Journal of Pediatric Nursing 89 (2026) 404–413

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

"Nothing is the same. We are all changed": European families' perspectives on adaptation and the nurse's role in supporting them

Camilla Ejlertsen [a,1], Hanna Seppänen [b,1,*], Eija Paavilainen [c], Erla Kolbrun Svavarsdottir [d], Henny Hraunfjord [e], Guðný Bergþóra Tryggvadóttir [e], Anna Olafia Sigurdardottir [f], Lígia Lima [g], Luísa Andrade [g], Sara Lemos [g], Maria do Céu Barbieri-Figueiredo [g], Rafaela Camacho-Bejarano [h], Dolores Merino-Navarro [i], Estela Dominguez-Carranza [j], Sonia Pastor-Montero [j], Tuija Leppäkoski [k], Anne Brødsgaard [l]

[a] Department of Public Health, Nursing and Healthcare, University of Aarhus, Aarhus C, Denmark
[b] Faculty of Social Sciences/Health Sciences, Tampere University, Tampere University Hospital, Etelä-Pohjanmaa Welfare Services County, Finland
[c] Faculty of Social Sciences/Health Sciences, Tampere University, Etelä-Pohjanmaa Welfare Services County, Finland
[d] School of Health Sciences, Faculty of Nursing and Midwifery, University of Iceland, Reykjavik; Landspitali University Hospital, Iceland
[e] Directorate of Health, Reykjavik, Iceland
[f] Landspitali University Hospital, Iceland, University of Iceland, School of Health Sciences, Faculty of Nursing and Midwifery, Iceland
[g] School of Nursing of Porto - University of Porto & RISE-Health, Portugal
[h] Faculty of Nursing, University of Huelva. Nursing and Health Care Research Unit (Investén-isciii) Health Institute Carlos III, The Research Network on Chronicity, Primary Care and Health Promotion (RICAPPS), Spain
[i] Faculty of Nursing, University of Huelva, Spain
[j] Juan Ramón Jiménez University Hospital, Andalusian Health Service, Faculty of Nursing, University of Huelva, Spain
[k] Faculty of social sciences/Health Sciences, Tampere University, Finland
[l] Copenhagen University Hospital Amager Hvidovre, Department of Paediatric and Adolescent Medicine, Department of Obstetrics and Gynecology; Aarhus University at the Department of Public Health, Nursing & Health; Roskilde University, Department for People and Technology, Health and Society, Denmark

ARTICLE INFO

Article history:
Received 7 November 2025
Revised 7 April 2026
Accepted 3 May 2026
Available online xxxx

Keywords:
Nursing
Pediatric nursing
Qualitative study
Family adaptation
Nursing support

ABSTRACT

Background: Caring for a child with a chronic condition places enduring emotional, relational, and practical demands on families. A deeper understanding of how families adapt, and how nursing care supports this process, is essential to strengthen family-centered pediatric nursing practice.
Purpose: This study explored parents' perceptions of their family's adaptation to a child's chronic condition and examined how they viewed the role of nurses in this process across diverse European healthcare contexts.
Methods: This qualitative sub-study was part of a multinational comparative project. Data comprised responses to three open-ended survey questions from parents of children (0–18 years) living with chronic conditions. Thematic analysis was conducted following Braun and Clarke's six-phase framework.
Findings: Two overarching themes were identified.
Meaning-Making in the Context of Family Vulnerability and Growth described families' experiences of psychological and relational burden, unmet support needs, and gradual adaptive growth.
Relational Care and Strengthening Family Agency captured how trust in professional competence, nurses' empathetic presence, and tailored guidance empowered families to manage care at home.
Parents reported ongoing strain and uncertainty but also described resilience and a sense of shared purpose when supported by relational and continuous nursing care.
Conclusion: Family adaptation to a child's chronic condition is a dynamic relational process shaped by both vulnerability and opportunities for growth. Nurses play a pivotal role in fostering trust, strengthening family agency, and alleviating emotional and practical burdens. Healthcare systems should prioritize continuity, relational depth, and accessible psychosocial and educational resources for families.

Introduction

A child's chronic condition places a considerable burden on families, profoundly influencing the quality of life of parents and caregivers

* Corresponding author.
E-mail address: hanna.seppanen@tuni.fi (H. Seppänen).
[1] Shared first authorship.

https://doi.org/10.1016/j.pedn.2026.05.002

(Chirani et al., 2025; Seppänen et al., 2025). Parents of children with chronic conditions or disabilities frequently report intense negative emotions such as grief, fear, and anger, in addition to persistent stress and uncertainty about the future (Bistaraki et al., 2025; Cici & Özdemir, 2024). The prolonged demands of caregiving may lead to parental exhaustion and diminished resilience, which can compromise condition management and the ability to fulfill parental roles (Cici & Özdemir, 2024). Notably, male caregivers often describe neglecting their own needs and highlight a desire for easily accessible emotional support (Lynch et al., 2021), while mothers, who typically assume the role of primary caregiver, experience a disproportionate level of strain (Chirani et al., 2025).

Caregiving burden has been conceptualized as the caregiver's physical, psychological, and social responses to the caregiving role (Chirani et al., 2025). Predictors of heightened burden include low socioeconomic status, frequent child hospitalizations in the preceding year, and high levels of intolerance of uncertainty (Doğaner & Celen, 2025). Coping strategies and patterns of adaptation vary considerably among parents and are shaped by individual characteristics and condition-related stressors (Chirani et al., 2025).

Lemos et al. (2024) examined technology-dependent children who rely continuously on one or more clinical devices. They found that families of children facing chronic conditions undergo reorganization, while parents experience various challenges and attempt to redefine their roles between parenting and caregiving. These experiences reveal the vulnerability of parents, highlighting the need for nursing support not only for the child but also for the parents.

Family nursing interventions are essential in addressing the multifaceted needs of families caring for children with chronic conditions. Grounded in the principles of Family Systems Nursing and Family-Centered Care (FCC), these interventions aim to enhance family resilience, reduce caregiver burden, and improve health outcomes for pediatric patients and their families (Shajani & Snell, 2023).

Health care professionals are pivotal in supporting families' adaptation to chronic childhood conditions, particularly through interventions that prioritize emotional support (Seppänen et al., 2025; Svavarsdottir et al., 2025). Evidence from a recent review suggests that, regardless of condition, families report substantial unmet needs for information, emotional support, and guidance in navigating healthcare services (Thomas et al., 2023). Identification of families at heightened risk, such as those with limited socioeconomic resources or children requiring frequent hospitalization, is essential to ensure the provision of tailored interventions, including professional support, peer support groups, and education on the care and management of chronic conditions (Doğaner & Celen, 2025).

Despite growing scholarly interest, substantial gaps remain in the literature. A comprehensive review has highlighted the paucity of studies focusing on non-cancer chronic conditions, the lack of standardized assessment tools and reporting practices, and the limited use of advanced research designs such as longitudinal studies (Thomas et al., 2023). In addition, few studies have explicitly adopted a multinational European perspective, despite considerable variation in healthcare systems and pediatric nursing practices across countries. Further clarification is also needed to advance understanding of parents' meaning-making processes in the context of pediatric chronic conditions, particularly beyond predominantly deficit-oriented accounts of caregiver burden and distress. Such research evidence is especially warranted at present, as pediatric healthcare is increasingly shifting from a focus on acute conditions toward long-term chronic conditions (Wijlaars et al., 2016). Although the study does not aim to compare countries, a multinational European design enables the identification of cross-contextual commonalities in how families navigate long-term caregiving demands. These shared relational and emotional patterns may strengthen the transferability of the findings across diverse pediatric care systems. Such an approach is particularly relevant given the growing emphasis on family-centered support in chronic care across Europe.

Given the pivotal role of healthcare professionals in supporting family adaptation, there is a clear need to deepen understanding of how parents experience both strain and joy in caring for a child with a chronic condition. Although previous research has largely concentrated on caregiver burden and emotional distress, less attention has been paid to parents' descriptions of resilience, meaning-making, and positive experiences as part of everyday family life. Addressing this gap is essential for informing more comprehensive and empathetic support strategies, particularly within pediatric nursing, for families navigating the long-term demands of caregiving. These gaps in the existing literature, particularly the limited European perspective and the lack of attention to parents' meaning-making and resilience, directly inform the aims of this study. To address these needs, we focus on parents' descriptions of family adaptation and on their perceptions of the pediatric nurse's role in this process. By integrating perspectives on meaning-making, family resilience, and relational pediatric nursing, the study seeks not only to illustrate but also to extend current conceptual understandings of how families adapt to long-term pediatric chronic conditions.

Aim

Against this backdrop, the present qualitative study aimed to explore how families across different European regions adapt to the challenges of living with a child diagnosed with a chronic condition. Specifically, the study sought to: (a) explore parents' perspectives on family adaptation to their child's chronic condition within diverse European contexts, and (b) examine how parents perceive the role of the pediatric nurse in supporting this adaptation process. To address these aims, two guiding research questions informed the qualitative study design:

- How do parents across Europe describe their family's adaptation to their child's chronic condition?
- How do parents perceive the pediatric nurse's role in this adaptation process?

Methods

Study design and data collection

This study forms part of an international comparative longitudinal study conducted between 2021 and 2023, aiming to explore the experiences and needs of families with children living with chronic conditions. Specifically, the survey sought to examine the impact of pediatric chronic conditions on family life and the support received from healthcare systems across selected Nordic countries (Iceland, Finland, Denmark) and Southern Europe (Spain, Portugal) (Andrade et al., 2024; Seppänen et al., 2025; Svavarsdottir et al., 2024). The survey was divided into five sections and included a total of 124 questions. It contained a battery of internationally validated questionnaires with fixed response options, focusing on the integration of chronic illness into family life. The qualitative analysis of this study was based solely on the two open-ended questions included in the survey. All questions were translated using a forward–backward translation process that involved both native and non-native speakers of the respective languages, all of whom were proficient in English. Forward translations were conducted from English into the local languages, followed by back-translation into English. The translated versions were compared and discussed within the research team to ensure conceptual and semantic equivalence across languages (Beaton et al., 2000).

Data were collected using an electronic survey. One parent from each family with a child aged 0 to 18 years with a chronic condition was invited to participate. The study included a total of 733 participants: 72 from Denmark, 76 from Finland, 178 from Iceland, 236 from Portugal, and 171 from Spain. Recruitment focused on families whose children

were receiving outpatient care for chronic conditions such as diabetes, heart conditions, intestinal and kidney diseases, and rheumatism. Only families whose child had been diagnosed at least six months prior to participation were included to ensure that the condition had sufficient time to influence family life. During routine outpatient visits, families received an information sheet outlining the study's purpose, procedures, and the online survey address. Parents completed the questionnaire at home, allowing for thoughtful reflection in a familiar and comfortable environment. Survey completion was encouraged through a subsequent reminder sent to families. Data in anonymous format were transferred from each country to Iceland using REDCap (Research Electronic Data Capture) (Harris et al., 2009). In line with the qualitative exploratory design, the sampling strategy was purposive rather than aimed at representativeness (Polit & Beck, 2017). Families were included across multiple European countries and a range of chronic conditions to capture diversity in family experiences and healthcare contexts, thereby supporting analytical depth and cross-contextual insight. For this qualitative sub-study, data from three open-ended survey questions were analyzed from Iceland, Denmark, Finland, Spain, and Portugal: one question (Q1: Anything else you want to mention regarding this chronic illness and your family's adaptation) addressing the chronic condition and the family's adaptation to it, and two questions (Q2: How have the nurses been helpful to your family?; Q3: What benefits, if any, do you and your family think you have had from the healthcare offered by nurses?) addressing perceived support from nurses and healthcare systems. Data were collected in the native language of each country and subsequently translated into English for the coding process.

Data analysis

The qualitative data were analyzed using reflexive thematic analysis, following the principles outlined by Braun and Clarke (2006, 2021). Their six-phase framework provided a structured approach to identifying patterns and constructing meaning from the lived experiences of families managing chronic conditions. Phase 1: Familiarization with the data – The data were read multiple times to build familiarity and gain a holistic understanding. Early reflections were noted to begin identifying patterns. Phase 2: Generating initial codes – Meaning units were coded inductively at a semantic level, capturing key aspects such as emotional strain, caregiving burden, and adaptation. Phase 3: Searching for themes – Codes were grouped and compared to identify preliminary themes based on shared meanings and relationships. Phase 4: Reviewing themes – Themes were refined through iterative review to ensure coherence within and distinction between themes. Phase 5: Defining and naming themes – Themes were clearly defined and structured into an overarching theme, sub-themes, and related categories, reflecting the complexity of family life with chronic conditions. Phase 6: Producing the report – Findings were synthesized into a thematic narrative, integrating representative data extracts and interpretative insights, and were presented.

Initial codes were generated inductively during Phase 2 (Table 1) by closely examining meaning units within the data and assigning descriptive labels that captured explicit content at a semantic level. Coding was first conducted individually by the researchers to allow for multiple analytic perspectives. Codes were then compared and discussed in pairs and in group meetings, where similarities, differences, and overlaps were examined. Through this iterative process, codes were refined, merged, or redefined to better capture patterns across the dataset.

During Phase 3, related codes were clustered into preliminary themes based on shared meanings and conceptual relationships. Analytic decisions regarding theme boundaries and coherence were made through reflexive discussion rather than agreement-seeking, with attention to how different interpretations illuminated distinct aspects of family adaptation. When divergent readings occurred, the original data excerpts were revisited, and alternative interpretations were explored to deepen analytic insight.

Table 1
Illustrative quotes for the code: "Confidence in the nurse's clinical skills and thoroughness".

Code	Citations
Confidence in the nurse's clinical skills and thoroughness	"Professional, solution-oriented and positive employees." "The nurse noticed high blood pressure in the child during admission and because of that, the child is undergoing tests because of it. No one else had thought about this pressure." "It is the nurses' merit that our child's well-being steadily improved during our hospitalization." "We have full trust in them, and they have truly managed to make every hospital visit a positive experience." "It is reassuring that they are so thorough." "They know how to take care of my child."

In Phases 4 and 5, themes were critically reviewed and further refined in collaboration with the wider international research team. This process supported analytic transparency and helped ensure that themes were internally coherent, clearly distinct, and firmly grounded in the data. Throughout the analysis, reflexive dialogue functioned as a key strategy for supporting rigor and trustworthiness rather than aiming for inter-coder reliability, consistent with reflexive thematic analysis.

Of the three open-ended questions analyzed, Q1 received 143 responses, Q2 received 305 responses, and Q3 received 229 responses, reflecting varying levels of participant engagement across items. Although the number, length, and richness of responses varied across questions and participants, all responses were treated as analytically meaningful. Short responses were coded alongside more elaborated accounts, contributing to the identification of recurring patterns and shared meanings across the dataset. Analytic emphasis was placed on the interpretive content of responses rather than their length or frequency, consistent with a reflexive thematic analytic approach. Variation in response depth was understood as reflecting differing opportunities, cultural communication styles, and levels of engagement rather than analytic relevance.

Analysis was conducted by the core author group, consisting of four nurses, two professors, and two junior researchers. The professors specialize in family nursing and health promotion and have nearly 30 years of clinical and research experience working with families in neonatology and pediatrics, both within and across healthcare sectors. The two junior researchers have worked in obstetrics and pediatric departments and have completed or are undertaking doctoral research in these fields with a family perspective. The wider author group consists of mainly nurses, as well as a psychologist and a statistician, working and conducting research within family nursing. As researchers with backgrounds in family nursing and pediatric care, we remained attentive to how our clinical experience might shape our interpretations. Reflexive discussions within the team were therefore used to critically examine our assumptions, explore alternative readings of the data, and ensure that the final themes were grounded in participants' accounts rather than professional expectations.

This study's reporting follows the guidelines of Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

Ethics

The international research study encompassing this study received ethical approval from the University of Iceland (VSN-21-006, January 19th, 2021; VSN-21-006-V2, October 20th, 2021). In Finland, the study was approved by the Ethics Committee of Tampere University Hospital (R20153H, March 16th, 2021). In Spain, the study was approved by the

Ethics Committee of Huelva of the Junta de Andalucía (PI 023/21, May 2021). In Portugal, the study was approved by four Ethics Committees of hospital institutions in Northern Portugal (No. 52/2021, April 14th, 2021; No. 38/2021, February 25th, 2021; No. 98/2021, May 26th, 2021; and No. 16/2021, March 1st, 2021). In Denmark, no approval from the Danish National Ethical Committee was required under Danish law, as the study did not involve the collection or use of human biological material. However, the study was registered with Pactius in the Capital Region in accordance with Danish data registration regulations (P-2021-205, March 23rd, 2021). The study followed the Declaration of Helsinki (World Medical Association) in all countries, including obtaining verbal and written consent, handling data anonymously, and maintaining confidentiality.

Findings

Parents' accounts of their family's adaptation to a child's chronic condition across Europe constitute the foundation for the findings presented below. The findings illuminate how families respond to and manage the challenges associated with long-term health conditions within differing cultural and healthcare contexts. Importantly, across these contexts, families' narratives illustrate how meaning-making processes, including how they interpret, emotionally process, and assign significance to their child's condition, become tightly interwoven with their capacity for resilience. Meaning-making serves not only as a way for families to understand the disruption caused by the illness but also as a mechanism that helps them reorganize routines, mobilize support, and cultivate new forms of agency. Thus, the two overarching themes reflect complementary dimensions of family adaptation: how families construct meaning from vulnerability, and how relational care supports these interpretations and strengthens the family's resilience over time.

The findings are presented according to the two overarching themes, Meaning-Making in the Context of Family Vulnerability and Growth (Table 2) and Relational Care and Strengthening Family Agency (Table 3), and their corresponding sub-themes identified in the analysis. To illustrate and substantiate these findings, anonymized quotations representative of each sub-theme are included, providing insight into the experiences that informed the thematic structure.

How do parents across Europe describe their family's adaptation to their child's chronic condition?

The overarching theme, Meaning-Making in the Context of Family Vulnerability and Growth (Table 2), illustrates how families across five European countries navigate the emotional, relational, and structural challenges of adapting to a child's chronic condition. The first overarching theme emerged from three interrelated sub-themes: Psychological and Relational Strain, Structural Gaps and Support Needs, and Adaptive Growth and Empowerment. Together, these sub-themes reflect the complex and dynamic process through which families make sense of their situation, seek support, and gradually develop new forms of resilience and agency.

Table 2
How do parents across Europe describe their family's adaptation to their child's chronic condition?

Theme	Sub-themes	Codes
Meaning-Making in the Context of Family Vulnerability and Growth	**Psychological and Relational Strain**	Emotional Burden and Individual Distress
		Strain on the Family and Interpersonal Relationships
	Structural Gaps and Support Needs	Unmet Needs and the Desire for Support
	Adaptive Growth and Empowerment	Family Growth and Positive Transformation
		Empowerment and Positive Emotional Responses
		The Importance of Peer and Social Support

Table 3
How does the family perceive the pediatric nurse's role in this process?

Theme	Sub-themes	Codes
Relational Care and Strengthening Family Agency	Safety and trust anchored in professional care	Confidence in the nurse's clinical skills and thoroughness
		Feeling secure during hospitalization and at home
		Trust in long-term follow-up and monitoring
		Relief from knowing the child is in good hands
		Building trust with a known professional
		Reliable availability between scheduled appointments
	Emotional Support and Recognition of the Whole Family	A sense of being followed and remembered
		Feeling cared for even outside the hospital
		Being seen, heard, and emotionally supported
		Encouragement, validation, and hope
		Respect for the child's fears and emotional needs
		Recognition of the emotional load on parents
		Presence and support in times of chaos or trauma
	Knowledge and Practical Support as a Foundation for Family Competence	Illness-specific education and tailored advice
		Guidance on medication, symptom management, and routines
		Feeling more prepared and confident at home
		Ongoing access to advice and clarification
		Help in navigating and understanding care options

Psychological and relational strain

Parents described the diagnosis and subsequent adaptation as a profound emotional challenge, often marked by fear, anxiety, and grief. This emotional burden was compounded by physical symptoms of stress and a perceived lack of understanding from others. As one parent expressed:

> *"Nothing is the same. We are all changed… We have become isolated and put all our needs and dreams aside so that we can take care of the child." (Iceland).*

The constant vigilance required in daily care created a sense of being permanently 'on duty,' leading to exhaustion, psychological strain, and a perception of social isolation from peers, community life, and everyday social activities:

> *"The fatigue caused by having to deal with the child, physiotherapy, and work." (Portugal).*

These pressures often disrupt family dynamics, resulting in social withdrawal, challenges in sharing responsibilities, and uncertainty

about the future. Single parents highlighted the heavy caregiving load and financial strain.

Structural gaps and support needs

Across countries, parents reported significant unmet needs for professional and psychosocial support from the healthcare sector. Many described feeling abandoned following the initial diagnosis, with little guidance on how to manage the condition or its emotional impact:

"We were given the diagnosis and then left completely on our own." (Finland).

Others emphasized that earlier intervention and counseling from nurses and other healthcare professionals could have prevented hospital visits, crises, and reduced the emotional toll:

"When a family is confronted with a child's health problem, they should be immediately referred to psychology sessions." (Portugal).

Parents also pointed to systemic shortcomings, such as a lack of evidence-based information, insufficient extended family training, and limited access to respite care, which amplified stress and uncertainty.

Adaptive growth and empowerment

Despite these ongoing challenges, many parents described positive transformations unfolding alongside persistent strain rather than replacing it. Strengthened family bonds, a renewed sense of perspective, and an increased ability to live in the present moment were portrayed as adaptive responses that coexisted with, and at times were shaped by, the continuous demands of the condition. This underscores family adaptation as a dynamic and non-linear process, marked by fluctuation rather than resolution.

"Every day we are learning to live with it, without wanting to look to the future." (Spain).

Parents also expressed pride, gratitude, and determination, recognizing their own and their child's resilience:

"We are positive and proud of our sick child and often take him as an example." (Iceland).

Peer and community support were highlighted as critical resources in navigating this ongoing tension between strain and adaptation. Social connectedness was described as sustaining families' capacity for adaptive growth, not by eliminating the burden associated with the condition, but by providing relational spaces for relief, meaning-making, and renewed coping in the midst of its constant presence.

In summary, these findings illustrate that families' adaptation to a child's chronic condition is not a linear process, but a dynamic interplay between vulnerability and growth. Despite structural inequalities and psychological stressors, families exhibit a notable capacity for resilience and empowerment when they are able to construct meaning within their sociocultural context.

Taken together, the three sub-themes illustrate that meaning-making is not merely an interpretive task but a dynamic resilience-building process. By making sense of emotional strain, navigating structural challenges, and identifying sources of growth, families create narratives that help families regain coherence, sustain hope, and mobilize internal and external resources. Meaning-making thus becomes the pathway through which vulnerability can be transformed into adaptive capacity, laying the foundation for the relational forms of support explored in the second theme.

How does the family perceive the pediatric nurse's role in this process?

While the first overarching theme highlighted how families engage in meaning-making to navigate the emotional and structural challenges of chronic illness, this second theme demonstrates how pediatric nurses actively support these meaning-making processes. Rather than merely addressing families' needs, nurses' relational presence and professional care function as stabilizing forces that help families translate their interpretations into a sense of clarity, confidence, and agency. In this way, relational care becomes a key mechanism through which families' own meaning-making efforts are strengthened.

The second overarching theme, Relational Care and Strengthening Family Agency (Table 3), illustrates how trust, emotional recognition, and knowledge sharing contribute to families' sense of safety, competence, and empowerment. This overarching theme emerged from three interrelated sub-themes: Safety and Trust Anchored in Professional Care, Emotional Support and Recognition of the Whole Family, and Knowledge and Practical Support as a Foundation for Family Competence. Together, these sub-themes illustrate how nurses and other healthcare professionals create safety, provide emotional and informational support, and thereby strengthen the families' agency in adapting to a child's chronic condition.

Safety and trust anchored in professional care

Families expressed deep trust in healthcare personnel, describing competence and continuity as crucial for safety and stability in everyday life. Trust in the team enabled parents to focus on their parental role.

"It's a feeling; I feel that we are well cared for and in good hands." (Spain).

Professional guidance and support provided by nurses strengthened the family's sense of competence in managing the child's condition even after hospital discharge.

"Giving the appropriate knowledge to manage the illness, always giving encouragement and strength." (Spain).

Familiarity with a few nurses was particularly valued, as they knew the child, the child's condition, and the family well.

"We get services in the outpatient department for diabetic children, and I think we gain a lot from the specialization and having the same nurse who is specialized in this field or knows him very well." (Iceland).

The significance of nurses' professional competence extends beyond the hospital setting. Families' sense of security is sustained by the knowledge that nursing support and expertise are within their reach.

"High security. They are there if something happens. Can be reached even if you are outside the hospital." (Iceland).

In particular, the accessibility of a nurse familiar with the family fosters a sense of security and reassurance that the family is being supported.

"My son's nurse has always been there and is in regular phone contact with me, and I love being able to rely on her […] she is always quick to answer back." (Iceland).

Emotional support and recognition of the whole family

Empathy, respect, and presence from nurses fostered feelings of being seen, heard, and emotionally supported. Such encounters alleviated stress and provided encouragement.

"I felt truly heard and safe after our visit." (Denmark).

Conversely, some families felt nurses were too focused on bureaucracy or technical tasks rather than the family's needs.

"I have never received any support from the nurses. Their role has been limited to bureaucratic aspects: giving the next appointment or a note for work and school." (Spain).

Families frequently recognized the nurse's heavy workload, which they interpreted as resulting in insufficient support and a sense of being left to cope independently. Families' perceptions reflect how structural constraints within healthcare can shape families' experiences of care and support.

"We were largely left to ourselves, and they were very busy." (Denmark).

Families emphasized the importance of nurses' affirmation and emotional support, reinforcing their confidence as parents and fostering a sense of being heard and valued.

"They have been good at complimenting me on how well I am doing to take care of the baby. They are always willing to listen." (Iceland).

Another central aspect of supportive care was child-centered interaction, where nurses' engagement with the child reassured parents that their child's needs were acknowledged and respected.

"They are really good at interacting with our child." (Denmark).

Families also underlined the value of support when navigating challenging circumstances. Nurses' ability to facilitate problem-solving and strengthen family resources was described as essential for resilience.

"Listened to us talk about our problems and pointed out helpful ways to work with ourselves. Taking care of the family during a difficult time." (Iceland).

Knowledge and practical support as a foundation for family competence

Families emphasized the importance of receiving education and guidance from nurses. Information about the condition, symptoms, treatment, and routines increased their confidence and preparedness to manage care at home.

"We have received most of our education from nurses. We can truly say that they are our holding rope." (Iceland).

Nurses also clarified treatment options and ensured that families had the knowledge to make informed decisions.

"Obtaining all the necessary information to understand the illness." (Spain).

In summary, the findings demonstrate that nurses play a pivotal role in supporting families' adaptation to a child's chronic condition by fostering safety and trust, offering emotional recognition and support, and strengthening families' competence through knowledge and guidance. While families emphasized gaps and challenges, the results highlight that relational, accessible, and family-centered nursing care can empower families and enhance their resilience in navigating the long-term demands of chronic conditions.

Together, these findings illustrate how families navigate Meaning-Making in the Context of Family Vulnerability and Growth and how Relational Care and Strengthening Family Agency (Figs. 1+2) shape their everyday management of chronic condition setting the stage for the discussion of the broader conceptual implications that follow.

Across both overarching themes, the findings reveal that meaning-making and family resilience are mutually reinforcing processes. Families' interpretations of the illness shape how they perceive challenges, seek support, and identify possibilities for growth, while relational and knowledge-based support from nurses strengthens the family's

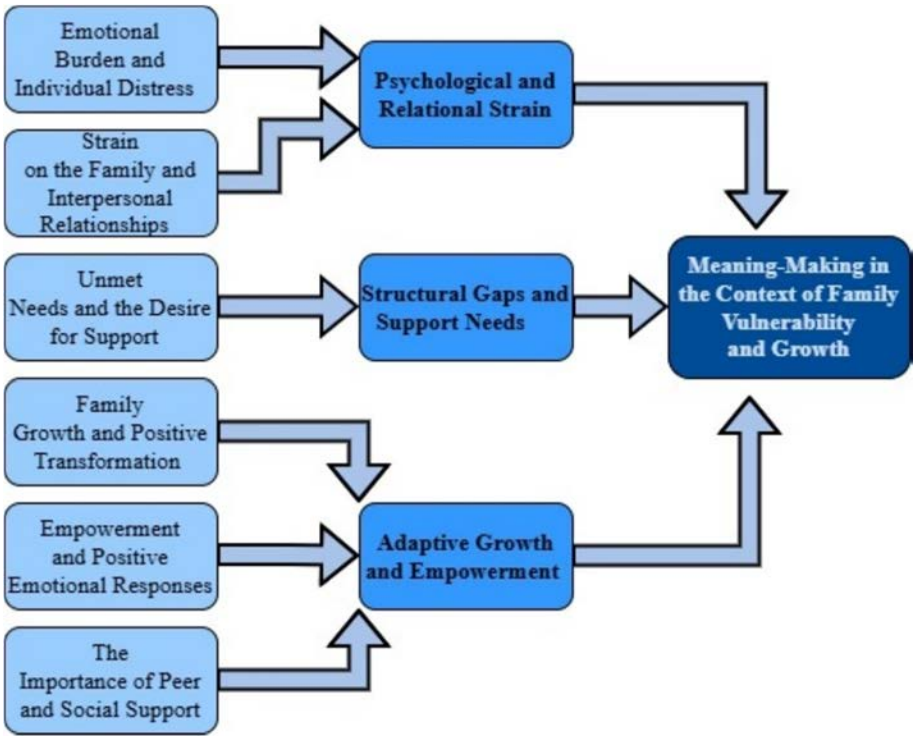

Fig. 1. How families across Europe construct Meaning-Making in the Context of Family Vulnerability and Growth.

capacity to sustain these interpretations over time. The integration of these perspectives shows that resilience is not a static trait but an ongoing, co-constructed process emerging from families' internal meaning-making efforts and the external relational support provided by pediatric nurses.

Fig. 1 illustrates the overarching theme "Meaning-Making in the Context of Family Vulnerability and Growth," including its three interrelated sub-themes (Psychological and Relational Strain; Structural Gaps and Support Needs; Adaptive Growth and Empowerment). Each subtheme is depicted with its underlying categories, demonstrating how emotional strain, unmet support needs, and adaptive growth processes collectively shape families' experiences when navigating a child's chronic condition across different European contexts.

Fig. 2 visualizes the overarching theme "Relational Care and Strengthening Family Agency," including its three sub-themes (Safety and Trust Anchored in Professional Care; Emotional Support and Recognition of the Whole Family; Knowledge and Practical Support as a Foundation for Family Competence). The figure depicts how specific forms of professional competence, emotional recognition, and tailored guidance contribute to strengthening families' sense of security, capability, and agency in managing their child's chronic condition.

Discussion

This study explored how families across different European contexts adapt to the complex reality of living with a child's chronic condition. The findings reveal that adaptation is not merely a response to medical challenges but a deeply relational and emotional process shaped by meaning-making, systemic support, and the quality of interactions with healthcare professionals. Taken together, these findings provide the basis for the following discussion of two central dimensions of this adaptation process: how families construct meaning in the face of vulnerability and growth, and how relational nursing care can serve as a foundation for strengthening family agency.

Meaning-making as a catalyst for adaptation and growth

The findings underscore the central role of meaning-making in how families across Europe adapt to the challenges of a child's chronic condition. While families described profound psychological strain and structural barriers, many also articulated a process of reinterpreting their experiences in ways that fostered resilience, strengthened relationships, and cultivated a renewed sense of purpose. Such patterns align with existing literature suggesting that meaning-making is a key mechanism

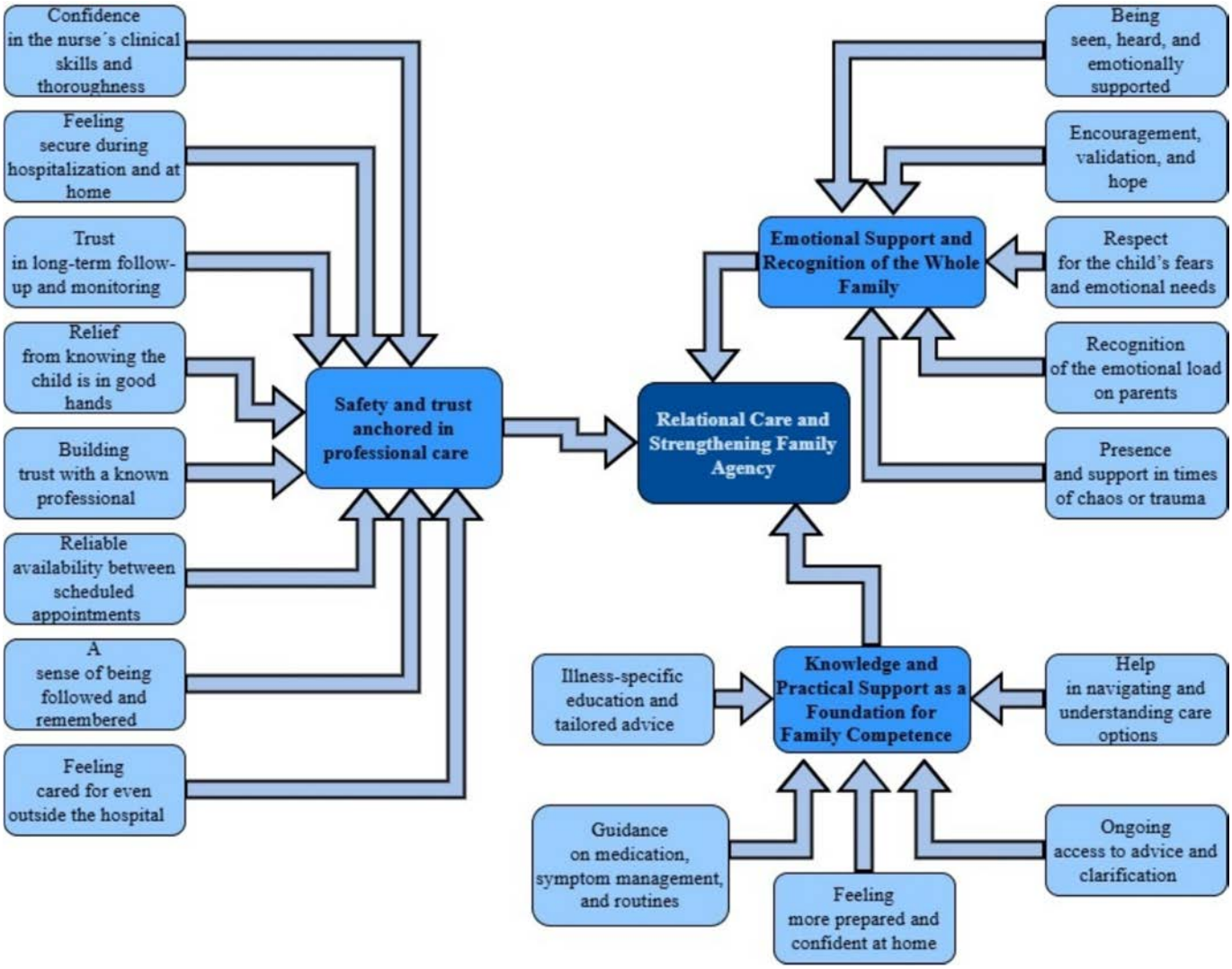

Fig. 2. How families perceive the pediatric nurse's role in Relational Care and Strengthening Family Agency.

through which individuals and families cope with adversity (Henry & Harrist, 2022; Park, 2010).

Families did not passively endure the stressors associated with chronic conditions; rather, they actively engaged in constructing narratives that allowed them to integrate the chronic condition into their family identity. For some, this involved reframing the experience as a source of strength or pride, while for others, it meant embracing a more present-focused perspective that prioritized emotional connection and daily functioning over long-term certainty. By integrating narratives, families were able to process and make sense of the chronic condition and its role within family life (Kokanović & Flore, 2017).

The process of meaning-making appeared to be both individual and relational. Parents often described how shared emotional experiences and mutual caregiving responsibilities deepened family bonds. At the same time, the absence of external support, particularly in the early stages following diagnosis, often left families feeling isolated and overwhelmed, suggesting that meaning-making is not only an internal process but one that is shaped by the availability of relational and systemic support. Importantly, meaning-making was not a linear or uniformly positive process. Families moved between moments of despair and empowerment, reflecting the nonlinear and recursive nature of adaptation. Such dynamics echo theoretical models of family resilience that emphasize flexibility, relational coherence, and the capacity to create coherence in the face of disruption (Patterson, 2002; Walsh, 2003).

The findings also point to significant structural gaps in healthcare systems, particularly in the continuity of care and emotional support following diagnosis. Parents' accounts of being left alone after receiving a diagnosis highlight not only experiences of inadequate support but also the need for more consistent and relationally anchored care. Such insights align with principles of family-centered care, which emphasize partnership, respect, and inclusion of the whole family in care processes (Brødsgaard et al., 2019; Rønne & Brødsgaard, 2025). As Shajani and Snell (2023) argue, nurses play a pivotal role in facilitating family adaptation—not only through clinical competence but through emotional engagement, trust-building, and knowledge-sharing.

Families in this study valued nurses who recognized their emotional needs, provided clear and accessible information, and acknowledged the broader impact of conditions. These relational interactions contributed to a sense of safety and competence, reinforcing the family's ability to act and adapt. However, families reported increased stress and uncertainty when such support was absent or fragmented, revealing persistent unmet needs and a strong desire for consistent, responsive support, underscoring the importance of health literacy and relational continuity in pediatric care. As Sørensen et al. (2012) emphasize, health literacy is not only about understanding medical information—it is a key determinant of health outcomes, enabling individuals and families to navigate healthcare systems, make informed decisions, and engage actively in care processes.

Taken together, these findings suggest that adaptation to pediatric chronic conditions is best understood as a relational and contextual process. Families do not simply adjust to medical realities. Rather, they reconstruct meaning, renegotiate roles, and seek coherence in the midst of disruption. Healthcare professionals, particularly nurses, are uniquely positioned to support this process by recognizing family vulnerability, facilitating meaning-making, and fostering empowerment (Rønne et al., 2023). However, this potential is contingent on systemic conditions allowing time, continuity, and relational depth. As such, our findings indicate the potential value of care models that prioritize family-centeredness, emotional labor, and health literacy as core components of managing chronic conditions. These insights may inform considerations for how healthcare systems support families in similar contexts.

Relational nursing care as a foundation for family agency

The findings highlight the pivotal role of nurses in supporting families' adaptation to a child's chronic condition, not only through clinical competence but through relational, emotional, and educational engagement (Shajani & Snell, 2023). The overarching theme, Relational Care and Strengthening Family Agency, illustrates how trust, emotional recognition, and knowledge-sharing contribute to families' sense of safety, competence, and empowerment.

Relational care emphasizes the quality of the relationship between the nurse and the patient, focusing on trust, respect, and meaningful connection. Family-centered care extends this approach by actively involving the family in care planning and decision-making, fostering collaboration between the nurse, patient, and family (Griffiths et al., 2025; Soklaridis et al., 2016). In this study, the issues raised by families align with the core concepts of family-centered care: partnership, communication, respect, and compassion (Seniwati et al., 2023). Family-centered care refers to caring for a sick child in ways that recognize the family as a whole, encompassing support for all family members and acknowledging the condition's impact on the entire family (Coyne et al., 2011; Svavarsdottir et al., 2025). The findings demonstrate that family-centeredness is a vital component of pediatric nursing practice. Improved quality of life for the child, enhanced patient safety, increased family satisfaction, the integration of humanistic values in nursing care, reduced hospitalization costs, and decreased stress, anxiety, and depression among family members are identified as outcomes of successful family-centered care (Seniwati et al., 2023).

Families valued nurses' competence, and this trust reinforced their sense of safety. This sense of safety is not purely experiential; research demonstrates that nurses' competence and expertise are critical components of patient safety culture in nursing practice, ensuring the delivery of safe and effective care. In this respect, effective family-centered care models rely on well-designed training initiatives that equip healthcare professionals with the skills and competencies needed to collaborate meaningfully with patients and families (Glarcher & Vaismoradi, 2025; Zaitoun et al., 2023). In pediatric nursing, trust between the family and the nurse enables the provision of high-quality and safe care, supports the child's healing and recovery, and provides a foundation for a healthy workplace culture. The development of trust is also rewarding and enriching for nurses themselves (MacKay et al., 2024).

Emotional support emerged as a critical dimension of nursing care. Interaction, and its success, was regarded as essential. Trust evolves over time and through repeated interactions (MacKay et al., 2024). Families valued being seen and heard not just as caregivers, but as whole persons navigating a life-altering experience. Nurses who offered empathy, encouragement, and presence helped alleviate stress and fostered a sense of being held within the healthcare system. Such practice echoes relational agency, where professionals engage with families not only to deliver care but to co-construct meaning and capacity. Within family-centered care, the nurse's role is to encourage and empower parents, and thereby the family, to actively participate in the delivery of primarily non-medical aspects of care (Coyne et al., 2011; Svavarsdottir et al., 2025). Families occasionally perceived nurses as busy. Previous research confirms that nurses themselves recognize this challenge. Many have emphasized the importance of adequate staffing resources, noting that lack of time and increased workload are central factors that negatively affect the ability to implement family-centered care (Coyne et al., 2011).

The provision of knowledge and practical guidance was foundational to families' sense of competence. Nurses were often described as the primary source of education about chronic conditions, treatment, and daily care routines. Information sharing and parent education are central components of family-centered nursing care. Information is not exclusively the transmission of facts; also, a means of fostering inclusion and building a sense of safety (Seniwati et al., 2023). The educational role fulfilled by nurses was transformational, enabling families to move from uncertainty to confidence. In this way, nurses acted as bridges between clinical knowledge and lived experience, helping families translate complex medical realities into manageable daily practices.

Strengths and limitations

This study employed a cross-national qualitative design to explore how families across different European contexts adapt to a child's chronic condition and perceive the role of nurses in that process. This approach allowed for a nuanced understanding of both shared and context-specific experiences. While the inclusion of families from both Northern and Southern Europe enhances the transferability of the findings, cultural and linguistic differences may have influenced how participants expressed their experiences and how these were interpreted. In line with the qualitative design of the study, the aim is not statistical generalizability but rather to provide insights that may be meaningfully transferred to similar contexts. Different cultural ways of expressing emotions or attributing meaning to events may have generated divergent expectations and demands regarding nursing care and may therefore have influenced how participants articulated and presented issues within the study. Despite efforts to ensure accurate translation and cultural sensitivity, some nuances in meaning may have been lost in cross-language analysis (Squires, 2009). However, as the study was conducted in different contexts, some perceptions regarding the needs of families and the role of nurses appeared to be common. This multinational design also strengthens the cross-contextual transferability of the findings.

The study relied on self-reported narratives, which are shaped by memory, emotion, and social desirability. Although this method is valuable for capturing lived experience, it introduces potential bias (Flanagan & Beck, 2025; Polit-O'Hara & Beck, 2012). Only one parent per family participated, which may not fully reflect intrafamily variation in experiences and perspectives. The qualitative questions were embedded within a broader survey instrument, which may have influenced the focus and richness of the open-ended responses, but allowed for a wide international sample. Compared with in-depth interviews, open-ended questionnaire data have an inherent limitation: the lack of opportunity to ask clarifying or probing questions and the variable richness of written responses. In addition, the written survey format tends to generate concise and readily articulated reflections, which may limit the depth and nuance typically obtained through interactive qualitative methods, while still allowing participants to express perspectives they might not have voiced in a face-to-face context. This limitation is related to the written format of the responses, and the absence of country-specific comparisons limits the extent to which contextual differences between participating countries can be explored. The number of written responses differed across questions, which may have influenced the analytical focus; however, all three questions and their responses contained largely overlapping content. The inclusion of families with diverse chronic conditions provides broad insight but precludes condition-specific analysis, which was not the aim of the study. Triangulation of data sources, including observations or interviews with healthcare professionals, could strengthen future research designs (Carter et al., 2014).

Further, methodological rigor was ensured through qualitative strategies, including reflexive thematic analysis, team-based coding, and interpretive discussion, analytic triangulation within the international research team, and adherence to the Standards for Reporting Qualitative Research (SRQR). In keeping with the qualitative exploratory design, rigor was established through transparency and reflexivity rather than statistical inference (Malterud, 2001). In addition, by integrating perspectives on meaning-making, family resilience, and relational nursing, the study offers a conceptual contribution to pediatric family nursing that extends these frameworks. The findings illustrate how meaning-making processes, relational dynamics, and resilience practices interact in families' everyday management of a child's chronic condition, thereby advancing theoretical understandings beyond descriptive themes. Finally, while this study focused on the family perspective, future research should include the voices of nurses and other healthcare professionals to understand better how they perceive their role in supporting families, and what systemic conditions enable or constrain relational and family-centered care. The findings also hold practical relevance for long-term pediatric chronic care settings by highlighting relational and family-centered support needs. One potential avenue for future research concerns how emerging technologies, such as teleconsultations and virtual services, reshape families' experiences of support from healthcare professionals and influence how nurses engage with families in clinical practice.

Conclusion

Families' adaptation to pediatric chronic conditions is a deeply human process of navigating uncertainty, loss, and transformation, as expressed by parents in this study. Our findings illuminate how families across diverse European contexts describe not only emotional and practical challenges but also interconnected processes of meaning-making, resilience, and reorientation of everyday life around care and connection.

Across participating countries, parents described similar needs for support—particularly emotional recognition, continuity, and opportunities for reflection. While these patterns emerged across diverse cultural and healthcare contexts, they should be understood as transferable insights rather than broadly generalizable findings. The findings deepen nurses' understanding and offer possibilities for individually tailored support according to each family's needs. Clinically, supporting families may involve not only providing information and services but also creating space for meaning-making through approaches such as narrative reflection, peer support, and emotional validation.

Within these contexts, nurses may play an important role in supporting family agency—the capacity to act, decide, and adapt—by fostering trust, recognizing emotional experiences, and supporting competence development. At the same time, parents' accounts highlight that such supportive roles are shaped by organizational and systemic conditions, including continuity of care and time for relational work. Taken together, these insights underscore that family-centered care in pediatric chronic conditions is most effective when relational practice, family agency, and structural conditions are aligned.

CRediT authorship contribution statement

Camilla Ejlertsen: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Hanna Seppänen:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Eija Paavilainen:** Writing – review & editing, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Erla Kolbrun Svavarsdottir:** Writing – review & editing, Supervision. **Henny Hraunfjord:** Writing – review & editing. **Guðný Bergþóra Tryggvadóttir:** Writing – review & editing. **Anna Olafia Sigurdardottir:** Writing – review & editing. **Lígia Lima:** Writing – review & editing. **Luísa Andrade:** Writing – review & editing. **Sara Lemos:** Writing – review & editing. **Maria do Céu Barbieri-Figueiredo:** Writing – review & editing. **Rafaela Camacho-Bejarano:** Writing – review & editing. **Dolores Merino-Navarro:** Writing – review & editing. **Estela Dominguez-Carranza:** Writing – review & editing. **Sonia Pastor-Montero:** Writing – review & editing. **Tuija Leppäkoski:** Writing – review & editing. **Anne Brødsgaard:** Writing – review & editing, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of Generative AI and AI-Assisted Technologies in the Writing Process

During the preparation of this manuscript, the authors used AI-assisted tools to support language refinement and improve clarity and readability. After using these tools, the authors carefully reviewed and edited the content and take full responsibility for the final version of the manuscript.

Declaration of competing interest

The authors declare no conflicts of interest.

Acknowledgments

We would like to thank all the parents who participated in the study by responding to the survey.

References

Andrade, L. M. C., Lemos, S. R. M., Barbieri-Figueiredo, M. D. C. A., & Lima, L. M. M. (2024). Quality of life and family management of paediatric chronic condition amidst the COVID-19 pandemic. *Journal of Pediatric Nursing*, *75*, e34–e41. https://doi.org/10.1016/j.pedn.2023.12.023.

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(24), 3186–3191. https://doi.org/10.1097/00007632-200012150-00014.

Bistaraki, A., Stefanopoulos, N., Kiekkas, P., Stamatopoulou, D., & Igoumenidis, M. (2025). "I'm not sad anymore, I'm proud to have such a child": The experiences of caregivers of dependents with cerebral palsy living in Greece. *Journal of Pediatric Nursing*, *81*, 89–96. https://doi.org/10.1016/j.pedn.2024.12.007.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide* (1st ed.). SAGE Publications.

Brødsgaard, A., Pedersen, J. T., Larsen, P., & Weis, J. (2019). Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis. *Journal of Clinical Nursing*, *28*(17–18), 3117–3139. https://doi.org/10.1111/jocn.14920.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545–547. https://doi.org/10.1188/14.ONF.545-547.

Chirani, Z. H., Pouralizadeh, M., Yaghobi, Y., & Kazemnejad Leili, E. (2025). Relationship of caregiving burden and adaptive behaviors in mothers of children with chronic diseases. *Journal of Pediatric Nursing*, *81*, e113–e120. https://doi.org/10.1016/j.pedn.2025.02.007.

Cici, A. M., & Özdemir, F. K. (2024). Examining resilience and burnout in parents of children with chronic disease. *Journal of Pediatric Nursing*, *75*, e176–e183. https://doi.org/10.1016/j.pedn.2024.01.011.

Coyne, I., O'Neill, C., Murphy, M., Costello, T., & O'Shea, R. (2011). What does family-centred care mean to nurses and how do they think it could be enhanced in practice. *Journal of Advanced Nursing*, *67*(12), 2561–2573. https://doi.org/10.1111/j.1365-2648.2011.05768.x.

Doğaner, F., & Celen, R. (2025). The effect of intolerance of uncertainty, sleep quality, and social support on caregiver burden in parents of children with chronic diseases: A cross-sectional study. *Journal of Pediatric Nursing*, *81*, e106–e112. https://doi.org/10.1016/j.pedn.2025.02.006.

Flanagan, J., & Beck, C. T. (2025). *Polit and Beck's nursing research: Generating and assessing evidence for nursing practice* (12th ed.). Wolters Kluwer.

Glarcher, M., & Vaismoradi, M. (2025). A systematic integrative review of specialized nurses' role to establish a culture of patient safety: A modelling perspective. *Journal of Advanced Nursing*, *81*(9), 5248–5263. https://doi.org/10.1111/jan.16105.

Griffiths, J. L., Foye, U., Stuart, R., Jarvis, R., Chipp, B., Griffiths, R., Jeynes, T., Mitchell, L., Parker, J., Rowan Olive, R., Quirke, K., Baker, J., Brennan, G., Lamph, G., McKeown, M., Lloyd-Evans, B., Trevillion, K., & Simpson, A. (2025). Quantitative Evidence for Relational Care Approaches to Assessing and Managing Self-Harm and Suicide Risk in Inpatient Mental Health and Emergency Department Settings: A Scoping Review. *Issues in Mental Health Nursing*, *46*(6), 529–565. https://doi.org/10.1080/01612840.2025.2488335.

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010.

Henry, C. S., & Harrist, A. W. (2022). Family resilience theory. In K. Adamsons, A. L. Few-Demo, C. Proulx, & K. Roy (Eds.), *Sourcebook of family theories and methodologies*. Springer. https://doi.org/10.1007/978-3-030-92002-9_4.

Kokanović, R., & Flore, J. (2017). Subjectivity and illness narratives. *Subjectivity*, *10*, 329–339. https://doi.org/10.1057/s41286-017-0038-6.

Lemos, S. R. M., Andrade, L. M. C., Lima, L. M. M., Fernández-Medina, I. M., & Céu Aguiar Barbieri-Figueiredo, M. D. (2024). Lived experience of parents with technology-dependent children: A phenomenological study. *Global Qualitative Nursing Research*, *2024*, Article 11. https://doi.org/10.1177/23333936241288858.

Lynch, A., Raziano, V., Feehan, K., Thompson, E., Massey, P., & Turchi, R. (2021). Unmet needs of male caregivers of children and youth with special health care needs. *Maternal & Child Health Journal*, *25*(12), 1992–2001. https://doi.org/10.1007/s10995-021-03248-7.

MacKay, L. J., Chang, U., Kreiter, E., Nickel, E., Kamke, J., Bahia, R., ... Meyerhoff, H. (2024). Exploration of trust between pediatric nurses and children with a medical diagnosis and their caregivers on inpatient care units: A scoping review. *Journal of Pediatric Nursing*, *78*, e1–e30. https://doi.org/10.1016/j.pedn.2024.05.030.

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *The Lancet*, *358*(9280), 483–488. https://doi.org/10.1016/S0140-6736(01)05627-6.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388.

Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, *136*(2), 257–301. https://doi.org/10.1037/a0018301.

Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology*, *58*(3), 233–246. https://doi.org/10.1002/jclp.10019.

Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Wolters Kluwer.

Polit-O'Hara, D., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.

Rønne, P. F., & Brødsgaard, A. (2025). Understanding the significance of family and social support in the recovery journey. In K. Jørgensen (Ed.), *Implementing recovery in mental health: From treatment to transformation (manuscript accepted for publication, November 1, 2024)*. Routledge.

Rønne, P. F., Esbensen, B. A., Brødsgaard, A., Biering-Sørensen, B., & Hansen, C. A. (2023). Patients' and family members' experiences of a novel nurse-led intervention using family conversations targeting families afflicted by chronic non-cancer pain. *Journal of Pain Research*, *16*, 3029–3043. https://doi.org/10.2147/JPR.S412721.

Seniwati, T., Rustina, Y., Nurhaeni, N., & Wanda, D. (2023). Patient and family-centered care for children: A concept analysis. *Belitung Nursing Journal*, *9*(1), 17–24. https://doi.org/10.33546/bnj.2350.

Seppänen, H., Koivisto, A. -M., Kylmä, J., Leppäkoski, T., Heino-Tolonen, T., & Paavilainen, E. (2025). The life situation of a family with a chronically ill child and the family's experience of support provided by healthcare professionals in Finland. *Journal of Pediatric Nursing*, *84*, 311–318. https://doi.org/10.1016/j.pedn.2025.06.021.

Shajani, Z., & Snell, D. (2023). *Wright & Leahey's nurses and families: A guide to family assessment and intervention* (8th ed.). F. A. Davis.

Soklaridis, S., Ravitz, P., Adler Nevo, G., & Lieff, S. (2016). Relationship-centred care in health: A 20-year scoping review. *Patient Experience Journal*, *3*(1), 130–145. https://doi.org/10.35680/2372-0247.1111.

Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, *12*(1), Article 80. https://doi.org/10.1186/1471-2458-12-80.

Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies*, *46*(2), 277–287. https://doi.org/10.1016/j.ijnurstu.2008.08.006.

Svavarsdottir, E. K., Flygenring, K. B., & Sigurdardottir, A. O. (2025). Contribution of the brief family strength-oriented therapeutic conversation intervention to early childhood sleep health: A quasi-experimental study. *Journal of Family Nursing*, *31*(1), 45–57. https://doi.org/10.1177/10748407241313463.

Svavarsdottir, E. K., Lemos, S., Andrade, L., Barbieri-Figueiredo, M. D. C., Tryggvadottir, G. B. , & Lima, L. (2024). Psychometric testing of the experience of integrating chronic illness into family life questionnaire. *Journal of Family Nursing*, *30*(2), 174–184. https://doi.org/10.1177/10748407241236010.

Thomas, S., Ryan, N. P., Byrne, L. K., Hendrieckx, C., & White, V. (2023). Unmet supportive care needs of families of children with chronic illness: A systematic review. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *32*(19/20), 7101–7124. https://doi.org/10.1111/jocn.16806.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, *42*(1), 1–18. https://doi.org/10.1111/j.1545-5300.2003.00001.x.

Wijlaars, L. P. M. M., Gilbert, R., & Hardelid, P. (2016). Chronic conditions in children and young people: Learning from administrative data. *Archives of Disease in Childhood*, *101*(10), 881–885. https://doi.org/10.1136/archdischild-2016-310716.

Zaitoun, R. A., Said, N. B., & de Tantillo, L. (2023). Clinical nurse competence and its effect on patient safety culture: A systematic review. *BMC Nursing*, *22*(1), Article 173. https://doi.org/10.1186/s12912-023-01305-w.