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Balancing on life's ladder: A meta-ethnography of the existential experiences of siblings of children with complex care needs



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Abstract

Aim: To synthesize and interpret existing qualitative research on the existential experiences of siblings of children with complex care needs.

Design: Noblit and Hare's interpretive meta-ethnography.

Methods: The study has been registered in the international prospective register for systematic reviews (PROSPERO). Noblit and Hare's 7-step procedure was followed and reciprocal translation was performed to analyse the data and develop a line of argument synthesis.

Data Sources: A comprehensive systematic literature search of five databases, along with extensive manual searches, was completed in November 2022. The final sample comprised 18 studies published between 2010 and 2022.

Results: A line of argument, expressed through an overarching metaphor, "balancing on life's ladder", illustrates the core findings of siblings' fluctuating experiences of existential well-being, and encapsulates four third-order themes: the emotional turmoil of siblings, interrupted family life, siblings strive to be themselves and siblings struggle to cope.

Conclusion: Growing up with a sibling with complex care needs made children feel invisible, lonely and struggling to find the courage to cope. By adopting a lifeworld approach, nurses can become aware of healthy siblings' unmet needs. Future research is needed on how nurses can contribute to siblings' existential well-being, in primary – and secondary health care settings.

Implications: The study provides insight into siblings' existential experiences and factors improving their well-being, enabling nurses to provide a more optimized lifeworld-led clinical practice.

Impact: Healthcare, nursing education and practice should be informed by the knowledge of existential issues. Nurses are well-positioned to work alongside families to provide family-centered care. Our findings have implications for health policies tailored to the needs of children with chronically ill siblings.

Reporting Method: This review adheres to the Equator and improving reporting of meta-ethnography (eMERGe) guidelines.

Patient or Public Contribution: No patient or public contribution, because the data comprised previously published studies.

 **What this study contributes to the wider global clinical community**

Siblings living with a brother or sister with complex care needs report life-changing experiences that impact their well-being.

Family dynamics and communication are threatened by changes in relationships, roles and responsibilities. Although siblings struggle to find the courage to continue, they find positive aspects amid challenges.

Understanding siblings' existential experiences illuminated by a lifeworld perspective, may help nurses alleviate their suffering.

Introduction

Providing care and support for the vulnerable population of children with complex care needs (CCN) is an essential aspect of primary health care nursing worldwide. Developments in medicine and nursing have significantly increased the number of children with CCN living at home. Estimating the prevalence of these conditions is challenging, because of their diversity and multiple definitions of the concept (Brenner et al., 2018). Approximately 7% to 17% of children have siblings with chronic illnesses (McKenzie Smith et al., 2018).

The recent transitions to a care at home context require a shift in care provision (LeGrow et al., 2022). Families face increased caregiver demands, resulting in strained relationships between parents and healthy siblings, reduced communication and a lack of awareness regarding the healthy siblings' needs (Lam et al., 2023). Although many siblings cope well, recent

research indicates that they feel invisible and would benefit from the support and engagement of healthcare professionals (Lummer-Aikey & Goldstein, 2021). Family-centered care acknowledges the family's vital role in children's well-being. To ensure that optimal care is delivered to these families, a strong multidisciplinary focus and coordination are necessary (Cassidy et al., 2023).

Emerging reviews focusing on siblings' experiences of growing up with a brother or sister with CCN have yielded mixed and inconsistent findings. According to recent meta-analyses (Martinez et al., 2022; McKenzie Smith et al., 2018; Pinguart, 2023), siblings are at increased risk of poor-psychological functioning. Additionally, previous reviews have highlighted daily disruptions in routines (Lummer-Aikey & Goldstein, 2021), and limited time with their parents (Havill et al., 2019), which often results in reduced communication and suppression of the healthy siblings' needs (Deavin et al., 2018). There is some evidence that these emotional stressors often negatively affect both self-esteem and the sense of self (Knecht et al., 2015).

Alongside the negative impacts, many siblings state that they gained values such as empathy, maturity and personal growth by living with an unwell brother or sister, resulting in stronger familial bonds (Hilário, 2022). However, siblings may struggle to identify the positive outcomes in their situation (Lummer-Aikey & Goldstein, 2021). Further research is needed to better understand the factors contributing to the siblings' existential well-being, which can aid healthcare professionals in alleviating their distress and promoting their health and well-being.

A useful entry point is to examine siblings' significant experiences of “what matters” in their lives, with the intention of strengthening the nursing care they receive (Galvin, 2021). Galvin and Todres (2013) lifeworld-led care theory, rooted in phenomenology, argues that well-being encompasses both the way we experience the world and our way of being in it. Hence, the best way to understand our lives is through our perspectives.

Siblings' views and experiences differ from those of their parents. Understanding their primary care needs is particularly relevant (Zdunek et al., 2019). Previous studies have found discrepancies between parents' and siblings' perspectives on how well the latter adjust (Fredriksen et al., 2023). Therefore, studies that include the authentic voices of siblings

are needed (Owen et al., 2022). According to Galvin (2021), research on existential issues remains underdeveloped and requires attention. Although previous qualitative reviews have investigated siblings' experiences of growing up with a chronically ill brother or sister (Deavin et al., 2018; Havill et al., 2019; Kelada et al., 2022; Knecht et al., 2015; Lummer-Aikey & Goldstein, 2021), to the best of our knowledge, none have explored their existential experiences.

The review

Aim

This meta-ethnography aimed to synthesize and interpret existing qualitative research on the existential experiences of siblings of children with complex care needs.

Design

Noblit and Hare's (1988) seven-step approach to meta-ethnography continues to be the most widely used method in healthcare wherein the aim is to develop novel interpretations of illness and care experiences (Cahill et al., 2018). We followed the eMERGe guidelines (France et al., 2019) to ensure rigour and transparency in developing higher-order constructs (Appendix S1 contains the eMERGe checklist). Our primary intention was to generate an innovative and deeper understanding of the existential experiences of siblings of children with CCN, that cannot be achieved from a single study (Soundy & Heneghan, 2022).

Search methods

The first author and a medical librarian performed a comprehensive literature search, including a systematic search of five databases, supplemented by manual search techniques (Appendix S2 includes the complete search strategies for the databases). The searches were conducted from October to December 2020 and covered the period 2010–2020, modified to suit the search criteria for each database. The SPIDER search strategy tool (Flemming & Noyes, 2021) was adapted to clarify the main concepts and to structure the systematic database search. To minimize the risk of missing relevant research, we manually supplemented our searches

by reviewing the reference lists of the retrieved studies and searching Google Scholar, including citation tracking. However, there is no consensus regarding when to terminate the search process in this method (Cooper et al., 2018). When the manual searches no longer yielded relevant studies, saturation was assumed (Booth, 2016).

Search outcomes

The search resulted in 1717 studies, which were exported to EndNoteX9 (Hupe, 2019). Duplicate articles were removed, resulting in 1209 articles for screening. Manual searches identified 15 studies, of which 11 were screened. Following the PRISMA flow diagram (Page, Moher, et al., 2021) shown in Figure 1, 170 abstracts and 37 full-text studies were evaluated before the final inclusion of 16 studies. An updated search conducted in November 2022 yielded 509 additional references for screening, adding two more articles that were published in 2021 and 2022 to the sample. Studies that met the predetermined eligibility criteria are listed in Table 1. All the authors were involved in the screening.

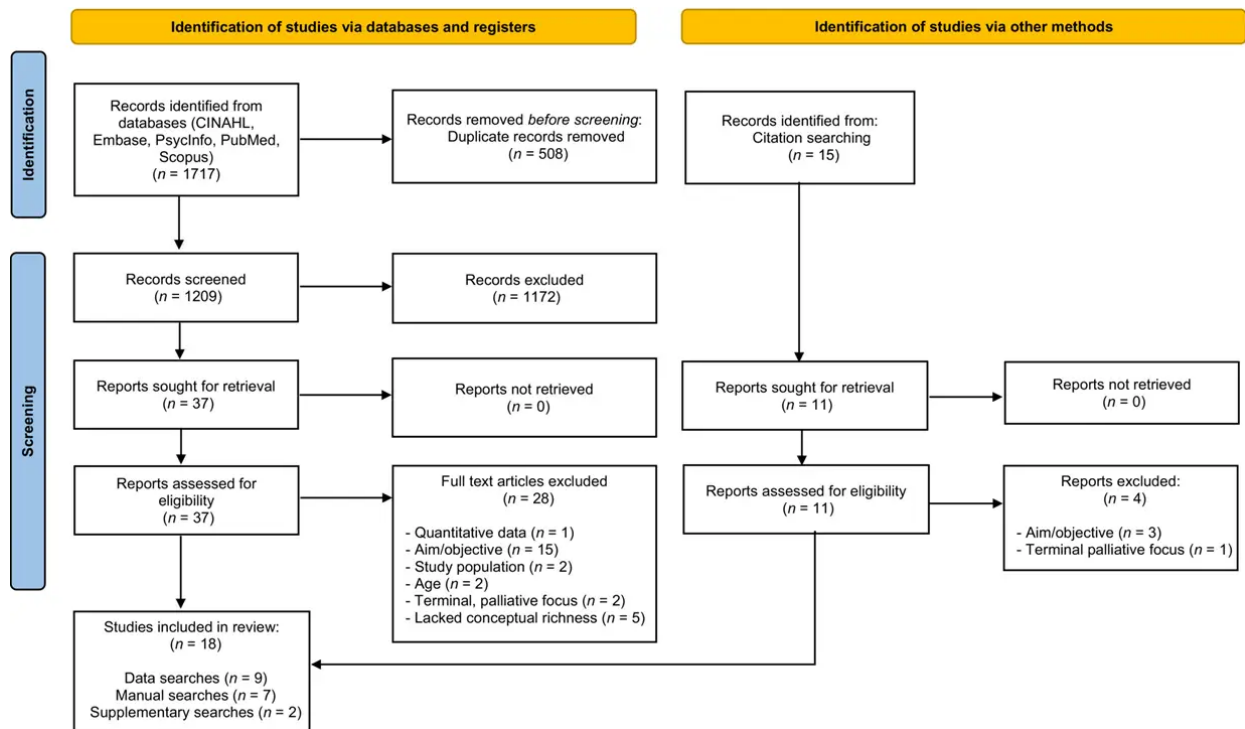


TABLE 1. Inclusion and exclusion criteria.

SPIDER tool	Inclusion criteria	Exclusion criteria
Sample	The first person's voice of siblings (<18 years) to children with CCN had to be adequately represented and have implications for nursing	Studies that report on siblings' experiences from others' perspectives
Phenomenon of interest	The experiences of young siblings growing up with a brother or sister with CCN, resulting from multiple concurrent long-term physical conditions, from a primary care setting	CCN with mental disorders, cognitive impairments, social vulnerability and children with life limiting diagnoses (children in palliative care). Research from secondary care settings, such as hospitals and other facilities
Design	Any theoretical framework, qualitative data collection and analysis method	
Research type	Published English primary qualitative articles or the qualitative part of mixed method research, in 2010–2020. Research conducted in all countries	Quantitative methodology, reviews. Articles in other languages than English and published before 2010

Quality appraisal

Although France et al. (2019) do not present a specific appraisal method, 92% of recent publications have used an appraisal tool (Dalton et al., 2017). We applied the Critical Appraisal Skills Programme (2018), a common appraisal tool used in meta-ethnographies (France et al., 2014). However, appraisal tools alone cannot determine study quality (Majid & Vanstone, 2018). All the authors independently assessed each study's quality and relevance and discussed discrepancies. None of the studies were excluded for quality reasons. Table 2 presents the details of the assessment process.

TABLE 2. Critical Appraisal Skills Program (CASP) checklist for qualitative research (Critical Appraisal Skills Programme, 2018).

Study	Questions									
	1	2	3	4	5	6	7	8	9	10
Agerskov et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Akhtar et al. (2012)	Y	Y	Y	Y	U	Y	Y	Y	Y	Y
Carlsen et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
D'Urso et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Heaton et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Israelsson-Skogsberg et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kaatsız and Öz (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Long et al. (2015)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lostelius et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Løkkeberg et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Porteous et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Prchal and Landolt (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Read et al. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tyerman et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Van Schoors et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Velleman et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Webster (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wennick and Huus (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note: Y=Yes, U=Unclear. Critical appraisal questions: (1) Was there a clear statement of the aims of the research? (2) Is a qualitative methodology appropriate? (3) Was the research design appropriate to address the aims of the research? (4) Was the recruitment strategy appropriate to the aims of the research? (5) Was the data collected in a way that addressed the research issue? (6) Has the relationship between researcher and participant been adequately considered? (7) Have ethical issues been taken into consideration? (8) Was the data analysis sufficiently rigorous? (9) Is there a clear statement of findings? (10) Was this research valuable?

Data extraction

The extraction process comprised two stages. Each study's descriptive characteristics were extracted by the first author and independently reviewed by the other authors. Subsequently, all the authors read and re-read each study to identify rich textual constructs such as metaphors related to the research topic. These constructs constituted the raw data for the meta-ethnography (Noblit & Hare, 1988). A meta-ethnographic approach emphasizes the use of clearly articulated metaphors in the text segments, such as phrases, ideas and concepts that the original authors use to express their research (Noblit & Hare, 1988).

Following Noblit and Hare's (1988) recommendations, a list of metaphors from each primary source was created. We differentiated between those originating from the primary participants' (first-order constructs) and the primary authors' interpretations (second-order constructs). Finally, these key metaphors were extracted verbatim into an extraction form adapted from

Sattar et al. (2021). Each researcher reviewed the selected metaphors to ensure their relevance.

Synthesis

Despite differences in context, we considered the selected studies to be comparable and appropriate for a meta-ethnography. We used a constant comparison approach to synthesize the studies (Cahill et al., 2018), beginning with the oldest (study 1). All the papers were given equal consideration. We created a table wherein the key metaphors formed the first column, and the metaphors from studies 1 and 2 were compared based on their similarities and differences. This procedure was continued until all included studies were translated into each other. The metaphors were further abstracted from the recurring patterns before being clustered into conceptual categories of shared meanings.

Each conceptual category expressed distinct fragments of siblings' experiences of growing up with a brother or sister with CCN, with similarities between most metaphors. Similarity across studies enables reciprocal translation (Noblit & Hare, 1988). However, opening the analysis to differences can add meanings to metaphors (Noblit & Hare, 1988). No refutational concepts were identified. However, contradictory elements were noted in the conceptual categories. This transposition yielded four third-order themes across the included studies. A line of argument was developed, resulting in an overarching metaphor. All the researchers reflected on the deeper understanding of the metaphors to optimize the final synthesis.

Findings

Study characteristics

In total, 11 Western countries, 239 siblings, 93 boys and 146 girls, ranging in age from 5 to 20 years, comprised the total sample. Nearly half of the papers were published in nursing journals, whereas the remaining studies were either from multidisciplinary or psychology, physiotherapy, sociology, paediatrics or genetics journals. The methodologies included grounded theory, hermeneutics, interpretive phenomenology and other qualitative descriptive methods. Most studies used individual interviews to collect data.

The siblings' perspective was evident in all the articles, although four articles included parents in the sample. The sibling sample consisted of brothers or sisters of a child suffering from a long-term physical illness with CCN. About half were siblings of a child with cancer; other conditions included acquired brain injury, cerebral palsy, Duchenne muscular dystrophy, spinal cord injury, epilepsy, diabetes and CFS/ME, wherein some required home mechanical ventilation. Table 3 provides the details of the studies. The reciprocal translation led to four themes.

TABLE 3. Characteristics of the included studies.

The emotional turmoil of siblings: “I was the only person who understood myself”

Siblings describe experiencing a roller coaster of emotions, ranging from worry, anxiety, cautious hope to grave disappointment, that fluctuates along with their sibling's health (Løkkeberg et al., 2020; Velleman et al., 2016). Sometimes, they expressed fear for their ill sibling's life (Agerskov et al., 2021; Long et al., 2015; Tyerman et al., 2019) and uncertain future (Heaton et al., 2022; Lostelius et al., 2019; Read et al., 2011). “I could be happy right now, but that doesn't mean that it's going to last. I try not to get too happy so I don't get too let down” (Long et al., 2015, p. 25). Siblings were also profoundly affected by their parents' vulnerability and emotional reactions when the ill sibling's condition worsened (Agerskov et al., 2021; Akhtar et al., 2012; Kaatsız & Öz, 2020; Løkkeberg et al., 2020; Prchal & Landolt, 2012; Read et al., 2011). One boy said about his parents: “I am worried that they will become worried. It is a vicious circle” (Israelsson-Skogsberg et al., 2019, p. 479). Others had witnessed traumatic events involving their ill sibling (Agerskov et al., 2021) and suffered from frightening flashbacks (Løkkeberg et al., 2020; Tyerman et al., 2019). Some felt scared, uncertain (D'Urso et al., 2017; Porteous et al., 2019) and frustrated (Tyerman et al., 2019).

Siblings' daily family life was unpredictable, causing conflicting emotions such as jealousy (Carlsen et al., 2019; Løkkeberg et al., 2020; Long et al., 2015; Prchal & Landolt, 2012; Read et al., 2011; Van Schoors et al., 2019), anger (Akhtar et al., 2012; Heaton et al., 2022; Velleman

et al., 2016), but also caring and understanding (Read et al., 2011; Wennick & Huus, 2012).

Some siblings felt guilty about continuing with their normal lives when their ill siblings could not (Velleman et al., 2016). They felt the need to express themselves openly: "Sometimes it just gets too much and I need to ... or I'll explode" (Lostelius et al., 2019, p. 168). They hid their emotions to protect their parents and ill siblings from further distress (Akhtar et al., 2012; Carlsen et al., 2019; Heaton et al., 2022, p. 7; Løkkeberg et al., 2020; Lostelius et al., 2019; Porteous et al., 2019; Van Schoors et al., 2019). This forced many healthy siblings to cope on their own (Akhtar et al., 2012; Carlsen et al., 2019; Løkkeberg et al., 2020; Van Schoors et al., 2019).

Siblings may experience a lack of understanding outside the family unit. Friends often avoided the subject (Løkkeberg et al., 2020; Long et al., 2015; Porteous et al., 2019; Prchal & Landolt, 2012; Velleman et al., 2016). Some avoided talking about their ill sibling's condition for fear of being teased by their peers (Heaton et al., 2022; Porteous et al., 2019) and preferred not to be asked. Nevertheless, they yearned for attention (Long et al., 2015; Porteous et al., 2019; Prchal & Landolt, 2012). The intense sense of loneliness from being unable to discuss their situation is described as a feeling of "Being alone on this earth" (Løkkeberg et al., 2020, p. 6). "So, I felt quite alone on this earth. Then I was the only person who understood myself. And no one understood me" (Løkkeberg et al., 2020, p. 6). Treatments for the ill sibling could force families to move permanently (Akhtar et al., 2012; Kaatsız & Öz, 2020; Van Schoors et al., 2019). For the healthy siblings, this was devastating, as they lost their friends (Kaatsız & Öz, 2020; Løkkeberg et al., 2020).

The disease is why we are here ... I am generally confident, I can talk to new people easily, but the first time I got here, I hated school. I started school, thinking that I would get out of this place once the disease was treated but it just keeps me from adjusting ... Moving has affected my life very much ... (Kaatsız & Öz, 2020, p. 80).

Some siblings expressed relief and hope for the future, especially if their ill sibling's health improved (Løkkeberg et al., 2020; Long et al., 2015; Velleman et al., 2016; Wennick & Huus, 2012). "I thought that it had to go well, and I never thought that it would not go well, that it was an alternative" (Løkkeberg

et al., 2020, p. 8). Nevertheless, siblings' contributions to the well-being of the ill child led to feelings of pride, gratitude and joy (Israelsson-Skogsberg et al., 2019; Porteous et al., 2019; Read et al., 2011; Tyerman et al., 2019) and they experienced happy times: “it gives us good memories to look back on and smile at” (Porteous et al., 2019, p. 125).

Interrupted family life: “I feel like I don't have a mom”

Caring for a chronically ill sibling negatively affects family roles and relationships (Kaatsız & Öz, 2020; Van Schoors et al., 2019). Changes in daily routines, roles and responsibilities can make family life seem unfamiliar (Israelsson-Skogsberg et al., 2019; Løkkeberg et al., 2020; Prchal & Landolt, 2012; Van Schoors et al., 2019). Family activities such as holidays had to be adapted or ceased to cater to the ill child.

... we had this way we said goodnight to each other. She always said it first, then me, then my little sister, my little brother...he goes to bed earlier than us, we always say it together and we just giggle. That's the thing I miss most of all. (Tyerman et al., 2019, p. 2943).

Siblings reported that the illness had become the main topic of conversation (Prchal & Landolt, 2012). They mentioned poor communication and negative interactions (Velleman et al., 2016). They sensed when their parents withheld important information from them (Carlsen et al., 2019; Kaatsız & Öz, 2020; Long et al., 2015; Porteous et al., 2019; Van Schoors et al., 2019).

My parents did not tell us much ... They were not talking much so that we would not get scared. Then, as the situation got worse, they said, “We are going to the hospital, you have a responsibility now” (Carlsen et al., 2019, p. 1442).

They found it difficult to talk to their parents or siblings (Akhtar et al., 2012; Carlsen et al., 2019; Løkkeberg et al., 2020; Lostelius et al., 2019; Porteous et al., 2019; Van Schoors et al., 2019; Velleman et al., 2016). Several siblings commented on their unstable relationship with an absent mother (Akhtar et al., 2012; Kaatsız & Öz, 2020; Tyerman et al., 2019). Maternal absence disrupted family routines and threatened family stability (Akhtar et al., 2012; Kaatsız & Öz, 2020; Van Schoors et al., 2019). One sibling stated: “I feel like I

don't have a mom" (Kaatsız & Öz, 2020, p. 81). Fathers often had to assume the mothers' roles (Kaatsız & Öz, 2020). Subsequently, siblings perceived their fathers as the stable attachment figure (Akhtar et al., 2012; Prchal & Landolt, 2012), who were interested in their welfare and to whom they related more emotionally (D'Urso et al., 2017).

However, most findings indicated increased family closeness (D'Urso et al., 2017; Løkkeberg et al., 2020; Long et al., 2015; Lostelius et al., 2019; Porteous et al., 2019; Prchal & Landolt, 2012; Read et al., 2011; Van Schoors et al., 2019; Wennick & Huus, 2012) and stronger family ties. Supportive family relationships were paramount for healthy siblings' well-being (Akhtar et al., 2012; Heaton et al., 2022; Lostelius et al., 2019; Porteous et al., 2019; Velleman et al., 2016). Their relationships with their ill siblings changed significantly. The majority of studies reported a closer, more protective and considerate relationship. Nevertheless, some siblings experienced relational distance (Akhtar et al., 2012; Israelsson-Skogsberg et al., 2019; Read et al., 2011; Tyerman et al., 2019; Van Schoors et al., 2019; Velleman et al., 2016). One sibling spoke of grief: "I've lost my brother ... we used to do everything together and now we just don't" (Velleman et al., 2016, p. 627).

A shift from playmate to caregiver often occurs (Heaton et al., 2022; Lostelius et al., 2019; Read et al., 2011; Tyerman et al., 2019; Velleman et al., 2016; Webster, 2018). Owing to long hospital stays, healthy older siblings took over household chores and care of younger siblings (Akhtar et al., 2012; Carlsen et al., 2019; Kaatsız & Öz, 2020; Løkkeberg et al., 2020; Long et al., 2015; Prchal & Landolt, 2012; Tyerman et al., 2019; Van Schoors et al., 2019; Velleman et al., 2016; Wennick & Huus, 2012).

I feel like I have kids that I have to cook for and do chores for, and I also feel like I have a job. School, work, home ... I go to work as well; I'm doing an internship. I work, I study, and I take care of the whole house (Kaatsız & Öz, 2020, p. 80).

Siblings generally accepted and appreciated their new roles as helpers (Israelsson-Skogsberg et al., 2019; Long et al., 2015; Tyerman et al., 2019; Van Schoors et al., 2019; Webster, 2018). Others had difficulty adjusting (Akhtar et al., 2012; Long et al., 2015; Read et al., 2011) and coping with the new responsibilities (Heaton et al., 2022; Read et al., 2011). "There is too much on my shoulders, I can't sit and relax, and I've always got to be watching him"

(Read et al., 2011, p. 25). Siblings even had to support their parents emotionally when they noticed their exhaustion and grief (Akhtar et al., 2012; Van Schoors et al., 2019; Velleman et al., 2016). “My sister can reduce my Mum to tears ... and she [Mum] obviously has to talk to someone and Dad's at work” (Velleman et al., 2016, p. 626). Staying together as a family was considered important, for example, during extended hospital stays (Israelsson-Skogsberg et al., 2019).

The constant presence of personal care assistants' affected family life in some households (Akhtar et al., 2012; Israelsson-Skogsberg et al., 2019; Lostelius et al., 2019). “It got a bit annoying really, having an extra person in the house who wasn't part of the family really” (Akhtar et al., 2012, p. 306). Nevertheless, some were positive towards care workers: “you will meet all the funny assistants” (Israelsson-Skogsberg et al., 2019, p. 478).

Despite disruptions to family life, siblings appreciated their relationship with their unwell brother or sister (Heaton et al., 2022; Porteous et al., 2019; Tyerman et al., 2019; Van Schoors et al., 2019). “I'm so thankful for my sibling” and “[They're] my favorite person in the whole world” (Heaton et al., 2022, p. 229).

Siblings strive to be themselves: “Sometimes, I touch my arm to be sure that I am still here ...”

Siblings' sense of self, quality of life and future plans were negatively affected by having a sibling with CCN (Heaton et al., 2022). They felt that their needs were prioritized less (Akhtar et al., 2012; Løkkeberg et al., 2020; Long et al., 2015; Porteous et al., 2019; Read et al., 2011; Tyerman et al., 2019, p. 2943; Van Schoors et al., 2019). Therefore, siblings often felt invisible and neglected (Akhtar et al., 2012; D'Urso et al., 2017; Porteous et al., 2019; Van Schoors et al., 2019). “I asked them [Mum and Dad] to go to the park ... “I'm too tired, I'm too tired.” That was their answer for everything like in the first months ...” (Tyerman et al., 2019, p. 2943). Family life revolved around the ill child (Heaton et al., 2022; Wennick & Huus, 2012), according to a sibling in Israelsson-Skogsberg's study (2019, p. 477); “The ill sibling is like a sun, where the family members form planets circulating around the sun”. One sibling referred to himself as “just the behind-the-scenes guy” (Long et al., 2015, p. 26).

The illness in the family made siblings redefine themselves. "... having a sibling that is different makes you a little different" (Israelsson-Skogsberg et al., 2019, p. 481). Siblings felt that they were defined as the siblings of the ill child, and this identity was reinforced when others constantly asked about their ill sibling but forgot to ask how they themselves were (Long et al., 2015; Prchal & Landolt, 2012). Rather than being pitied or expected to cope (Løkkeberg et al., 2020), siblings wished to be seen as separate persons: "... going to a different school has helped a lot because you are known separately ... it is up to you to make sure people notice like who you are ..." (Akhtar et al., 2012, p. 308). The school was a space where siblings could be themselves and regain their childhood (Read et al., 2011).

Siblings strived to be themselves (Løkkeberg et al., 2020). It was difficult to give up activities that could lead to infections threatening the ill child's health (Israelsson-Skogsberg et al., 2019; Kaatsız & Öz, 2020). They tried to maintain their hobbies and friendships to preserve their sense of self (D'Urso et al., 2017; Løkkeberg et al., 2020; Prchal & Landolt, 2012; Read et al., 2011). "My friends helped me; I could get away from it all when I spent time with them, and I could forget about the illness for a moment. I could be a little happy with them" (Prchal & Landolt, 2012, p. 137).

Finding no relief from sadness and isolation was devastating for siblings' self-esteem (Akhtar et al., 2012; Lostelius et al., 2019). Some lost faith in themselves (Carlsen et al., 2019).

Sometimes I touch my arm to be sure that I am still here. It is like no one sees me. I understand that they must focus on my brother. He is fighting; they would have done the same for me. But still, it makes me feel hopeless. Will they ever look at me in the same way as they used to? Will I ever stop being invisible to them? (Carlsen et al., 2019, p. 1442).

Others felt different from their peers, described as a "feeling of being on another human level" (Løkkeberg et al., 2020, p. 6).

Siblings felt that they had to grow up and mature quickly (D'Urso et al., 2017; Israelsson-Skogsberg et al., 2019; Kaatsız & Öz, 2020; Lostelius et al., 2019; Porteous et al., 2019; Read et al., 2011; Van Schoors et al., 2019; Velleman et al., 2016). Forced independence was not always viewed positively (Akhtar et al., 2012; Israelsson-Skogsberg et al., 2019; Løkkeberg et al., 2020; Van

Schoors et al., 2019). Some mourned the loss of their childhood (Akhtar et al., 2012; Kaatsız & Öz, 2020; Read et al., 2011).

I had to grow up very fast, I was 12 years old, and I had to manage myself. I had to pack my clothes and toiletries and such things myself. And then I had to make sure somebody could wash those clothes, so I had to ask about it ... had to ask to be driven here and there, to football training, and so on. It was not a matter of course anymore, I had to ask around (Løkkeberg et al., 2020, p. 7).

Siblings learned to become more patient and understand others' needs better (Heaton et al., 2022; Løkkeberg et al., 2020; Lostelius et al., 2019; Porteous et al., 2019; Read et al., 2011; Wennick & Huus, 2012).

I think I have learned to feel it when people are suffering. When my brother was sick, no one could see that I was suffering, although I did not feel well inside. This made me aware that people might be sad inside, even though they seem happy outside (Løkkeberg et al., 2020, p. 7).

Some siblings felt stronger, more confident and able to accept and adjust (Akhtar et al., 2012; D'Urso et al., 2017; Israelsson-Skogsberg et al., 2019; Løkkeberg et al., 2020). Their sibling's illness made them aware of life's unpredictability (D'Urso et al., 2017; Van Schoors et al., 2019), changed their life perspective, (D'Urso et al., 2017; Heaton et al., 2022; Løkkeberg et al., 2020; Lostelius et al., 2019), values, and life direction (D'Urso et al., 2017), and had added to their growth (Porteous et al., 2019). "Having [my sibling] in my life has made me the person that I am today" and "without [my sibling] I think I would be like, a totally different person" (Heaton et al., 2022, p. 227).

Siblings struggle to cope - "You feel that no one is there for you"

Siblings coping strategies differed. Disclosing feelings and thoughts to others, particularly parents, relieves stress and promotes emotional well-being (Kaatsız & Öz, 2020; Løkkeberg et al., 2020; Long et al., 2015; Porteous et al., 2019; Prchal & Landolt, 2012; Van Schoors et al., 2019). Some described emotional outbursts as a form of catharsis (Kaatsız & Öz, 2020; Porteous et al., 2019).

Except for Akhtar et al. (2012), Carlsen et al. (2019), Israelsson-Skogsberg et al. (2019), Lostelius et al. (2019) and Webster (2018), all the other studies reported that sufficient and timely information from parents or healthcare professionals, particularly concerning medical matters is important. Adequate information helped build siblings' hope and confidence (Løkkeberg et al., 2020), to deal with anxiety (Velleman et al., 2016). In the absence of information, siblings turned to online sources, which are often unreliable, and may be perceived as frightening or confusing (Kaatsız & Öz, 2020; Long et al., 2015; Read et al., 2011). "I was always researching things and trying to find out more about it. (...) I just looked for good news, not bad" (Long et al., 2015, p. 24).

Siblings tried to restrain their negative emotions (Read et al., 2011) or used humour to dissipate tension (Porteous et al., 2019; Read et al., 2011). Religion (Løkkeberg et al., 2020; Long et al., 2015) and spiritual coping strategies (Kaatsız & Öz, 2020) were also mentioned. A few preferred keeping things to themselves, avoiding contact with others (Lostelius et al., 2019) and not talking about their sibling's illness (Kaatsız & Öz, 2020; Long et al., 2015; Porteous et al., 2019; Prchal & Landolt, 2012; Read et al., 2011; Velleman et al., 2016, p. 625): "I didn't want my friends thinking that I was an emotional wreck or anything like that" (Porteous et al., 2019, p. 123). Others sought relief through denial (Velleman et al., 2016).

I am a big fan of denial. Someone would tell me something and I'd act like I had no idea what was going on. I go out just to get away from everything ... I go out with my friends and come home and act like nothing ever happened. I just want to avoid getting upset (Long et al., 2015, p. 28).

Many sought distractions in hobbies and social activities (Long et al., 2015; Porteous et al., 2019; Tyerman et al., 2019; Velleman et al., 2016). Attending school provided predictability and consistency (Porteous et al., 2019), as did caring teachers (Agerskov et al., 2021; Akhtar et al., 2012; D'Urso et al., 2017; Løkkeberg et al., 2020) and counsellors (D'Urso et al., 2017; Long et al., 2015; Porteous et al., 2019; Tyerman et al., 2019). As one 12-year-old girl said: "I had a teacher, she was really good at talking about it with me, because she knew me really well" (Agerskov et al., 2021, p. 246). However, some siblings mentioned inconsistent school support (Long et al., 2015).

Siblings also felt that they did not receive adequate support from health care services (D'Urso et al., 2017; Kaatsız & Öz, 2020; Lostelius et al., 2019).

I could have used some help. Children should get more psychological support and should be taught that they should hold on to life because there is nothing else they can do; you feel that no one is there for you ... If you don't help yourself, no one can. That's what I've realized (Kaatsız & Öz, 2020, p. 80).

On the other hand, being acknowledged by friendly hospital staff was viewed positively (Løkkeberg et al., 2020; Porteous et al., 2019; Prchal & Landolt, 2012; Tyerman et al., 2019; Van Schoors et al., 2019). Joyful activities, privileges and gains owing to the ill sibling's hospital stays compensated for some of their negative experiences (Akhtar et al., 2012; Israelsson-Skogsberg et al., 2019; Porteous et al., 2019).

My brother got all the attention, gifts and so on, so actually I was a bit jealous. Then I got a brand-new iPad. I became happy, not only because of the iPad itself, but mostly because he (the nurse) saw me (Løkkeberg et al., 2020, p. 8).

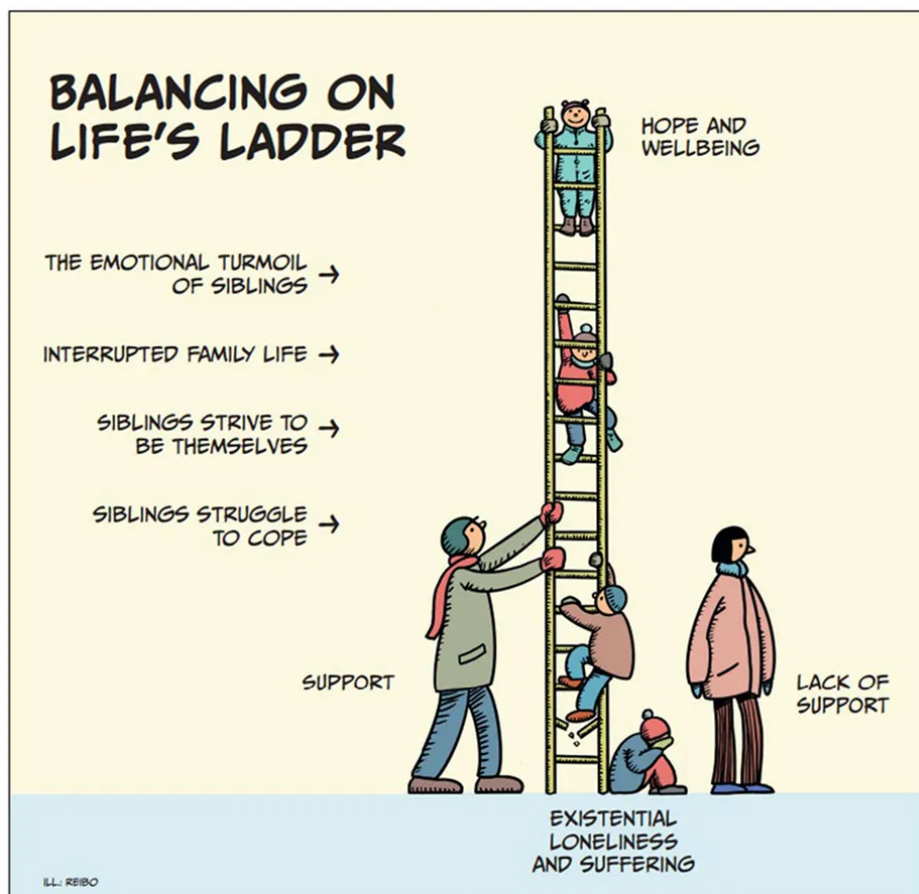
Time spent with other siblings of ill children in the hospital or support groups was considered beneficial (Israelsson-Skogsberg et al., 2019; Løkkeberg et al., 2020; Long et al., 2015; Prchal & Landolt, 2012; Read et al., 2011; Wennick & Huus, 2012). “You can hear other people's stories and stuff (...). They understand what you're talking about” (Porteous et al., 2019, p. 125). An optimistic attitude helped siblings cope (Løkkeberg et al., 2020; Long et al., 2015; Porteous et al., 2019). A sibling in Porteous et al. (2019, p. 123) said, “Think of the positive things, not the negative things. So, the things that you want to happen, not that could happen” (Porteous et al., 2019, p. 123).

A line of argument: Balancing on life's ladder

An overarching metaphorical phrase – “Balancing on life's ladder”, captures the core elements of our findings, suggesting that siblings' experiences resemble balancing on a ladder. The ladder is a metaphor for the fluctuating experiences of existential well-being, ranging from hope to despair. Being a sibling of a child with CCN entails navigating the ups and downs of everyday

family life, embracing both the constraints and opportunities for well-being. Finding existential well-being is a difficult balancing act for the healthy siblings, who carry the heavy burden of experience on their young shoulders. Each rung of the ladder represents a metaphorical space where they can rest, but risk falling from if the ladder is poorly supported.

Figure 2 illustrates this metaphor in a lifeworld context. To facilitate the siblings' journey, the ladder must be secured, the rails reinforced and the rungs adequately spaced to enable the climber to rest and retain or regain balance. A ladder's stability depends on its structure, angle support. The best built ladder will fall if on unsteady ground or not adequately supported. The metaphorical elements of the ladder that provide stability represent the support network (family, peers, teachers, and healthcare providers) that can give siblings the courage to carry on. Falling off the ladder only takes a second, but the existential impact on siblings' well-being may be long-lasting.



Discussion

This meta-ethnography aimed to synthesize and interpret existing qualitative research on the existential experiences of siblings of children with complex care needs. The overall findings underscore daily unpredictability, constant changes and the need for adjustment contributing to an imbalance in siblings' lives, leaving them with few opportunities to experience stability and comfort. The siblings in the selected studies seemed to struggle to find the courage to carry on within the constraints of their family life. However, despite prolonged suffering, many managed to find hope amid their challenges.

Galvin and Todres' (2013) lifeworld approach implies that a situation is experienced as balanced when it promotes well-being. They refer to the terms dwelling and mobility. Dwelling represents a sense of peace and being at home, whereas mobility can be literal or imaginative. Existential mobility is a form of imaginative movement that provides energy, a sense of freedom and future hope. Well-being is ideally achieved by intertwining dwelling and mobility to arrive at a balance that provides vitality. Without dwelling and mobility, vitality, a sense of being at home, present-centeredness, comfort, sense of belonging or hope are difficult (Galvin, 2021). This theoretical perspective provides a framework for our discussion and adds to the knowledge of healthy siblings' needs.

Our findings reveal that the siblings were overwhelmed by a wide range of emotions. Their ongoing worries and fears fluctuated alongside their siblings' health and parents' emotional reactions. However, they have difficulty expressing their deepest emotions and often avoid talking about their feelings to protect their parents from further worry and distress. Conversely, research on parents' perspective revealed that parents are reluctant to discuss their feelings about the ill child with their other children for fear of increasing their emotional pain (Page et al., 2020). Our findings illustrate that healthy siblings benefit from their parents' openness about their child's illness. Researchers have found that knowledge of the disease reduced anxiety (Deavin et al., 2018; Piotrowski et al., 2022) and enabled siblings to assess its seriousness (Agerskov et al., 2021). Furthermore, parents concealing their emotions to protect their children might make the children internalize such behaviour, as discussed in Fredriksen et al. (2023). Withholding important information from children can be worse than telling the truth (Lummer-Aikey & Goldstein, 2021).

Interestingly, only a few siblings in the included studies mentioned support from healthcare professionals. Franklin et al. (2018) reported that siblings' absence or invisibility in clinical settings made it difficult for healthcare workers to respond to their needs and provide support. Our findings stress the importance of professionals recognizing siblings' existential needs, although recent research has found them to be inadequately equipped to meet these needs (Chan & Shorey, 2022; Lummer-Aikey & Goldstein, 2021).

A meta-synthesis by Deavin et al. (2018) noted that the siblings' situation may interfere with other aspects of their lives, particularly school performance. They may find it difficult to concentrate in class and complete homework. Our findings show that supportive and understanding teachers are important, and that school can be a place where siblings feel comfortable and experience normalcy.

Siblings keenly desire to return to normal family life. The lack of normality leaves them in a state of emotional turmoil and agitation. A prior meta-analysis confirmed the risk of depression among siblings of children with CCN (Martinez et al., 2022). According to Galvin and Todres (2013, p. 113), agitation is closely associated with anxiety and depression. Our findings support those of previous studies that siblings are often left alone with their emotions. A recent meta-analysis indicated that siblings of children with long-term illnesses adjust well emotionally if integrated care services acknowledge their feelings and support the entire family (Pinquart, 2023).

Galvin and Todres (2013, p. 114) argued that mood is intertwined with other dimensions of life. In this meta-ethnography, the existential dimensions of mood and identity are clearly related. We found that the loss of control and preferred activities may weaken the siblings' sense of self. These findings concur with Weiner and Woodley's (2018) that illness in the family makes children feel insecure about themselves and threatens their identity.

Although siblings accept that the unwell child's condition has altered family life, most feel uncomfortable and like outsiders forgotten by their own family. They perceived themselves as being downgraded to the lowest rung on the family ladder. They did not want to be bothersome, create problems, or occupy space. Hanvey et al. (2022) used the term "glass children" to refer to siblings of children with chronic illnesses, as their parents look right through their needs to meet those of the unwell child.

This meta-ethnography shows how easy it is for healthy siblings of CCN to drift into isolation and loneliness and lose faith in themselves. Galvin and Todres (2013, p. 111) explain that suffering entails the feeling of losing oneself and uselessness, leading to a sense of fragmentation and loss of coherence. One of the siblings in Løkkeberg's (2020, p. 6) study said: – “I felt quite alone on this earth”. Research has found that parents are concerned about the impact of having insufficient time for their healthy children (Page et al., 2020).

Although overwhelming emotions and loss of identity affect siblings' existential freedom and growth, some siblings benefitted from their experiences. They reported developing inner strength, compassion, maturity, insight and empathy for others. These findings align with those of Weiner and Woodley (2018). Haukeland et al. (2015) highlighted the complexity of siblings' emotional perspectives, comprising diverse and contradictory feelings. Inconsistencies in research exploring siblings' emotional adjustment to everyday situations (Lummer-Aikey & Goldstein, 2021) mirror this complexity. Nonetheless, the positive developmental outcomes of siblings growing up with a brother or sister with CCN have scarcely been studied (McKenzie Smith et al., 2018), calling for greater research focus.

Being present and participating in the care of an ill child provided stability and tightened family bonds, enabling siblings to cope with uncertainty, build courage and self-esteem and deal with difficult existential challenges. Kelada et al. (2022) showed that siblings of chronically ill children who have care responsibilities report enhanced psychological functioning, giving siblings a sense of belonging and strengthening family bonds (Hilário, 2022). However, in our meta-ethnography, we found that caring for ill siblings can also be a burden. High expectations of themselves and others can make siblings feel guilt and resentment.

All the synthesized studies indicated that siblings' relationships with significant others changed because of the illness in the family. Good bonds with parents, teachers, friends, and healthcare professionals were essential to helping them cope with their daily struggles. Weiner and Woodley (2018) reported that coping strategies tend to improve with time and adequate support. In our study, parental attentiveness was crucial to supporting siblings' needs, however, parents were often unavailable owing to

hospitalizations and disrupted family life. Siblings suffered, particularly in their mothers' absence. Recently, Fredriksen et al. (2023) reported that this population have stronger relationships with their mothers than with their fathers. Fathering in families with a child with CCN is scarcely mentioned in existing research (Vatne et al., 2023), which largely focuses on mothers' contributions (Smith et al., 2015; Swallow et al., 2012). We identified that fathers' enhanced involvement in managing the illness strongly affected the healthy siblings' lives.

Furthermore, siblings benefitted from close relationships with their peers. However, not all siblings wanted to turn to their peers as they no longer shared similar life experiences and values. According to the lifeworld theory, people feel at home with themselves in relaxed situations that provide a sense of belonging and togetherness (Galvin & Todres, 2013). In this study, it was important for siblings to have friends who understood their life situation, especially those who were more mature or had faced similar challenges.

Our findings highlight the importance of sibling support groups, consistent with Kirchhofer et al. (2022) review findings that social support is associated with positive adjustment and resilience. However, our meta-ethnography also revealed negative aspects of social support, such as excessive focus on ill children at the expense of healthy well siblings. Previous research has shown that social support can enhance children's awareness of their negative circumstances (Kirchhofer et al., 2022). Despite experiencing many losses and struggling to remain hopeful, siblings in all the included studies described moments when they felt at home with themselves.

Our synthesis indicates that when siblings are involved in valued activities such as music, sports, or spending time with the whole family, they cultivate a sense of satisfaction and hope. We found hope to be mainly associated with short-term future orientation. A sibling may look forward to an evening without the ill child's personal assistant or to intensive care unit staff making a chocolate cake for the sibling's birthday. These findings may be related to the term "renewal" in the lifeworld-led theory, referring to a well-being experience of the temporal intertwining of mobility and dwelling. A sense of present well-being and openness to the future constitute the deepest form of this existential dimension (Galvin & Todres, 2013, p. 84).

Our findings indicate that siblings must balance on life's ladder between accepting an uncertain future and anticipating positive outcomes. Future orientation was evident in all the included studies. Siblings used several strategies, such as accepting the situation, positive thinking and maintaining hope for the future. Previous research has found that hope reduces feelings of loss, strengthens feelings of control, and improves psychological well-being and coping (Duggleby et al., 2021). A meaningful purpose in life can improve well-being, providing mobility and continuity (Galvin & Todres, 2013, p. 83) enabling the siblings to move up life's ladder with steady steps.

Our line of argument synthesis highlights the importance of establishing a solid ground for the siblings' "ladder" to stand on. Family belonging and support from teachers, healthcare professionals and peers can ensure stability. This focus on foundation aligns with Galvin and Todres' (2013, p.95) well-being concept of how "grounded vibrancy" can enhance feelings of renewal, vitality and belonging.

Strengths, limitations and reflexivity

Detailed methodological descriptions have been provided to enhance the credibility and consistency of this meta-ethnography. The authors faithfully represented the primary studies through the use of illustrative quotes and contextual information from the source (Sim & Mengshoel, 2022).

Furthermore, consistency was incorporated through systematic database and extensive manual searches of literature (Booth, 2016). Almost half of the primary studies were identified through a manual search. This supports the reported difficulty of finding qualitative research in scientific databases. Ambiguities regarding the definition of "children with complex care needs" (Brenner et al., 2018) might have influenced the search results, since the search strategy depended on the researchers' epistemological perspective (Booth, 2016). It is possible that other search terms would have resulted in a different sample. Nevertheless, our strategy led to the discovery of a relatively high number of studies eligible for synthesis.

The included articles covered a variety of countries and contexts; unfortunately, few studies were available from Eastern Europe, Asia and Africa. This ensured diversity in the findings and a broader understanding of the complexity of the experiences of growing up with a sibling with a CCN.

The authors acknowledge that these findings may not be applicable to all contexts.

Not all primary studies reported the gender and age of the participants. This data may influence how they define themselves and how others perceive them. We encourage future researchers to specify siblings' gender and age when publishing their work to simplify the review process and increase the confirmability of the data. Some studies examined siblings' experiences at the time of diagnosis and onset of symptoms, whereas others described everyday life with a chronically ill sibling. Different experiences along the illness trajectory may broaden our understanding of the phenomenon of living with a sibling with CCN (Henly et al., 2011). Moreover, this meta-ethnography included different genders, ages, and conditions of children with CCN, ensuring diversity in our findings.

We argue that the findings of this meta-ethnography are novel. Noblit and Hare's (1988) method allows for a higher level of interpretation, and a more comprehensive and original understanding of siblings' lifeworld. Additionally, our study emphasizes siblings' existential needs and the use of Galvin and Todres (2013) theory of lifeworld-led care. The authors of this study are nurses with broad clinical backgrounds in caring for patients and their families. All the authors work as educators and qualitative researchers with expertise in meta-syntheses and extensive knowledge of the literature on family nursing. The close collaboration within the research team strengthened the rigour of this study (Lee et al., 2015).

Conclusion

A strong sense of invisibility and need for belonging dominated the findings. The ladder metaphor can be useful as a pedagogical tool in clinical settings and nursing education to illustrate siblings' vulnerability and existential needs and improve dialogue between siblings and nurses. Our findings indicate that nurses' support may serve as an important contribution to healthy siblings' well-being. Hospital and primary care nurses can become aware of siblings' unmet needs using a lifeworld approach and ensure that their voices are heard. Our findings show that children require regular age-appropriate information about their ill siblings' condition. Further research on the unique experiences of siblings in relation to their age and

development stage is required. Nurses are well-positioned to work alongside families who have a child with CCN and provide family-centered care.

Future research can focus on how nurses can contribute to siblings' existential well-being in primary and secondary healthcare settings. Health policies and nursing education may benefit from leveraging the evidence from this research to ensure that families of children with CCN receive personalized care.

AUTHOR CONTRIBUTIONS

Following the guidelines of the International Committee of Medical Journal Editors, all authors contributed substantially to the conceptualization, methodology, investigation and formal synthesis of data. Carina Nygård drafted the manuscript, which all authors critically revised several times for important intellectual content. Gabriele Kitzmüller was responsible for the project administration leading to the final publication. This meta-ethnography form part of a PhD, supervised by Anne Clancy and Gabriele Kitzmüller. Additionally, each author has contributed sufficiently to this research to take public responsibility for the content and has agreed to be accountable for all aspects of the work, ensuring that questions related to the accuracy and integrity of any part of the manuscript are appropriately investigated and resolved. Each author has agreed that all three authors' contributions are accurate. All authors approved the submitting of this meta-ethnography.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.





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