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Journeying through the landscape of home-based pediatric cancer care: Needs and expectations from the perspectives of children and parents

Hazal Ozdemir Koyu, PhD, RN *, Ebru Kilicarslan, PhD, RN

Gazi University Nursing Faculty Department of Pediatric Nursing, Ankara, Türkiye

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ABSTRACT

Purpose: Children with cancer and their parents face multidimensional demands in home-based pediatric cancer care, spanning informational, practical, and psychosocial domains, often requiring acute decision-making at home. However, qualitative evidence integrating both children's and parents' perspectives remains limited. This study aimed to explore and understand the needs, expectations, and experiences of children with cancer and their parents during home-based care.

Methods: A qualitative dyadic child–parent study was conducted in a pediatric oncology ward of a university hospital. Purposeful sampling continued until thematic saturation. Data were collected using a researcher-developed Characteristics Information Form and semi-structured interviews informed by Empowerment Theory. Reflexive thematic analysis guided by theoretical frameworks was used. Ethical approval was obtained, and trustworthiness was ensured through strategies addressing credibility, dependability, transferability, and confirmability.

Results: Eighteen children and eighteen parents participated. Two overarching themes emerged: (1) Navigating Challenges in Home-Based Pediatric Cancer Care, encompassing physical, informational, clinical, emotional, and psychosocial difficulties; and (2) The Lighthouse of Empowerment: Guiding Support, highlighting the need for tailored, structured support mechanisms, including home-care education, symptom management guidance, coordinated communication pathways, digital tools, psychological support modules, and clear emergency roadmaps.

Conclusion: The study reveals complex challenges and empowerment needs of children with cancer and their parents during home-based care. Findings emphasize the importance of family-centered and child-focused, empowerment-oriented, and technology-supported approaches to enhance home-care competence and psychosocial well-being.

Implications for practice: Pediatric oncology nurses can enhance home-based care by providing structured education, individualized symptom guidance, empowerment-focused interventions, digital tools, clear communication, and emergency planning, thereby improving family confidence, continuity of care, and psychosocial outcomes.

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Introduction

Childhood cancer is an extremely challenging experience that affects not only the child but also their parents, who often assume the role of primary caregiver. Each year, approximately 400,000 children worldwide and nearly 5000 children in Türkiye are diagnosed with cancer (Kutluk & Yeşilipek, 2023; World Health Organization [WHO], 2022). Advances in treatment have improved survival outcomes; however, they have also shifted a substantial proportion of care responsibilities from hospital settings to the home. Home-based pediatric oncology care, defined as the daily management of the child's condition by parents, includes tasks such as medication administration, symptom management, and provision of emotional support, all of which are critical to maintaining the child's well-being (Christensen & Carlsen, 2022; Flon et al., 2021; Jibb et al., 2022). Beyond psychosocial adaptation, home-based care encompasses interrelated domains, including education and practical skills for home procedures, symptom management, coordination and communication with healthcare providers, safety and emergency decision-making, access to trustworthy digital resources, and sustained psychosocial support (Ozdemir Koyu & Kilicarslan, 2025; Yan et al., 2025).

The home environment may offer comfort and familiarity, promote a sense of normalcy and supporting quality of life for children with cancer. Nevertheless, it also introduces significant physical, emotional,

* Corresponding author at: Gazi University Nursing Faculty Department of Pediatric Nursing, Emek District. 6th Street No: 2, 06490 Ankara, Turkey.
E-mail address: hazalozdemirkoyu@gazi.edu.tr (H. Ozdemir Koyu).

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and logistical challenges for both children and their parents (Jibb et al., 2021). Parents, often without continuous professional supervision, are required to manage complex responsibilities such as medication regimens, symptom and side-effect monitoring, nutritional care, and catheter maintenance. These responsibilities are accompanied by emotional challenges, including uncertainty, fear, and fluctuating distress related to the child's illness trajectory (Hammer et al., 2023; Jibb et al., 2021). Parents' caregiving roles are dynamic and require ongoing adaptation to the child's changing needs, emotional demands, and treatment-related risks, necessitating the development of psychological resilience and coping strategies (Luo et al., 2021; Salem et al., 2021). Concurrently, children face challenges within the home setting related to symptom management, emotional regulation, and communication of their needs and concerns (Cho et al., 2023; Hoeg et al., 2023; Kim et al., 2023).

Parents frequently assume clinical and organizational responsibilities at home that exceed their preparedness and the support available to them (Washington et al., 2025; Zhou et al., 2025). Previous studies have documented substantial caregiver burden and stress, persistent unmet informational and psychosocial needs, and dissatisfaction with the timeliness and accessibility of professional guidance, particularly in managing complications and navigating healthcare services (Ozdemir Koyu & Kilicarslan, 2024; Washington et al., 2025; Zhou et al., 2025). Challenges in care coordination and communication further intensify uncertainty and caregiver burden during transitions between hospital and home. Within this context, psychological empowerment emerges as a cross-cutting mechanism that enables families to translate education and guidance into confidence, proactive coping, and resilient day-to-day management at home (Kim et al., 2023; Ziegler et al., 2022; Zimmerman, 1995). Empowerment-oriented, evidence-based supports in pediatric oncology can strengthen families' capacity to manage symptoms, communicate effectively with healthcare providers, and make timely and safe decisions in the home setting.

Despite increasing recognition of these challenges, an integrated understanding of both children's and parents' priority needs and expectations across multiple domains of home-based pediatric cancer care remains limited. Much of the existing literature focuses primarily on parents or addresses isolated domains, such as psychological support or education, providing limited insight into how needs intersect or diverge between children and parents and how these needs can be translated into actionable, family-centered support strategies (Uysal & Yigit, 2025; Washington et al., 2025; Zhou et al., 2025). Although structured home-care programs offering comprehensive support—such as symptom management guidance, emergency preparedness, psychological interventions, and, in some settings, delivery of selected treatments at home—exist in certain countries (Cheng & Tan, 2021; Kok et al., 2019; Salem et al., 2021), pediatric oncology–specific home-care services remain limited in many regions. Consequently, families are often required to manage complex care responsibilities without sufficiently tailored professional support. Accordingly, this qualitative study aimed to explore the needs and expectations of children with cancer and their parents in the context of home-based pediatric cancer care, with the goal of informing the development of targeted, family-centered, and empowerment-oriented nursing interventions.

Methods

Study design

This qualitative study explored the needs and expectations of children with cancer and their parents during the home-based cancer care journey. The study report adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines (Tong et al., 2007). In addition, the Child-Centered Research Checklist endorsed by the EQUATOR Network was used as an adjunct framework to ensure that children's rights, participation, and perspectives were explicitly considered throughout the study design, data collection, analysis, and reporting (Foster et al., 2025).

Theoretical framework

The theoretical framework of this study and the semi-structured interview questions are based on the Psychological Empowerment Theory. This theory focuses on the individual's need to gain awareness of their experiences and to actively participate in their environment through proactive management skills requiring competencies to deal with these experiences (Ziegler et al., 2022; Zimmerman, 1995). The conceptual framework consists of three components: intrapersonal, interactional, and behavioral. The intrapersonal component centers on emotions, perceptions, and self-efficacy (i.e., perceived competence to influence desired outcomes); the interactional component involves problem-solving and understanding the resources and systems needed to achieve goals; and the behavioral component includes taking action, proactive coping, and adapting to change (Ziegler et al., 2022; Zimmerman, 1995).

In this study, we used the theory as a sensitizing lens to explore needs and expectations across key domains of home-based care. Specifically, the internal component (self-efficacy, perceived competence) was associated with confidence in knowledge/skill requirements and daily symptom management; the interactive component (critical awareness of resources and systems) was associated with the need for coordination/communication with providers and timely, reliable access to guidance (including digital resources); and the behavioral component (action-taking, proactive coping) was associated with the need for safety/emergency planning and implementing decisions about symptom management at home (Jibb et al., 2022; Ziegler et al., 2022; Zimmerman, 1995). This concept-to-domain alignment informed the wording of our interview prompts to ensure coverage beyond coping/empowerment and to capture overarching needs and expectations, while interviews simultaneously allowed inductive elaboration so participants could introduce additional domains of importance beyond the framework.

Study participants and recruitment

Participants of the study were children aged 8–18 years and their parents undergoing cancer treatment in the pediatric oncology ward of a university hospital. In this study, children and their parents were approached in dyads to capture the interconnected nature of their experiences during cancer care at home. This dyadic approach provided a holistic understanding of the common and individual challenges faced by children and their parents, emphasizing the relational dynamics in the caregiving process.

Purposeful sampling was used to reach potential participants and obtain rich data relevant to the research question.

Inclusion criteria in the study were as follows:

For children: Aged between 8 and 18 years, diagnosed with cancer (leukemia or solid tumors), and having received at least one cycle of treatment.

For parents: Being the primary caregiver of a child aged 8–18 undergoing cancer treatment, with experience of at least one cycle of home-based care.

Exclusion criteria from the study were as follows:

- Newly diagnosed children,
- Children who are in the terminal period or who are treated for relapse,
- Presence of another important disease (such as chronic disease, psychiatric diagnosis) in the family that may prevent coping, other than the child followed up with the diagnosis of cancer.

Participant recruitment for the interviews continued until data saturation was achieved, defined as the point at which no new themes or meaningful variations emerged from the data. Saturation was determined through an iterative process involving independent analysis of interview transcripts by two researchers and regular discussions to confirm thematic consistency. Ultimately, a total of 18 dyads (18 children with cancer and 18 parents) were interviewed between November 2022 and April 2023.

Data collection

The data were collected with 'Characteristics Information Form' and the 'Semi-Structured Interview Form'.

Characteristics Information Form: This form was developed by the researchers to obtain demographic and clinical information of the participating children and parents. It included information about children such as age, gender, and duration of treatment, and about parents such as age, gender, and educational status.

Semi-Structured Interview Form: A semi-structured interview guide was developed based on a comprehensive literature review and informed by Psychological Empowerment Theory, which served as a sensitizing framework to explore needs and expectations in home-based pediatric cancer care. The guide was designed to ensure consistency across interviews while allowing flexibility for participants to share their individual experiences and perspectives. The main interview questions addressed key domains of home-based care, including informational and practical skills, symptom monitoring and management, coordination and communication with healthcare providers, safety and emergency decision-making, access to trustworthy digital resources, and psychosocial support, while also exploring coping and empowerment as cross-cutting elements. The main questions and probe questions for children and parents are presented in Table 1.

After obtaining written informed consent and ethical approval, individual face-to-face interviews were conducted in a quiet and private environment within the pediatric oncology ward of a university hospital. Participants were identified during hospital-based treatment and follow-up visits, during which eligibility screening, study information, and consent procedures were completed. Because many families traveled from other provinces for care, conducting in-home interviews was often impractical during active treatment. When feasible, following hospital-based briefing and consent, online interviews were scheduled to be completed from the family's home in order to better reflect the home-care context and accommodate participant preferences. Each interview lasted approximately 30–40 min, depending on the participant's responses and willingness to share. All interviews were audio-recorded with participants' permission and transcribed verbatim for analysis.

Interviews with children were conducted using age-appropriate language and flexible interviewing techniques to promote comfort, understanding, and voluntary participation. Children were informed that they could decline to answer any question or stop the interview at any time. To ensure that children's voices were authentically captured and not overshadowed by parental perspectives, interviews with children were conducted separately from their parents. Child-friendly communication strategies, including simplified language, visual aids, and interactive techniques such as drawing or storytelling when appropriate, were used to facilitate engagement and support expression of children's experiences.

All interviews were conducted by the primary researcher (Researcher 1), a female PhD-trained pediatric oncology nurse with expertise in qualitative research methods. The interviewer had no prior clinical or personal relationship with the participants, ensuring neutrality and minimizing potential bias. Prior to data collection, the interviewer received comprehensive training in qualitative interviewing techniques, pediatric communication skills, and ethical considerations specific to pediatric oncology contexts. Ongoing supervision and methodological guidance were provided by the second researcher (Researcher 2), a female professor with extensive expertise in pediatric oncology and qualitative research, to support rigor and reflexivity throughout the data collection process.

Since this study included qualitative interviews with children, who are considered a vulnerable population, additional control measures were adopted to ensure ethical and sensitive data collection. These measures included creating a safe and supportive interview environment, using age-appropriate language, and providing participants with the option to pause or terminate the interview at any time.

To ensure that children's voices were authentically captured and not overshadowed by their parents' narratives, several age-appropriate strategies were employed. Interviews with children were conducted to encourage open and independent expression of their experiences. The interviewer utilized child-friendly communication techniques, including simplified language, visual aids, and interactive methods such as drawing or storytelling, when necessary, to facilitate children's comfort and engagement. These strategies ensured that children's unique experiences and viewpoints were clearly articulated and accurately represented.

Data analysis

The data were analyzed using a reflexive thematic analysis approach, following Braun and Clarke's six-step framework (Braun & Clarke, 2023). We conducted a theoretically informed (directed) reflexive thematic analysis. Psychological Empowerment Theory functioned as a sensitizing framework that shaped an initial, deductive coding scaffold (e.g., intrapersonal: self-efficacy, confidence, perceived competence; interactional: problem-solving, navigation of resources and services, coordination/communication; behavioral: taking action, proactive coping, safety/emergency decision-making). Using Braun and Clarke's six steps, we first familiarized ourselves with the data (Step 1) and generated initial codes (Step 2) by combining these theory-informed code families with inductive, data-driven codes for content that extended or did not fit the framework (e.g., digital

Table 1
Semi-structured interview guide for children and parents.

Thematic Domain	Main Interview Questions	Probe Questions
Overall home-care experience	What has your experience of caring at home during cancer treatment been like? What aspects have gone well, and what has been difficult?	Can you describe these experiences in more detail? Which needs or expectations felt most important or urgent to you?
Emotional experiences	What emotions do you experience while providing care or living with care needs at home? What aspects of the home-care setting do you find emotionally challenging?	How did these emotions affect your daily life, coping, or sense of confidence at home?
Problem-solving and coping	What problem-solving or proactive coping strategies do you use to manage challenges in home-based care?	What strategies were most helpful? Were there situations where coping felt difficult or insufficient?
Empowerment needs	If there were aspects of home-based care that would empower you, what would you want them to be? In which areas do you feel most in need of empowerment?	What specific resources, training, or support would help you feel more confident or capable at home?
Contextual differences	Do your needs or expectations differ between hospital days and days at home?	Are there differences between child and parent perspectives regarding these needs and expectations?

guidance needs, care transitions, logistics). We then collated codes into candidate themes (Step 3), reviewed and refined themes against coded extracts and the full dataset (Step 4), defined and named themes to capture both framework-aligned and emergent aspects (Step 5), and produced the analytic narrative with illustrative quotations (Step 6). In contrast to a purely inductive thematic analysis—which would derive the entire coding frame from the data without a priori sensitizing concepts—our approach was theoretically directed at the outset but explicitly retained inductive openness to ensure that children's and parents' articulated needs and expectations were not constrained by the framework. This iterative and systematic approach was chosen to ensure transparency, dependability, and clarity throughout the analytical process. Given the dyadic nature of the study, the experiences of children with cancer and their parents were analyzed both individually and relationally, capturing the interconnected yet distinct aspects of their experiences during home-based pediatric oncology care (Alvesson et al., 2022).

Initially, each interview was transcribed verbatim by the Researcher 1 within 24 h of data collection. Transcripts were labeled sequentially based on interview order (e.g., "Child 1," "Parent 2") and stored securely. To gain an in-depth understanding of the data, the primary researcher engaged in repeated readings of the transcripts, noting initial patterns, key points, and preliminary insights. Following transcription, a Researcher 2 independently reviewed all transcripts to ensure accuracy, completeness, and methodological rigor. This independent review process enhanced the reliability of the data and minimized potential transcription errors. Subsequently, the primary researcher systematically coded the data, identifying and labeling meaningful segments that reflected the experiences, challenges, coping strategies, and empowerment needs expressed by children and their parents. To further refine and validate these initial codes, a collaborative coding process was conducted among all authors. Multiple rounds of discussions and iterative revisions were carried out, ensuring that the codes accurately and comprehensively represented the participants' narratives. This collaborative approach significantly enhanced the credibility and depth of the analysis.

In the next phase, the research team carefully reviewed and synthesized the coded data to identify emerging patterns and connections, leading to the formulation of overarching themes. After finalizing themes, we compiled a participant-level coverage summary for each sub-theme to aid transparency. Specifically, for each child ($N = 18$) and parent ($N = 18$), we recorded whether the sub-theme was mentioned at least once and reported the proportion as a descriptive indicator. These coverage counts were compiled post hoc for descriptive purposes only; consistent with reflexive thematic analysis, thematic importance and interpretation were not determined by frequency, and no statistical inferences were made. These themes were thoughtfully defined and named to capture the core essence of both shared and individual experiences of children and their parents in the context of home-based pediatric oncology care.

Finally, to validate the authenticity and reliability of the identified themes, representative participant quotes were incorporated into the findings. The inclusion of direct quotations ensured that the themes remained firmly grounded in the actual voices and lived experiences of the participants, further enhancing the trustworthiness and credibility of the study's results.

Ethical considerations

Ethical approval for the study was obtained from the University Ethics Committee (Approval No: 2022/1171), and written permission was granted by the hospital where the research was conducted. Written and verbal information about the study was provided to both children and their parents prior to participation, and informed consent was obtained from parents. In addition to parental consent, children's willingness to participate was assessed in an age-appropriate manner, and verbal assent was obtained before the interviews.

During the interviews, both children and parents were informed that audio recordings would be made, and written consent for audio recording was obtained. Throughout the data collection process, particular attention was paid to protecting children's emotional well-being, autonomy, and right to decline participation or withdraw from the study at any time without any impact on their care.

Rigor and reflexivity

We implemented several established qualitative research strategies to ensure methodological rigor and reflexivity (Alvesson et al., 2022; Braun & Clarke, 2023). Two researchers independently coded all interview transcripts, followed by regular consensus meetings to resolve discrepancies and integrate diverse perspectives. Participant confirmation was conducted by inviting participants to validate the accuracy of extracted codes and themes. Additionally, detailed methodological descriptions aligned with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist were provided to enhance transferability and transparency (Alvesson et al., 2022).

Results

This qualitative research on the needs and expectations for empowerment of children with cancer aged 8–18 and their parents regarding home care has revealed multifaceted insights. In an analysis of the main characteristics of children with cancer and their parents, it was determined that the children had an average age of 12.50 ± 3.05 years, with 55.6 % girl. Notably, 38.8 % of these children were diagnosed with leukemia. Their mean time since child's diagnosis was found to be 5.94 ± 3.07 months. As for the parents, 83.3 % were identified as mothers with an average age of 37.16 ± 4.98 years. Also, in terms of educational status, 77.8 % had completed high school or higher education level (Table 2).

The study identified two main themes and five sub-themes, which are presented in Table 3. These themes provide a comprehensive understanding of the challenges faced by children and their parents during home-based pediatric cancer care, as well as their needs and expectations for empowerment. The first theme, "Navigating Challenges in

Table 2
Main characteristics of children ($n = 18$) and parents ($n = 18$).

Characteristics of Children		n	%
Age (Mean ± SD) (12.50 ± 3.05)	8–12 years	8	44.4
	13–18 years	10	55.6
Gender	Girl	10	55.6
	Boy	8	44.4
Diagnosis	Leukemia	7	38.8
	Sarcoma	5	27.8
	Lymphoma	4	22.3
	CNS tumors	2	11.1
Time since child's diagnosis (Mean ± SD) (5.94 ± 3.07)	6 months and under	12	66.7
	6 months above	6	33.3
Characteristics of parents		**n**	**%**
Parents	Mother	15	83.3
	Father	3	16.7
Parents Age (Mean ± SD) (37.16 ± 4.98)	25–35 years	7	38.9
	36–45 years	11	61.1
Education Status	Elementary	4	22.2
	High school	8	44.5
	University and above	6	33.3

Abbreviations: CNS, central nervous system; SD, standard deviation.

Table 3
Categories, main themes, and sub-themes in the study.

Categories	Main Themes	Sub-Themes
Home-Based Pediatric Cancer Care: Needs	Navigating Challenges in Home-Based Pediatric Cancer Care	**Physical care challenges** - Managing medications - Symptom and side-effect management - Nutrition concerns and challenges - Challenges and fears in catheter care **Emotional and psychosocial challenges** - Ups and downs in emotion management - Difficulties in finding coping mechanisms - The need for social support and reinforced networks
Home-Based Empowerment in Pediatric Cancer Care: Expectations	The Lighthouse of Empowerment: A Guiding Support	**Digital interventions in home-based pediatric cancer care** - Digital accessibility - Interactive support platforms **Psychological support and coping in home-based pediatric cancer care** - Emotional and psychological empowerment modules - Therapeutic interactions in home-based care **Emergency roadmap for home-based pediatric cancer care** -Emergency Digital Protocols: A clear, accessible roadmap -Emergency blueprint

Home-Based Pediatric Cancer Care," explores the physical and emotional difficulties encountered by children and their parents. The second theme, "The Lighthouse of Empowerment: A Guiding Support," highlights the tools and interventions needed to empower families in managing home care effectively. These themes and sub-themes are summarized in Table 2. Also, Table 4 presents the number and percentage of participants (children and parents) who mentioned each sub-theme at least once.

Theme 1: Navigating challenges in home-based pediatric cancer care

Participants described home-based pediatric cancer care as a period marked by heightened responsibility, uncertainty, and emotional strain, during which families were required to assume complex caregiving roles traditionally managed within clinical settings. Both children and parents emphasized that transitioning care to the home environment introduced multifaceted challenges that extended beyond physical tasks, encompassing emotional, psychological, and organizational demands. These challenges were experienced as unpredictable and cumulative, often intensifying feelings of vulnerability and inadequacy in managing care independently. These findings are illustrated with exemplar child and parent quotations in Table 5.

Theme 1.1: Physical care challenges

Children and parents consistently portrayed physical care at home as a complex and anxiety-provoking process requiring constant attention and decision-making. Core caregiving responsibilities—including medication administration, symptom and side effect management, nutritional care, and catheter maintenance—were not perceived as routine tasks, but rather as high-stakes activities undertaken without immediate professional support. The home environment amplified concerns about safety, correctness, and potential harm, underscoring families' need for clear guidance, accessible resources, and practical, context-specific support.

Medication management emerged as a central challenge, particularly due to complex regimens involving multiple drugs, varying dosages, and strict timing requirements. Parents expressed persistent fear of making mistakes that could adversely affect their child's health, while children described confusion and uncertainty about medication adherence and bodily responses. These experiences reveal a gap between prescribed treatment plans and families' confidence in safely implementing them at home.

Symptom and side effect management further compounded caregiving stress. Children reported difficulty recognizing, articulating, and interpreting symptoms such as pain or nausea, often leading to fear and emotional distress. Parents described uncertainty regarding appropriate responses to symptom escalation, particularly in the absence of clear thresholds for concern or actionable guidance. This uncertainty heightened emotional burden and reinforced reliance on trial-and-error approaches in managing care.

Nutritional challenges were described as dynamic and emotionally taxing, driven by fluctuating appetite, nausea, and dietary restrictions. Parents expressed concern about meeting nutritional requirements while avoiding potential risks, whereas children reported anxiety related to food choices and their perceived safety at home. These challenges highlighted the limitations of standardized dietary advice when applied to the nuanced realities of daily home care.

Catheter care was frequently associated with fear and heightened vigilance, particularly regarding infection risk and accidental dislodgement. Routine activities such as bathing or sleeping were described as sources of anxiety for both children and parents. The lack of practical, easily accessible guidance for catheter management at home contributed to ongoing worry and a heightened sense of responsibility.

Theme 1.2: Emotional and psychosocial challenges

The unpredictable course of childhood cancer gave rise to substantial emotional and psychosocial challenges for both children and parents during home-based care. Participants described the home environment as emotionally demanding, marked by heightened vulnerability,

Table 4
Participant-level coverage of sub-themes among children ($n = 18$) and parents ($n = 18$).

Main and Sub-Themes	n (Children)	%	n (Parents)	%
Navigating Challenges in Home-Based Pediatric Cancer Care				
Physical Care Challenges	15	83.3	17	94.4
Emotional and psychosocial challenges	14	77.7	16	88.8
The Lighthouse of Empowerment: A Guiding Support				
Digital interventions in home-based pediatric cancer care	12	66.6	18	100
Psychological support and coping in home-based pediatric cancer care	13	72.2	18	100
Emergency roadmap for home-based pediatric cancer care	7	38.8	16	88.8

* Values indicate the number (n) and percentage (%) of participants who mentioned each sub-theme at least once.

Table 5
Exemplar quotations from children and parents across sub-themes.

Theme	Sub-theme	Child exemplar quote	Parent exemplar quote
Theme 1	Physical care challenges	*"Sometimes I'm not sure if I've taken my medicine, and I'm scared of taking it twice or missing it completely. It's confusing… "(Child:7)*	*"At home, five different drugs must be given in different dosages and at different times. It's like scheduling a medication schedule every day, and it's confusing…I constantly worry if I've given the right dose to my child. The last thing I want is to make a mistake that could harm them." (Parent:2)*
		"At home, I sometimes get these weird pains and it scares me. I don't always know how to make them go away or how to tell my parents exactly where it hurts. I wish I had a better way to understand and manage what I feel." (Child: 4)	*"Especially when my daughter has severe headaches, I don't know what to do. I need more information and support to cope with the symptoms and side effects we experience at home."(Parent:11)*
Theme 1	Emotional and psychosocial challenges	*"When I'm at home, I have too much time to think about my illness… at home, I feel alone with my thoughts, and it makes me more anxious." (Child:7)*	*"At home, I feel completely responsible for my child's emotional state… I often feel helpless and unsure about how to comfort him." (Parent:12)*
Theme 2	Digital interventions in home-based care	*"Sometimes everything can be overwhelming for me, but apps can give me a sense of control… to assess my symptoms at home, get recommendations, or remind myself when to take medications." (Child:11)*	*"When I encounter an issue, I want to find an answer instantly… reaching out to the doctor or nurse can be time-consuming." (Parent:16)*
Theme 2	Psychological support and coping in home-based care	*"…I just close my eyes and take a deep breath. I feel that the storm of difficult emotions inside me calms down for a moment." (Child:18)*	*"Throughout this rollercoaster journey, inner peace serves as a guiding compass for me… support for emotional well-being feels like anchoring in the middle of a storm." (Parent:3)*
Theme 2	Emergency roadmaps for home-based care	*"Sometimes, I suddenly feel bad at home, and my mom and dad don't know what to do… I wish there was a simple app or website that tells us what to do next." (Child:4)*	*"A digital roadmap we can access at any time would be a game changer in how we manage home care." (Parent:13)*

fluctuating emotions, and a sense of isolation. These challenges shaped expectations for sustained emotional support, effective coping strategies, and stronger social connections throughout the home-care period.

Children frequently described emotional ups and downs associated with spending extended periods at home, where worries about illness and treatment became more prominent. In contrast to the hospital environment—where the presence of healthcare professionals and peers provided reassurance—being at home often intensified feelings of loneliness and anxiety. Children reported that having "too much time to think" about their illness increased emotional distress and made it harder to regulate their emotions independently.

Parents emphasized the emotional burden of assuming primary responsibility for their child's psychological well-being in the home setting. Without immediate access to professional support, parents described feeling unprepared to respond to their child's emotional needs, particularly during moments of fear, sadness, or distress. This responsibility often generated feelings of helplessness and self-doubt, as parents struggled to balance caregiving demands with their own emotional strain.

Both children and parents reported difficulties in identifying and sustaining effective coping mechanisms. Children expressed uncertainty about how to manage difficult emotions at home, while parents described frustration and emotional exhaustion when their efforts to support their child felt insufficient. These challenges reflected a gap between families' emotional needs and the availability of structured coping guidance within home-based care.

Social support and reinforced networks emerged as a critical source of emotional resilience for both groups. Children highlighted the importance of connecting with peers who shared similar experiences, describing such interactions as comforting and normalizing. Parents similarly emphasized the value of connecting with other families facing pediatric cancer, noting that shared experiences fostered emotional strength and a sense of collective coping. However, opportunities for consistent social connection were often limited during home-based care, exacerbating emotional vulnerability.

Emotional and psychosocial difficulties have been intertwined with and persistently experienced alongside the responsibilities of pediatric cancer care at home. Participants' narratives emphasize the necessity of accessible, family-centered psychosocial support that promotes emotional regulation, coping skills, and social connectedness for both children and parents at home.

Theme 2: The lighthouse of empowerment: a guiding support

This theme captures children's and parents' expectations for empowerment-oriented supports that would enable them to navigate the uncertainties and demands of home-based pediatric cancer care more confidently. Participants described empowerment not merely as receiving information, but as gaining a sense of control, emotional stability, and preparedness, particularly in contexts where professional support is less immediately accessible. Three interrelated sub-themes were identified: digital interventions, psychological support, and emergency roadmaps, each reflecting different yet complementary dimensions of empowerment in the home-care setting. These findings are illustrated with exemplar child and parent quotations in Table 5.

Theme 2.1: Digital interventions in home-based pediatric cancer care

Participants consistently emphasized the need for digital interventions that are accessible, interactive, and tailored to the realities of home-based care. For both children and parents, digital tools were perceived as mechanisms that could reduce uncertainty, support decision-making, and enhance autonomy by providing timely, trustworthy guidance outside the hospital environment.

Children highlighted that digital platforms could help them better understand and monitor their symptoms, remember medication schedules, and feel more actively involved in their own care, thereby fostering a sense of control. Parents similarly viewed digital tools as facilitators of more structured and confident caregiving, particularly when faced with complex symptom management or uncertainty about next steps at home. Interactive features that allowed real-time questioning and immediate feedback were described as especially critical, as delays in accessing professional advice often intensified anxiety and decisional burden.

Theme 2.2: Psychological support and coping in home-based pediatric cancer care

Beyond physical caregiving demands, participants described emotional challenges as more pervasive and difficult to manage in the home-care context. Both children and parents emphasized the need for structured psychological support that could enhance emotional

awareness, self-efficacy, and resilience during prolonged periods at home.

Children described simple emotional regulation strategies—such as breathing or mindfulness practices as potentially calming and stabilizing during moments of distress, while parents emphasized the importance of psychological support that acknowledged their own emotional needs alongside those of their child. Such support was perceived as a way to reduce feelings of isolation, emotional exhaustion, and helplessness that often-accompanied home-based care.

Participants also underscored the value of therapeutic interactions, particularly those facilitated through accessible formats such as online platforms. These interactions were seen as opportunities for emotional expression, normalization of experiences, and strengthening the parent–child relationship during a highly stressful period. Psychological empowerment was thus conceptualized as both an individual and relational process, enabling families to cope more effectively with the emotional complexity of home-based pediatric cancer care.

Theme 2.3: Emergency roadmap for home-based pediatric cancer care

A prominent source of anxiety for both children and parents was the absence of clear, structured guidance for managing emergencies at home. Participants described emergency situations as moments of heightened panic and cognitive overload, during which uncertainty about what to do next intensified feelings of vulnerability.

Children expressed fear when they sensed their parents' uncertainty during sudden symptom escalation, while parents highlighted logistical challenges such as geographical distance from treatment centers. In this context, emergency roadmaps—particularly in digital formats—were perceived as critical empowerment tools that could provide step-by-step guidance, reinforce preparedness, and reduce panic during acute situations. Emergency roadmaps were therefore framed as mechanisms that enhance safety, decisional confidence, and continuity between home and hospital care, contributing to a stronger sense of preparedness for both children and parents.

Discussion

The home-based care of children with cancer and their families presents a complex and multifaceted landscape that extends beyond clinical interventions, encompassing physical, emotional, and psychosocial dimensions (Jibb et al., 2022). This study, which explores the experiences and expectations of children with cancer and their parents during home-based care, provides critical insights into the challenges and empowerment needs of families navigating this journey. By adopting a dyadic approach, the study uniquely captures the interconnected experiences of children and their parents, offering a holistic perspective on the dynamics of home-based pediatric cancer care. Previous qualitative studies similarly indicate that pediatric cancer care at home entails significant informational, practical, and psychosocial needs for children and parents (Mueller et al., 2022; Jibb et al., 2022; Hammer et al., 2023; Ozdemir Koyu and Kilicarslan, 2024).

The first main theme, "Navigating Challenges in Home-Based Pediatric Cancer Care," underscores the intricate and often overwhelming nature of managing pediatric cancer care at home. The findings reveal that families face significant physical and emotional challenges, which align with existing literature emphasizing the complexity of home care in non-clinical environments (Cheng & Tan, 2021; Mueller et al., 2022; Orford et al., 2023; Ross et al., 2023). The sub-theme "Physical Care Challenges" highlights the difficulties families encounter in managing medications, symptoms, side effects, dietary adjustments, and emergencies. These findings resonate with studies such as Mueller et al., which emphasize the potential of mobile applications like "The Cope 360" to assist parents in monitoring symptoms, managing medications, and planning for emergencies (Mueller et al., 2022). The need for structured and accessible tools to address these challenges is evident, as families often lack the resources and guidance necessary to navigate the physical demands of home care. This aligns with broader research advocating for the integration of digital tools to simplify and enhance the management of physical health in home settings. Current qualitative studies consistently report comparable concerns about medication scheduling, symptom monitoring, line/port care, and nutrition, underscoring the need for plain-language, actionable guidance for home care (Hammer et al., 2023; Orford et al., 2023; Ross et al., 2023). The sub-theme "Emotional and Psychosocial Challenges" reveals the profound psychological impact of home-based care on both children and their parents. The unpredictable progression of the disease amplifies the need for emotional management strategies and robust support networks. Greenzang et al. emphasize the importance of social support and connections with other families during the treatment process, which aligns with our findings highlighting the need for structured emotional roadmaps and peer support systems (Greenzang et al., 2023). These insights underscore the critical role of nurses and healthcare professionals in recognizing and addressing the emotional needs of families, thereby improving the quality of care and patient outcomes.

The second main theme, "The Lighthouse of Empowerment: A Guiding Support," emphasizes the transformative potential of digital interventions in pediatric cancer home care. In an era of digital transformation, the integration of technology into home care emerges as a pivotal strategy for empowering families and addressing their unmet needs. Participants in this study expressed a strong need for user-friendly, web- or app-based platforms that provide real-time, interactive support. These findings align with research on the COG KidsCare app, which demonstrates the value of digital tools in bridging knowledge gaps and providing practical, psychosocial, and emotional support to families (Landier et al., 2023). Similarly, Greenzang et al. highlight the potential of eHealth resources to enhance understanding of treatment pathways and provide psychosocial support during the treatment process (Greenzang et al., 2023). Evaluations of pediatric oncology e-health tools in the qualitative literature echo these preferences for interactive, just-in-time guidance, while noting that trust, usability, and local tailoring shape uptake (Ross et al., 2023; Uysal ve Yigit, 2025). Our findings reinforce the importance of creating digital scaffolds that offer timely, individualized, and tangible support, transforming the isolating journey of home care into a collaborative and empowering experience (Luo et al., 2021; Park et al., 2022; Weaver et al., 2021).

The sub-theme "Psychological Support and Coping in Home-Based Pediatric Cancer Care" underscores the need for interventions that go beyond passive support to actively empower families. Structured psychological empowerment modules focusing on self-efficacy, proactive coping, and problem-solving skills are critical for fostering resilience in both children and parents. Existing evidence in pediatric oncology supports the development of such modules, which can enhance emotional well-being and equip families with the tools needed to navigate the challenges of home care (Cheng et al., 2023; Oliveira Silva et al., 2023; Greenzang et al., 2023; Hansson et al., 2022; Jin et al., 2022; Kim et al., 2023; Li et al., 2022; Luo et al., 2022; Rosenberg et al., 2019). Furthermore, therapeutic interactions facilitated through digital platforms can strengthen parent-child bonds and provide a constant sense of support, addressing the emotional turbulence of home care.

The sub-theme "Emergency Roadmap for Home-Based Pediatric Cancer Care" highlights the urgent need for systematic, comprehensive, and easily accessible emergency protocols. Families often find themselves unprepared for medical emergencies, which can transform the home environment from a place of comfort to one of uncertainty and fear. Real-time digital protocols, as suggested by recent studies, can bridge the gap between home care and hospital care, providing immediate clarity and guidance during emergencies (Landier et al., 2023; Mueller et al., 2022). These protocols not only enhance the safety and confidence of families but also ensure a more seamless integration of home and clinical care.

This study offers a dyadic, theory-informed analysis grounded in matched child–parent interviews, delineating shared and distinct perspectives and identifying priority targets for the tailored delivery of empowerment-focused supports. Also, present study provides a comprehensive perspective on the home-based pediatric cancer care. The findings highlight an urgent call to action for the need to adopt an integrated, technology-based, empathetic, and empowering paradigm for pediatric oncology care at home. Also, it is expected that the results of this study can act as a beacon that accelerates transformative changes in the home-based pediatric cancer care environment and guides it to a more compassionate, family-centered, and empowering trajectory.

Strengths and limitations

This qualitative study offers a comprehensive exploration of the experiences and expectations of children with cancer and their parents within the context of home-based pediatric cancer care. By employing a reflexive thematic analysis approach, the study captures the nuanced and contextually grounded experiences of participants, providing rich and detailed qualitative data. The use of semi-structured interviews, developed based on a thorough literature review and guided by Empowerment Theory, ensures a robust and systematic exploration of the research questions. Furthermore, the inclusion of a diverse sample of children with cancer and their parents enhances the depth and transferability of the findings, contributing to a broader understanding of the challenges and needs in home-based care.

Despite these strengths, the study has certain limitations. First, most interviews were conducted in the pediatric oncology-hematology ward rather than in participants' homes due to accessibility and safety considerations during active treatment and follow-up. Participants were identified on-site, and consent was obtained during hospital visits; when feasible, a subset of interviews ($n = 6$) was conducted online while families were at home to better reflect the home-care context. Nevertheless, the hospital setting may have constrained the naturalistic capture of the home environment and precluded direct observation and triangulation, which could have further enriched the finding. Second, the study was conducted in a specific cultural and institutional setting, which may limit the generalizability of the findings to other contexts or cultures. However, given the limited evidence in pediatric oncology nursing, this study provides a valuable foundation for future research exploring home-based pediatric cancer care across diverse cultural and healthcare settings. Lastly, the study focuses exclusively on the perspectives of children with cancer and their parents, without incorporating the views of healthcare professionals or other stakeholders involved in pediatric cancer care. Future research should aim to include these perspectives to provide a more holistic understanding of the challenges and opportunities in home-based care.

Implications for practice

This study identifies specific areas where pediatric oncology nursing practice can significantly enhance home-based care for children with cancer and their parents. Pediatric oncology nurses should prioritize the integration of practical digital tools, such as mobile applications and eHealth platforms, to facilitate real-time symptom management, communication, and emergency preparedness. Additionally, pediatric oncology nurses should actively develop and implement structured psychological support programs aimed at strengthening self-efficacy, emotional resilience, and proactive coping skills among parents. Establishing clear, accessible emergency protocols and providing targeted education to parents will further equip them to confidently manage critical situations at home. These practice-oriented strategies can directly improve the quality and continuity of pediatric oncology care in home settings.

Conclusion

This study underscores the critical need for systemic and holistic improvements in home-based pediatric oncology care. The findings highlight that addressing the comprehensive physical, emotional, and psychosocial needs of children with cancer and their parents requires innovative, evidence-based nursing interventions. Pediatric oncology nurses are uniquely positioned to advocate for and lead transformative changes in care delivery models, emphasizing family-centered approaches and empowerment. Ultimately, this research serves as a call to action for healthcare systems and nursing professionals to collaboratively enhance the home care experience, thereby improving overall well-being and outcomes for children and their parents.

An ethics approval statement

Ethical approval for the research was obtained from the Gazi University Ethics Committee (Approval No: 2022/1171).

CRediT authorship contribution statement

Hazal Ozdemir Koyu: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Conceptualization. **Ebru Kilicarslan:** Writing – review & editing, Supervision, Methodology, Investigation, Conceptualization.

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Declaration of competing interest

The authors declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2025.12.029.

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