314.
30. Aoun SM, Gill FJ, Phillips MB, Momber S, Cuddeford L, Deleuil R, et al. The profile and support needs of parents in paediatric palliative care: comparing cancer and non-cancer groups. Palliat Care Soc Pract. 2020;14:2632352420958000.
31. Quigley L, Lacombe-Duncan A, Adams S, Hepburn CM, Cohen E. A qualitative analysis of information sharing for children with medical complexity within and across health care organizations. BMC Health Serv Res. 2014;14(1):283. doi:10.1186/1472-6963-14-283
32. Schröder J, Riiser K, Holmen H. The needs of healthcare personnel who provide home-based pediatric palliative care: a mixed method systematic review. BMC Health Serv Res. 2024;24(1):45.
33. Schröder J, Riiser K, Holmen H. Healthcare personnel's perspectives on health technology in home-based pediatric palliative care: a qualitative study. BMC Palliat Care. 2024;23(1):137. doi:10.1186/s12904-024-01464-w
34. Fisher V, Fraser L, Taylor J. Experiences of fathers of children with a life-limiting condition: a systematic review and qualitative synthesis. BMJ Support Palliat Care. 2023;13(1):15-26. doi:10.1136/bmjspcare-2021-003019
35. Sjuls M, Ludvigsen MS, Robstad N, Fegran L. Fathers' experiences of living with a child with a progressive life-limiting condition without curative treatment options: a qualitative systematic review. J Adv Nurs. 2024;80(5):1670–85.
36. Malterud K. Theory and interpretation in qualitative studies from general practice: why and how? Scand J Public Health. 2016;44(2):120–9.