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The experiences and perceptions of healthy siblings of children with a long-term condition: Umbrella review

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ABSTRACT

Problem: The lives of healthy siblings living with a sibling with a long-term condition are often shaped by the family, type of illness, length of illness, age of the child, caregiver demands, and support provided to the family, ill sibling, and healthy sibling. While the experiences of healthy siblings are documented in the literature by parent proxy, literature on healthy siblings self-reported experiences of living with a sibling who has a long-term condition remains scarce.

Purpose: This umbrella review aims to synthesize reviews on the self-reported experiences of healthy siblings of children living with a sibling who has a long-term condition.

Eligibility criteria: Published peer-reviewed reviews in English language exploring the self-reported experiences of healthy siblings under 24 years old, whose siblings are diagnosed with a long-term condition.

Sample: Using a developed search strategy, seven electronic databases (CINAHLPlus, Scopus, PubMed, PsycINFO, Cochrane Database of Systematic Reviews, Clinical Key, and Google Scholar) were searched from 2018 till December 2023. Eleven reviews met the inclusion criteria and were subjected to narrative synthesis.

Results: Four themes (adjusting to changes, wanting to help, living the ups and downs, living the changes), and eight subthemes were generated from the syntheses.

Conclusion: This is the first umbrella review undertaken on healthy siblings self-reported experiences of living with a sibling who has a long-term condition. The impact of a long-term condition on healthy siblings of children with a long-term condition suggests a need for healthcare providers and organisations to provide better emotional, psychological, and informational support to healthy siblings and their families.

Implications: Findings from this review will inform healthcare providers, organisations, researchers, and policy-makers on the development of future clinical practices and research for healthy siblings.

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Introduction

While research about children with long-term conditions has grown significantly, much less attention has been given to siblings of those children. Over the same time, family centred care (FCC) approaches have become normalised as the way to help children and families engage with health services. Yet, despite FCC having a central tenet that “care is planned around the whole family... in which all the family members are recognised as care recipients” (Shields et al., 2006, p. 1318; Weiner & Woodley, 2018), the needs of siblings may not be as

immediate as those of the unwell child and caregivers (Pinquart, 2013). Further, the experiences and care needs of siblings are at times reported via parental proxies rather than in the young people’s voices (Baker & Claridge, 2023; Kelada et al., 2022).

A long-term condition (LTC) can be defined as any ongoing, long term or recurring condition that can have a significant impact on people’s lives (NHC, 2007; Te Whatu Ora Health New Zealand, 2024). Related terms for LTC are ‘chronic condition’ or ‘chronic disease or illness’ where chronic disease or illness is defined as a health care problem lasting at least three months that involves frequent hospital admissions, at home medical care and/or other forms of health care (Mokkink et al., 2008). While the estimates vary significantly, the current percentage of children and young people in the world living with a LTC can range from 13 to 27% per cent of the population (Denny et al., 2014; Perrin et al.,

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2007). As many as one in five children may have special care needs with many of those having significant lifestyle changes because of the condition (Baker & Claridge, 2023; Ghandour et al., 2022).

Increased prevalence of children with a LTC may relate to improvements in treatments and improved survival rates for many childhood conditions (e.g. prematurity, cystic fibrosis, congenital heart disease) alongside greater awareness of mental health and neurodevelopmental conditions (Perrin et al., 2014). Families of children with LTCs often manage complex care requirements, negotiate across multiple healthcare teams, incorporate often unplanned hospital visits while also adapting to the emotional load that illness in a child presents (Jessup et al., 2017). Families living with a child with LTC incur significant material costs, which are also associated with poverty in these families (Perrin et al., 2014).

Having a child with a LTC impacts the whole family, including healthy siblings (Jessup et al., 2018). Sibling relationships are instrumental in development of identity and sense of self (Hilário, 2022), even without the complexity of a LTC. Siblings of children with LTCs can experience impacts on multiple life spheres including family relationships and roles, family routines, friendship, and schooling, and on their own physical, psychosocial and emotional well-being (Baker & Claridge, 2023; Lummer-Aikey & Goldstein, 2021). Healthy siblings are at risk of feeling inequitable care from parents, poorer engagement at school, reduction in self-esteem and may exhibit antisocial behavioural issues (Baker & Claridge, 2023); and will often take on traditional adult carer roles to support family functioning (Jessup et al., 2018).

It is important to note that individual socio-demographical characteristics such as age, gender, birth order and context have an influence on this experience. Healthy siblings describe their sibling relationship as different based on age (childhood, adolescent, emerging adulthood), where issues such as petty bickering; role discrepancies; and conflict/rivalry lessened when age increased, or as relationships strengthened or when geographical distance increase due to leaving home (Hamwey et al., 2019; Hudson et al., 2014; Webster, 2018). In addition, studies suggest that age and gender influence the caring role of healthy siblings, where older, females in families with a higher child to parent ratio take on more caring responsibilities (Boyle et al., 2023; Hilário, 2022; Webster, 2018). The benefits and challenges of this caring role is reported in equal measures. Benefits include an increased sense of empathy/emotional intelligence and maturation, lower anxiety symptoms, greater use of problem-focused coping, and a greater sense of companionship with the affected sibling (Hilário, 2022). However, these increased responsibilities of caring can also be perceived as burden that impacts on the healthy siblings mental and emotional well-being (Kale & Siğirtmaç, 2021). Researchers have described how healthy siblings may experience loneliness, worry about the prognosis of their sibling as well as experience stress related to the LTCs impact on daily family life (Haukeland et al., 2015; Nabors & Liddle, 2017). In contrast, other findings suggest that siblings' levels of depression and quality of life are like those of peers without a sibling with a long-term condition (Velleman et al., 2016), and potential positive outcomes reported for healthy siblings, with benefits included a 'sense of purpose', strengthened intra-family relationships, and development of resilience characteristics not necessarily evident in their peers (Lummer-Aikey & Goldstein, 2021).

Despite the contradictory findings of studies in healthy siblings and the disagreement among researchers on the pervasiveness of negative impacts of having a sibling with a LTC, siblings of children and young people with a LTC do deserve attention, love and protection. Given the large number of systematic reviews on healthy sibling's experiences (Chan & Shorey, 2022; Deavin et al., 2018; Elliott et al., 2020; Kirchofer et al., 2022; Martinez et al., 2022; Mooney-Doyle et al., 2021) and the often-divergent outcomes and conclusions this review aims to synthesize these findings into an organised and accessible format. Much of the research on families of children living with a long-term condition has focussed on impacts on parents, particularly as

'caring' has tended to be seen as an adult responsibility (Hilário, 2022); parental reports however are not accurate representations of siblings' experiences (Lummer-Aikey & Goldstein, 2021). Children, and young people with experience in healthcare are increasingly recognised as reliable reporters of their experience (Carter et al., 2017), therefore, this review only included studies presenting perspectives of siblings.

A preliminary search for existing umbrella reviews was conducted in JBI Library, Cochrane Library, CINAHL (EBSCO), MEDLINE (PubMed), and PROSPERO databases but no similar reviews were found. This review's distinct contribution lies in its thorough examination of the existing systematic reviews, which are presently scattered across various sources.

The aim of this study was to conduct an umbrella review and syntheses of review articles published between 2018 and 2023 on experiences and perceptions of healthy siblings of children and young people with a LTC. The project commenced in February 2023 and this time frame window was selected in order to provide current (within the last five years) and applicable systematic reviews to address the question (Dang et al., 2021). The objectives were: (1) to describe healthy siblings' (aged 0–24 years) experiences and perceptions living with sibling with a LTC; (2) to develop evidence-based recommendations for clinical practice and research. This umbrella review will provide direction for future clinical practice initiatives and research.

Methods

This review was informed by the Joanna Briggs Institute (JBI) umbrella review methodology which is designed to combine all types of synthesis of research evidence (Aromataris et al., 2020). An umbrella review builds upon an area of research well covered by existing systematic reviews and has been defined as a review of reviews (Booth, 2016). When describing primary reviews within this paper, we are referring to the reviews included in the umbrella review; the studies included in the primary reviews are primary/empirical studies. In this paper we refer to 'healthy siblings', however, acknowledge that some siblings may have an underlying LTC themselves. Information about the health status of the healthy sibling was either not presented or identified within the reviews or the process of this study. The protocol for this umbrella review was registered on PROSPERO 11/02/2023 (CRD42023395704) (Blamires et al., 2023).

Search strategy

Comprehensive searches for research synthesis in seven databases (Cumulative Index of Nursing and Allied Health Literature (CINAHLPlus), Scopus, PubMed, PsychINFO, Cochrane Database of Systematic Reviews, Clinical Key, and Google Scholar) were undertaken between November–December 2023. The search strategy was conducted with the assistance of a research librarian. The keywords included (siblings or brothers or sisters or sibling or brother or sister) AND (long term conditions or chronic disease or chronic conditions or chronic illness) AND (experiences or perceptions or attitudes or views) AND (systematic review or meta-analysis or literature review or review of literature). All types of reviews (meta synthesis, narrative, scoping, integrative, and literature reviews) were eligible for inclusion. Eligibility criteria are presented in Table 1. Inclusion and Exclusion Criteria.

Search outcome

In the first instance, all records ($N = 562$) returned from the searches were screened by two authors; 527 were excluded as were duplicates ($n = 27$) or did not meet the inclusion criteria ($n = 500$). Thirty-five reviews were downloaded into the Rayyan software system (Ouzzani et al., 2016) and were screened by all authors using title, abstracts, and key words; nine were excluded. The Rayyan software

Table 1
Inclusion and exclusion criteria.

PICo	Inclusion Criteria	Exclusion Criteria
Participants	Healthy CYP with sibling with long term condition Participant siblings aged 0–24 Sibling with LTC aged 0–24	Families Health care clinicians Parents as proxy
Phenomena of Interest	Healthy siblings self-reported perceptions/experiences/responses Siblings's psychosocial outcomes Siblings lived experience Siblings QoL	Siblings of child in PICU Siblings of child under palliative care Intervention specific reviews
Context	Healthy siblings of CYP people with a long-term condition of any gender, ethnicity (LTC-can be defined as any ongoing, long term or recurring conditions that can have a significant impact on people's lives (MOH, 2020) Related terms for LTC are 'chronic condition' or 'chronic disease')	Acute care settings Palliative care/end of life care
Types of Reviews	Internationally accepted review methodologies (i.e., syntheses of empirical research evidence including but limited by systematic reviews, mixed-methods reviews, meta-synthesis, meta-ethnographies, literature reviews, integrative reviews, scoping reviews)	Review protocols Research syntheses that incorporate theoretical studies or text and opinion as their primary source of evidence

CYP children and young people, LTC long term condition, MOH Ministry of Health, PICU paediatric intensive care unit, QoL quality of life.

system enabled this process to be blinded. Twenty-six full-text reviews were then screened by all authors with 15 being excluded leaving 11 reviews meeting criteria. At every stage of the screening process, authors independently completed this in Rayyan and then through discussions came to consensus. The main reasons for exclusion were wrong outcome, wrong publication type, wrong population, foreign language, wrong age, wrong study design, or inability to extract siblings voice from other participants in the reviews (i.e., parents or other family members). Fig. 1 PRISMA flowchart demonstrates the selection process for the final 11 included synthesis.

Quality appraisal

Quality appraisal of 11 research syntheses were assessed by two authors independently using the Joanna Briggs Institute (JBI) Critical Appraisal Instrument for Systematic Reviews (Aromataris et al., 2020). The JBI tools requires reviewers to answer one question regarding the methodological rigor and quality of the synthesis (Supplementary Table 1). Each question was rated as “Yes”, “No” or “Unclear” based on the evaluation by the two independent reviewers, where yes (Y) received a score of 1, and no (N) or unsure (U) received a score of 0. Prior to independent appraisal, it was decided that any discrepancies in the outcomes of critical appraisal would be resolved through discussion between the reviewers. There were no studies with more than a two-point difference in quality scores and no disagreements between reviewers about including or excluding (Supplementary Table 2).

Data extraction

A standardised data extraction table based on the recommendations of Aromataris et al. (2020) was employed to minimise risk of bias. The data extraction table included the following headings: objectives, type of review, method, participants, setting and context, range of publication years of primary studies, number of studies included in the research synthesis, and results relevant to the umbrella review question (Supplementary Table 3). The 11 reviews were divided among two sets of author pairs, who independently extracted the data.

Data abstraction and synthesis

In the first phase of data abstraction and synthesis, two authors, with backgrounds in child and youth nursing, nursing education and experience analysing quantitative and qualitative child health research data, directly extracted and numbered 62 individual key findings and illustrations from the 11 reviews (Supplementary Table 4). The key findings were those labelled and described as such by the authors of the included reviews. The illustrations were descriptions of the findings or

quotations demonstrating the finding. Quotations were selected that best represented the authors' description of the key finding. Both the key findings and illustrations were extracted directly from the reviews included. In the second phase, three authors (two authors as above plus one additional author who was an experienced child and youth health nurse and academic) independently created initial codes and groupings for the findings. The authors met to discuss the differences and discrepancies and could not agree on the synthesised themes so two additional authors (with backgrounds in neonatal and child health nursing, academia and research) were asked to review and consolidate the key findings and codes, this time using the relevant illustrations to develop key themes. This resulted in four synthesised themes (and eight subthemes) that describe the experiences and perceptions of healthy siblings of children and young people living with a LTC. Some of the associated review findings were applied to more than one 'synthesised theme', which aligns with the methods for an umbrella review described by Wiechula et al. (2016). As per the guidance of Aromataris et al. (2020) the key synthesised findings are presented and summarised in Table 2. The description of the synthesised findings and the related subthemes will be provided within the results section.

Results

Review characteristics and design

The 11 included reviews were published between 2018 and 2022 and the number of primary studies included within different reviews ranged from 8 to 102. The total number of primary studies in this review was 243. Of these 35 studies were included in multiple reviews, representing an 1.4% slight overlap of primary evidence as calculated by the corrected covered area index (Kirvaldize et al., 2023). The 11 reviews consisted of five systematic reviews (Chan & Shorey, 2022; Chudleigh et al., 2019; Long et al., 2018; Martinez et al., 2022; Quintana Mariñez et al., 2022), three scoping reviews (Orm & Fjermestad, 2021; Piotrowski et al., 2022; Tay et al., 2021), one meta synthesis of qualitative studies (Deavin et al., 2018), one integrative review (Weiner & Woodley, 2018) and one literature review (Grant & McNeilly, 2021) (Table 3). Two of the syntheses excluded qualitative primary studies (Martinez et al., 2022; Orm & Fjermestad, 2021) with the rest including quantitative, qualitative, and mixed methods primary studies. Six of the syntheses focused on healthy siblings' experiences having a sibling with a specific condition such as childhood cancer (Long et al., 2018; Weiner & Woodley, 2018); attention deficit disorder (Orm & Fjermestad, 2021); chronic kidney disease (Piotrowski et al., 2022); cystic fibrosis (Chudleigh et al., 2019); and type 1 diabetes (Chan & Shorey, 2022). The remaining reviews took a broader perspective including primary studies about the experiences of siblings with a variety of chronic,

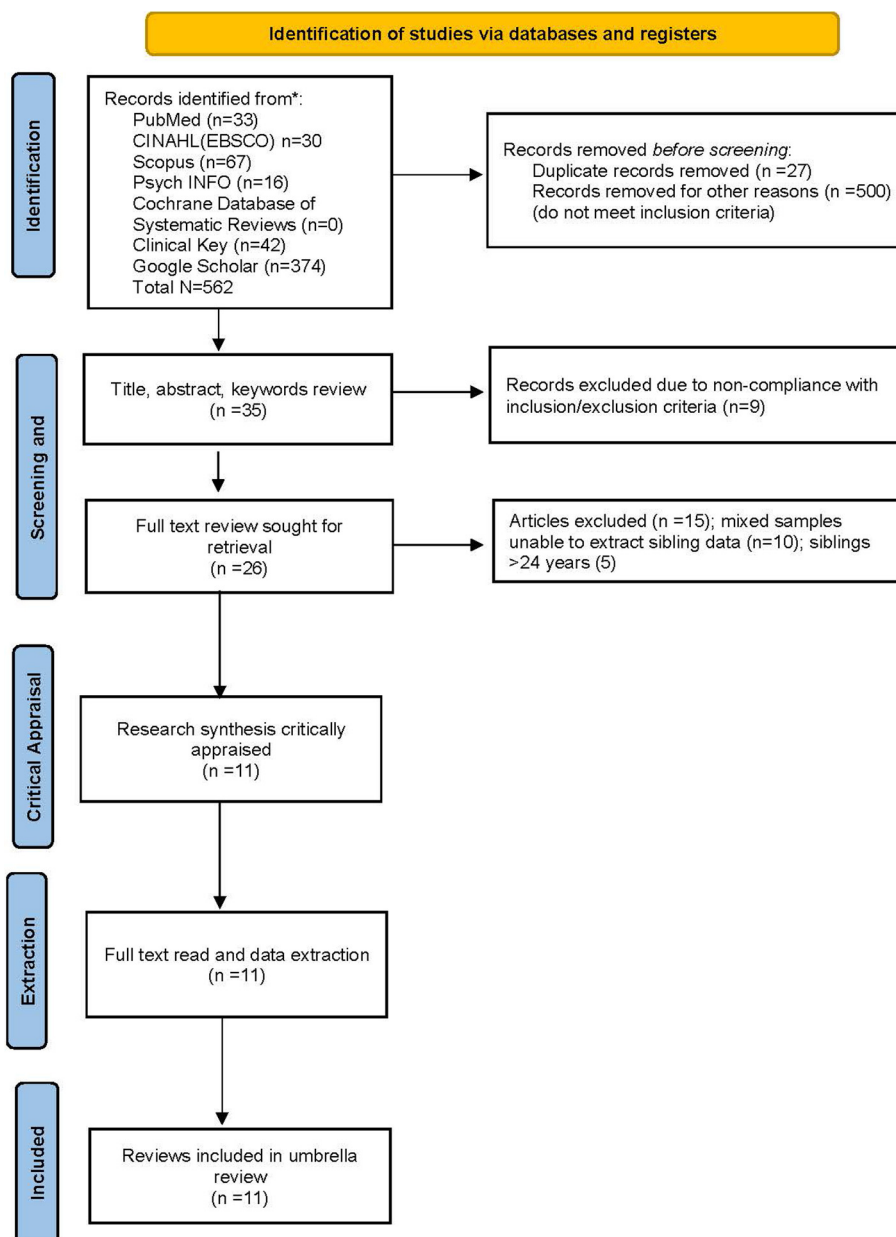


Fig. 1. Flowchart of selection process for research synthesis.

long term or complex illnesses (Deavin et al., 2018; Grant & McNeilly, 2021; Martinez et al., 2022; Quintana Mariñez et al., 2022; Tay et al., 2021). The age range of the healthy siblings was 4–24 years. Most reviews did not include the age range of siblings with the LTC however the reviews were focused on the experiences of the siblings of ‘children’ with a LTC and therefore when age was reported this was reported as under 20 years of age. The syntheses represented data from a range of countries including Argentina, Australia, Belgium, Canada, China, Denmark, Finland, France, Greece, Hong Kong, Israel, India, Iran, Italy, Japan, Netherlands, Norway, Sweden, Switzerland, Turkey, Taiwan, United States, and the UK (Table 3).

Summary of included synthesis

The synthesis resulting in four key themes and eight subthemes that describe the experiences and perceptions of healthy children and young people living with a sibling with a LTC. This is represented in Fig. 2.

Theme 1 Adjusting to changes

Disrupted routines. Healthy siblings experienced significant disruptions that impacted on family life, personal routines, and school functioning (Grant & McNeilly, 2021; Long et al., 2018; Piotrowski et al., 2022; Tay et al., 2021; Weiner & Woodley, 2018). Family life and routines were disturbed from the moment of diagnosis because parents spent more time with the child with the LTC, were away from home or there was a need to incorporate new treatments and routines into family life (Grant & McNeilly, 2021; Long et al., 2018; Piotrowski et al., 2022; Weiner & Woodley, 2018). This was sometimes due to the care needs of the child with a LTC where ‘parents were unable to leave the house due to the high demands of care’ (Grant & McNeilly, 2021, p. 24). This necessity to stay at home affected family time including interfering with vacations, family activities, extracurricular activities, visiting relations, and school (Grant & McNeilly, 2021; Long et al., 2018; Piotrowski et al., 2022; Tay et al., 2021; Weiner & Woodley, 2018).

Table 2
Synthesis of findings.

Synthesis	Associated review finding	
Adjusting to changes	Disrupted routines	Disruption to routine (41), School functioning (29), Disruption in family routine (49), Family functioning (27), Adjustment in diet and daily activities (7), Extracurricular activity changes (60), Family life (24), Changing relationships to self (18), Displaying empathy and being a source of emotional support (3), School (52), School life changes (59)
	Longing for attention	Changing family relationships (17), Family Functioning (27), Emotional & behavioural adjustments (5), Fear fuelled by unfamiliarity and lack of knowledge (1), Feelings of anger 7 jealousy (2), Views of (parents) & siblings (10), Views of unaffected siblings (11), Conditions specific differences (16), Family Environment of Siblings of Children with ADHD (38)
Wanting to help	Being involved	Psychosocial services and unmet needs (32), Recommend support for caregiving siblings (9), Sense of pride and increased knowledge (8), Childhood (psychosocial impact) (12), Education about CF (15)
	Being supportive/and supported	Recommended support for caregiving siblings (9), Support from friends, peers, and support groups (20), Coping strategies (47)
Living the ups and downs	Wellbeing matters	Condition specific differences (16), Mental Health in siblings of Children with ADHD (37), Resilience in Siblings of Children with ADHD (40), Mental health outcomes (34), Emotional and Behavioural functioning (25), Psychosocial and physiological impact (61) Risk and Protective factors(33), Physical health (35), Emotional and behavioural adjustments (5) Psychosocial wellbeing (48), Negative reactions from others (21), Fear fuelled by unfamiliarity and lack of knowledge (1), Quality of life (26), Mortality (36), Quality of life in siblings of children with ADHD(39)
	Isolated and lonely	Changes in family environment (50), Community (53), Friends (45), Relationship changes (57), Social functioning (28), Coping (55), Psychological wellbeing (53), Health behaviours and somatic functioning (30)
Living the changes	Handling it	Strained sibling relationships (6), Coping (55), Coping, acceptance, and adjustment (19), Family and home life changes (58), Emotional experiences 22), Coping strategies and support (23), Adherence (42), Parents (44), Changes in family relationships (51)
	Growing up fast	Displaying empathy and being a source of emotional support (3), Assuming caregiving responsibility (4), Childhood (psychosocial impact) (12), Resilience (31), An array of emotional changes (56), Siblings fear, worry and anxiety (43), Views of unaffected siblings (11), Psychological well-being (46), Resilience (31), Coping strategies (47)

Disruptions also occurred for usual childhood social and extracurricular activities (Chan & Shorey, 2022; Long et al., 2018), where these were frequently reduced (Long et al., 2018), postponed, and/or put on hold (Grant & McNeilly, 2021; Weiner & Woodley, 2018). Despite having a desire to be doing other activities, siblings sometimes missed out due to prioritizing the needs of the child with the LTC over their own, as they felt a sense of responsibility to their family and their sibling (Grant & McNeilly, 2021). They would, for example, decide that if their sibling with the LTC was unable to participate in a particular activity they would ‘avoid these activities for the sake of their sibling’ (Chan & Shorey, 2022, p. 6). Grant and McNeilly (2021), highlighted that ‘siblings became used to last-minute changes to and cancellation of events or extracurricular activities because of their brother or sister’s needs’ (p.24).

Impacts on school functioning occurred across a range of areas including decreased concentration (Deavin et al., 2018), frequent absenteeism (Long et al., 2018), school aversion (Long et al., 2018; Weiner & Woodley, 2018), and relocation and changing of schools (Long et al., 2018). An overall decline in academic performance was highlighted by one review as being related to healthy siblings wanting ‘to miss school, to visit the hospital’ and therefore having ‘less time for schoolwork due to the child being at hospital’ (Weiner & Woodley, 2018, p. 116). In addition, Piotrowski et al. (2022) correlated nonattendance at school, among lower income families, to be directly related to the healthy sibling taking on more caregiver responsibilities.

Longing for attention. It was obvious that the family dynamic and needs changed when one child in the family had a LTC (Deavin et al., 2018; Long et al., 2018). Siblings reported a disrupted family environment, where family members were often separated (Long et al., 2018), they had less time with their parents (Tay et al., 2021), parent-sibling relationships were altered, and they perceived a lower level of family support and cohesion (Orm & Fjermestad, 2021). The shift of parental focus to the child with LTC (Chan & Shorey, 2022; Deavin et al., 2018) led to less attention, activities, and parent-child-time for the healthy sibling (Long et al., 2018). Siblings felt that they were ‘overlooked’, ‘neglected’ and treated differently by their parents ‘particularly when their brother/sister was hospitalised’ (Piotrowski et al., 2022, p. 3023) and that parents overprotected/overindulged their brother/sister, tolerated bad behaviour to a greater degree, and had more engagement with school teachers and during mealtimes than with them (Chudleigh et al., 2019; Piotrowski et al., 2022; Tay et al., 2021). Younger siblings felt displaced as parents

were more accommodating and attentive to the child with the long-term condition (Tay et al., 2021). They subsequently felt left out and invisible (Chan & Shorey, 2022) as they believed they were treated differently by their parents, leading to a decentralised position in the family (Chudleigh et al., 2019; Tay et al., 2021).

Bitterness, anger and jealousy (Chan & Shorey, 2022; Deavin et al., 2018; Long et al., 2018) resulted from feelings that their sibling with the LTC took advantage of their illness with one participant describing how their sibling, ‘kind of milks the system (imitating youth with T1DM) ... I’m sick’, ‘I can’t do this’, or ‘I can’t [be]cause I’m not feeling good’ (Chan & Shorey, 2022, p. 5). They felt that their siblings not only received special treatment from their parents (Chudleigh et al., 2019; Long et al., 2018) but also from teachers (Tay et al., 2021). To meet the changing needs of the family, healthy children had to adjust to their new role as a sibling of a child with a LTC, which included developing greater independence (Chan & Shorey, 2022), new skills and responsibilities (Deavin et al., 2018), and being more mature than other children of the same age (Piotrowski et al., 2022).

Theme 2 Wanting to help

Being involved. Healthy siblings yearned to be more involved and have knowledge about their sibling’s condition and treatment (Chan & Shorey, 2022; Chudleigh et al., 2019; Deavin et al., 2018; Long et al., 2018; Piotrowski et al., 2022; Weiner & Woodley, 2018). Some siblings wanted more information about disease treatment, progression, prognosis, and mortality and indicated they were not as informed as they would like to be (Long et al., 2018; Piotrowski et al., 2022) or that they recognised this as an ‘evolving process’ (Deavin et al., 2018, p. 13). Others made sure to get detailed information regarding test results and progress of the condition and ‘valued and paid close attention’ to this information ‘when it was provided’ (Piotrowski et al., 2022, p. 3024). Healthy siblings preferred and wanted to obtain this information from healthcare professionals (Long et al., 2018; Weiner & Woodley, 2018), and hoped for more positive support from them despite often feeling overlooked (Chan & Shorey, 2022), or ‘not paid attention to’ (Weiner & Woodley, 2018, p. 117). A healthy sibling from Chan and Shorey (2022) illustrates this well.

‘Nurses should talk to us... so that we can help our siblings and parents...I often feel ignored during clinic visits...’ (p.5).

Table 3
Summary of methods, characteristics and key findings of review (N = 11).

Author (year)	Review typology	Number of studies (Types of study)	Country of origin of studies included	Total Population across review/context	Key findings from review
Chan and Shorey (2022)	Mixed studies systematic review using narrative syntheses.	13 studies (10 qualitative, 3 quantitative) from 1987 to 2018.	Sweden (n = 5), United States (n = 4), Australia (n = 2), France (n = 1), Turkey (n = 1).	287 siblings (<18 years old) of children diagnosed with T1DM.	Four themes and 9 sub-themes: Emotional responses to the sibling's condition (fear fuelled by unfamiliarity and lack of knowledge, feelings of anger and jealousy); Stepping out of comfort zone (displaying empathy and being a source of emotional support, assuming caregiving responsibility); Changes in family dynamics (emotional and behavioural adjustments, strained sibling relationships, adjustment in diet and daily activities); Takeaways and a way forward (sense of pride and increased knowledge, recommended support for caregiving siblings).
Aim: to consolidate and examine the experiences and needs of siblings of children with Type 1 Diabetes Mellitus.					
Chudleigh et al., 2019	Systematic review using a narrative synthesis.	13 studies (4 qualitative, 2 mixed methods, 7 quantitative) from 1993 to 2016.	United States of America (n = 6), United Kingdom (n = 3), Belgium (n = 2), Sweden (n = 2).	432 siblings of children diagnosed with CF & CF (+ other condition)	Three themes and 7 sub-themes: Family functioning (views of parents and siblings, views of unaffected siblings); Psychosocial impact (childhood, adulthood); Knowledge of CF (genetic knowledge, education about CF, condition specific differences).
Aim: To conduct a systematic review of the evidence to determine the impact of cystic fibrosis (CF) on unaffected siblings.					
Deavin et al., 2018	Meta synthesis of qualitative research.	12 studies (12 qualitative) from 1991 to 2016.	United States of America (n = 6), United Kingdom (n = 4), Canada (n = 1), Sweden (n = 1).	387 siblings (<20 years old) of children with a chronic and non-communicable physical health condition.	Two themes and 5 sub-themes: Changing relationships (changing family relationships, changing relationships to self); Managing changes (coping, acceptance, and adjustment, support from friends, peers and support groups, negative reactions from others).
Aim: The meta-synthesis explored the experiences of siblings of children with paediatric chronic illnesses to understand their perspectives; in particular what they feel had influenced their emotional wellbeing, in order to target interventions.					
Grant & McNeilly, 2021	Literature review using a narrative synthesis.	9 studies (3 qualitative, 4 mixed methods, 2 quantitative) from 2013 to 2017.	United Kingdom (n = 4), Australia (n = 2), Canada (n = 2), Norway (n = 1).	8896 siblings of children with complex health needs.	Three themes: Emotional experiences, coping strategies and support, family life.
Aim: To examine studies on the effects on siblings of having a brother or sister with complex health needs based on parental reports and sibling self-reports.					
Long et al., 2018	Systematic review using a narrative synthesis.	102 studies (35 qualitative, 4 mixed methods, 63 quantitative) from 2008 to 2016.	United States of America (n = 56), United Kingdom (n = 2), Switzerland (n = 7), Sweden (n = 10), Japan (n = 3), India (n = 3), France (n = 2), Australia (n = 4), Other (n = 15).	363 siblings of children with cancer.	Nine themes: Emotional and behavioural functioning, quality of life, family functioning, social functioning, school functioning, health behaviours and somatic functioning, resilience, psychosocial services and unmet needs, risk and protective factors.
Aim: To understand sibling adjustment and risk/resiliency factors of having a sibling with cancer to inform clinical implications and assess the methodological rigor of sibling studies published since 2008.					
Martinez et al., 2022	Systematic review and Meta Analysis.	36 studies (36 quantitative) from 1986 to 2018.	United States of America (n = 14), United Kingdom (n = 3), Turkey (n = 3), Canada (n = 3), Netherlands (n = 3), Sweden (n = 2), Finland (n = 1), India (n = 1), Greece (n = 1), Taiwan (n = 1), Denmark (n = 1), England and Wales (n = 1).	59,988 siblings (<18 years old) of children with a chronic health condition.	Three main areas reported on: Mental health outcomes (anxiety, depressions, disordered eating, post-traumatic stress, ADHD, anxiety, conduct disorder), physical health, mortality.
Aim: To assess clinical mental and physical health outcomes of siblings of children with chronic health condition(s) compared with siblings of healthy children or normative data.					
Orm & Fjermestad, 2021	Scoping review using a narrative synthesis.	15 studies (15 quantitative) from 1996 to 2019.	United States of America (n = 8), Europe (n = 5), Asia (n = 2).	3729 siblings (<18 years old) of children with ADHD.	Three themes: Mental Health in Siblings of Children with ADHD, family Environment of Siblings of Children with ADHD, quality of Life in Siblings of Children with ADHD, resilience in Siblings of Children with ADHD.
Aim: To identify all relevant studies of psychosocial variables among sibling of children with ADHD, and to identify gaps in the literature to inform and guide further research in this domain.					
Piotrowski et al., 2022	Scoping review using a narrative synthesis.	8 studies (5 qualitative, 1 mixed method, 2 quantitative) from 1985 to 2021.	United Kingdom (n = 8), Turkey (n = 1), Denmark (n = 3), Argentina (n = 1).	107 siblings (<25 years) of children with chronic kidney disease.	Four themes: Family functioning, significant relationships, psychological well-being, coping strategies.
Aim: To summarize and synthesize current literature related to sibling experiences and well-being in families affected by CKD.					
Quintana Mariñez et al., 2022	Systematic review using a narrative synthesis.	16 studies (8 qualitative, 1 mixed method, 5 quantitative, 1 systematic review, 1 meta-analyses) from 2012 to 2022.	United States of America (n = 2), United Kingdom (n = 3), Turkey (n = 1), Canada (n = 1), Iran (n = 3), Italy (n = 1), Norway (n = 2), China (n = 1), Australia (n = 2).	9716 siblings (<21 years) of children with chronic disease.	Four themes: Psychosocial wellbeing, emotional and behavioural difficulties: healthy siblings of children show more susceptibility to, young children appear to be more affected than older children.

Table 3 (continued)

Author (year)	Review typology	Number of studies (Types of study)	Country of origin of studies included	Total Population across review/context	Key findings from review
Aim: To examine the effects on the mental health of healthy siblings who have a sibling with a chronic disease. Tay et al., 2021	Scoping review using a narrative synthesis.	34 studies (17 qualitative, 6 mixed methods, 11 quantitative) from 1977 to 2018.	United States of America (n = 16), United Kingdom (n = 9), Sweden (n = 3), Canada (n = 2), Israel (n = 1), Netherlands (n = 1), New Zealand (n = 1), Hong Kong (n = 1).	1357 siblings (<20 years) of children with a life-threatening illness.	Themes: Family functioning, disruption in family routine, changes in family environment, changes in family relationships, social well-being includes two subthemes: (a) school and (b) community, psychological wellbeing, coping.
Aim: To map findings from healthy siblings' experiences of living with a child with any life-threatening illness. Weiner & Woodley, 2018	Integrative review using a narrative synthesis.	18 studies (12 qualitative, 6 quantitative) from 2012 to 2017.	United States of America, United Kingdom, Sweden, Canada, Switzerland, Taiwan.	951 siblings (<20 years old) of children with cancer.	Seven Themes: An array of emotional changes, relationship changes, family and home life changes, school life changes, extracurricular activity changes, psychosocial and physiological impact, need for informational and special desires.
Aim: To synthesize and analyze relevant findings related to the siblings' experiences of childhood cancer.					

ADHD attention deficit hyperactivity disorder, CF cystic fibrosis, T1DM type one diabetes mellitus.

Not knowing led to confusion, misunderstandings, feelings of being left out, neglect, and anxiety (Chan & Shorey, 2022; Deavin et al., 2018; Grant & McNeilly, 2021; Piotrowski et al., 2022). There was repeated finding that siblings desired more comprehensive information at an earlier stage, particularly when it pertained to the disease of their sibling and its consequences (Chan & Shorey, 2022; Deavin et al., 2018). One older sibling shared, 'I'm scared for her...I don't want anything to happen to her in the future or anything. I wish I can take over her illness' (Chan & Shorey, 2022, p. 4). Having information and knowledge was perceived as being helpful to reduce fears and uncertainty (Tay et al., 2021), including fear of needles, of developing the condition themselves, and of what to expect in the future regarding outcomes of the condition (Chan & Shorey, 2022; Piotrowski et al., 2022).

Being supportive and being supported. Siblings also wanted to be more included in treatment and care (Weiner & Woodley, 2018) as well as being able to attend the hospital. They felt distanced from the family when visiting policies restricted them from being there or when parents withheld information or avoided talking to them about their siblings treatment or illness (Chan & Shorey, 2022; Long et al., 2018). This 'parental silence' (Deavin et al., 2018) led to withdrawal and withholding of the healthy siblings own feelings (Long et al., 2018; Weiner & Woodley, 2018). They described how they would 'keep their feelings to themselves' as they did not want to further burden their family (Deavin et al., 2018; Tay et al., 2021), or worry their parents as they had 'enough to worry about' (Chudleigh et al., 2019, p. 114; Deavin et al., 2018, p. 9). Siblings described that when the family

was working together 'contributing to the unwell sibling's care', they shared experiences and talked about these together as a family and this brought them closer together in a supportive family environment (Deavin et al., 2018, p. 9).

Weiner and Woodley (2018) highlighted how siblings deemed it important for health professionals to provide information to parents about how to communicate with and provide support for the healthy siblings. In addition, healthy siblings also wanted more formal support services to meet their unique needs (Long et al., 2018) and spoke about the important role that family, friends, and teachers played in providing them this much needed social and emotional support (Deavin et al., 2018; Long et al., 2018; Piotrowski et al., 2022; Weiner & Woodley, 2018). One review highlighted the positive role that formal support groups played for siblings (Deavin et al., 2018) while another described a greater need for opportunities to connect and share experiences with others who had experience similar to theirs (Long et al., 2018).

Theme 3 Living the ups and downs

Wellbeing matters. Siblings experienced significant impact to their emotional and behavioural functioning, as well as their mental health and adjustment (Chan & Shorey, 2022; Chudleigh et al., 2019; Long et al., 2018; Martinez et al., 2022; Quintana Mariñez et al., 2022). Worry and fear for their sibling's future and potential for death (Chan & Shorey, 2022; Chudleigh et al., 2019; Long et al., 2018; Quintana Mariñez et al., 2022), as well as concerns about how their siblings were treated by others (Deavin et al., 2018) impacted on the mental health and well-being of healthy siblings. In addition, concerns about their own status (Chudleigh et al., 2019; Long et al., 2018), lack of knowledge (Chan & Shorey, 2022), and the experience of having seen relatives die from a similar condition added to this fear and impacted negatively on their day-to-day life (Chan & Shorey, 2022; Long et al., 2018). The findings highlight how feelings of anxiety, depression, and stress put healthy siblings at higher risk overall for posttraumatic stress disorder (PTSD) and other mental health disorders and symptoms (Martinez et al., 2022; Quintana Mariñez et al., 2022; Weiner & Woodley, 2018). The reviews indicated that age may influence the impact on mental health of healthy siblings, where emotional and behavioural difficulties and challenges with coping were found by three reviews to be more significant among younger siblings (Chan & Shorey, 2022; Long et al., 2018; Quintana Mariñez et al., 2022) whereas in contrast Chudleigh et al. (2019) found that older siblings reported a greater impact on their mental health compared to younger siblings.

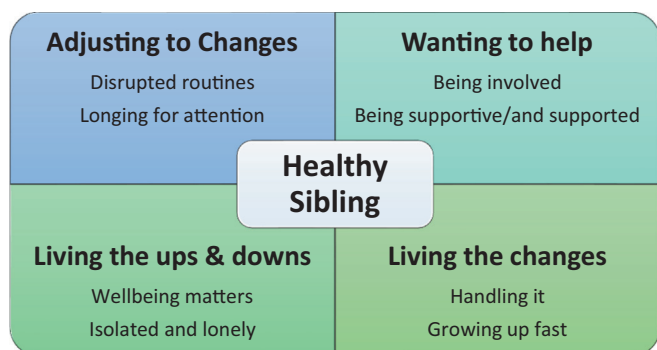


Fig. 2. Synthesis of findings.

Quality of life of healthy siblings was also impacted and appeared to be influenced by the nature of the LTC of their sibling, where those who had siblings with cancer had worse outcomes than those with cystic fibrosis, diabetes and congenital heart disease (Long et al., 2018), siblings of children with attention deficit hyperactivity disorder reported lower overall life satisfaction and satisfaction with family (Orm & Fjermestad, 2021), and greater mortality was reported in siblings with conduct and foetal alcohol spectrum disorders (Martinez et al., 2022).

Isolated and lonely. Three reviews reported on healthy siblings' isolation and loneliness resulting from living with a sibling with a LTC (Long et al., 2018; Tay et al., 2021; Weiner & Woodley, 2018). Siblings were reported to often feel lonely and isolated at home, at school, and among their peers. At home, isolation was attributed to returning home to an empty house as parents were rarely there, or spending time with substitute caregivers (Tay et al., 2021). From a community perspective siblings felt 'isolated and neglected by others such as neighbours and family friends as all the attention was on the ill child. While siblings recognized that everyone was concerned with the ill child, they expressed the need to also feel comforted and acknowledged' (Tay et al., 2021, p. 7). Some siblings reported being the 'most unhappy family member', where uncertainty regarding the prognosis, concern over their parents, and potentially being a carrier of their sister/brother's condition created a further sense of isolation and loneliness (Chudleigh et al., 2019, p. 114). In addition to these strong emotional responses, one review reported somatic symptoms such as difficulty with sleeping, headaches, stomach aches, and other pain symptoms, associated particularly with the time their sibling was diagnosed (Long et al., 2018).

Healthy siblings needed and valued the opportunity to connect with peers and friends (Deavin et al., 2018) as this was described as a 'welcome distraction' (Long et al., 2018, p. 1472) and an 'important source of support' (Piotrowski et al., 2022, p. 3024). While siblings enjoyed the company of peers, they did find that their 'social activities were curtailed' (Piotrowski et al., 2022, p. 3024), and three reviews highlighted how siblings had limited social experiences as they often sacrificed their social interaction time to spend with the sibling with the LTC (Long et al., 2018; Tay et al., 2021; Weiner & Woodley, 2018). In doing so, they found their friendships were affected, both strengthened because of the need for additional support and/or 'weakened by changes in the ability to relate to friends' (Long et al., 2018). Weiner and Woodley (2018) similarly reported this dichotomy of gaining and losing friends. In some cases, isolation was attributed to self-alienation from friends and family where healthy siblings would engage in distraction activities as a way of coping (Tay et al., 2021).

Theme 4 Living the changes

Handling it. After getting over the shock of diagnosis, siblings initially felt jealous of the inequitable attention they received, then quickly had to develop coping skills and resilience to adapt (Piotrowski et al., 2022; Tay et al., 2021). One review reported how siblings would feel 'distant' from their sibling with LTC as parental attention was focused on their sister/brother and their sibling relationship changed to being one about the condition, 'We've grown farther apart [be]cause now we fight over the diabetes' (Chan & Shorey, 2022, p. 5). Siblings felt responsible for and tried to encourage their sibling's adherence to medication, treatment, and diet regime which caused siblings to experience an array of emotions including 'anger', 'stress', 'frustration', as well as 'heightened concerns for their sibling's wellbeing' (Orm & Fjermestad, 2021; Piotrowski et al., 2022). In addition, siblings experienced an array of mixed emotions including sadness and worry but through this experience developed a resilience with one review quoting a sibling as saying 'you get used to it, and get used to change... it sometimes gets better, worse, generally more worse... I've got used to it' (Grant & McNeilly, 2021, p. 23). Despite the fact that many siblings reported feeling overlooked and neglected at times (Piotrowski et al., 2022; Tay et al., 2021), there were also examples where healthy siblings reported a strong sense of

responsibility for protecting family harmony and felt they acted as the 'social glue' holding the family together (Tay et al., 2021, p. 7). In addition, healthy siblings made various adaptations to their experience (Deavin et al., 2018; Tay et al., 2021). Their ability to handle the existential stressors of not knowing the outcomes for their sibling improved over time (Deavin et al., 2018). The healthy siblings employed multiple strategies in order to cope, including compartmentalisation of feelings, maintaining a sense of normality, seeking out information about their sibling's condition, distraction, and wishful thinking (Deavin et al., 2018; Tay et al., 2021).

Growing up fast. Healthy siblings reported feeling more mature than many of their peers who had not had the same experience (Piotrowski et al., 2022). The healthy siblings reported having to grow up prematurely, needing to act with autonomy beyond their years, reporting more maturity, empathy, and better communication than their peers (Chudleigh et al., 2019; Long et al., 2018). Taking on caregiver responsibilities or roles beyond those of their peers contributed to this sense of growing up quickly. For example, siblings of children with T1DM supported their siblings through contributing practically to their households: "...I had to do more chores, things my mother normally does...so that she can focus on my sister" (Chan & Shorey, 2022, p. 5). Taking on a caregiver role, they worried about the health and well-being of their sibling and the family itself (Deavin et al., 2018; Piotrowski et al., 2022; Tay et al., 2021). Supporting their siblings through unpleasant procedures or hospitalisations, healthy siblings often considered the needs of the family ahead of their own (Tay et al., 2021). The shifting roles and responsibilities siblings reported were often positive with two reviews reporting deepened relationships with their unwell sibling (Deavin et al., 2018; Piotrowski et al., 2022). Only one review described a strong link between age (i.e. being an older sibling) and assuming the role of primary caregiver or feeling a sense of responsibility to help (Chan et al., 2022). None of the reviews indicated gender differences as significant regarding growing up fast or taking on caregiver responsibilities for their sibling.

Discussion

This umbrella review highlights the complexity and often overlooked lives of siblings of children with long term conditions. This umbrella review has provided a syntheses and cohesive description on the available literature (reviews) of healthy siblings self-reported lived experience in living with a sibling who has a long-term condition to inform future evidence based clinical practice and research.

It was evident in this review that healthy siblings experienced significant disruption to their usual daily routine due to the increased care needs of the child with a LTC which impacted on their psychosocial physical and emotional wellbeing, academic performance, school attendance, and family/sibling relationships (Grant & McNeilly, 2021; Long et al., 2018; Piotrowski et al., 2022; Tay et al., 2021; Weiner & Woodley, 2018). In addition, siblings' social and extracurricular activities were often reduced, postponed, or sacrificed for the sake of their sibling's needs, (Chan & Shorey, 2022; Grant & McNeilly, 2021; Long et al., 2018; Weiner & Woodley, 2018). Similarly, siblings' adaptation to change were reported in the literature when 78 research reports on healthy siblings were analysed within a 'creating a tenuous balance framework' (Havill et al., 2019). Here, siblings experienced abandonment, a loss of family structure, and yearned for a pre-diagnosis normality, with family outings and attention from parents without the strict routines and control imposed by their sibling's condition management regimes (Havill et al., 2019). Healthy siblings understood the necessary changes and wanted to help support their sibling by taking on more responsibilities, but felt their lives had irrevocably changed to revolve around treatment and medical/hospital admissions of the sibling with the LTC, including long absences of one or more family members from their home (Havill et al., 2019). These are in keeping with the findings of this umbrella review.

Our review and other recent literature articulates how siblings adjusted to these significant life changes by assuming more of a parent-like role, accepting the new reality, feeling less resentment and more empathy/confidence, which overtime increased family cohesion, connectedness, and extended family relationships (Chan & Shorey, 2022; Deavin et al., 2018; D'Urso et al., 2017; Havill et al., 2019; Jenholt Nalbris et al., 2014; McClelland et al., 2013; Piotrowski et al., 2022; Van Schoors et al., 2019). Alternatively, siblings in this review and the wider literature reported their reactions to change included acting out, feeling neglected/marginalised/displaced, overlooked, being treated differently, and losing a sense of self particularly when the ill sibling was hospitalised (Chan & Shorey, 2022; Deavin et al., 2018; Long et al., 2018; Orm & Fjermestad, 2021; Piotrowski et al., 2022; Tay et al., 2021).

Along with impacts on family life, this umbrella review highlighted how having a sibling with a LTC had a negative impact on school functioning, leading to decreased concentration, frequent absenteeism, school aversion, and sometimes school relocation, ultimately resulting in an overall decline in academic performance (Deavin et al., 2018; Long et al., 2018). These findings are in keeping with previous sibling's research which similarly identified school problems among healthy siblings ranging from decreased academic performance (Bortes et al., 2020; Donnan et al., 2015), negative impacts on school social experiences (Prchal & Landolt, 2012) and what one older study described as 'school phobia' (Van Riper, 2003). Schools are obligated to protect, promote the welfare, and improve the education of children in their care, however siblings of children with long term conditions are potentially overlooked (Gan et al., 2017). A one-to-one, manualised support intervention (Sibs Talk) holds potential and warrants further trials as it has shown how increased understanding and knowledge from teachers can contribute towards positive outcomes for siblings (Hayden et al., 2019).

Healthy siblings in this umbrella review identified how they wanted more support from their family, healthcare professionals, friends, and the school as well as opportunities to connect with peers who had similar experiences (Deavin et al., 2018; Long et al., 2018). D'Urso et al. (2017) emphasised the importance of supportive networks among siblings of children with cancer and noted that support from professionals or other adults was critical to coping. The notion that some young people appreciate talking to peers with similar experiences is supported by the literature and highlights how siblings enjoy and benefit from the opportunity to share their experiences with peers (Feriante et al., 2022; Joosten et al., 2019).

Healthy siblings desired to be more informed about their ill sibling's condition and treatment, seeking detailed information from their parents and healthcare professionals and hoping for increased support (Chan & Shorey, 2022; Chudleigh et al., 2019; Deavin et al., 2018; Long et al., 2018; Piotrowski et al., 2022; Weiner & Woodley, 2018). Similarly, it is reported siblings desired more information and wanted to be consistently informed (Havill et al., 2019) and involved in their siblings care yet were often left out of these conversations or overheard confusing medical terminology at home and during clinic appointments (Marsac et al., 2018; Vatne et al., 2019). This lack of information, specifically the identity and cause of the long-term condition, created confusion, uncertainty, and misconceptions for healthy siblings (Vatne et al., 2019). Of interest, Haukeland et al. (2020) explored healthy siblings' satisfaction in undertaking a five-session joint parent-sibling intervention program that focused on communication, knowledge, and shared experiences between healthy siblings and parents in Norway. Here, a significant improvement over five-sessions in sibling-reported parent-sibling communication, increased knowledge, and adaptation to having an ill sibling was reported (Haukeland et al., 2020). It is further reported that increased parent-sibling communication facilitated greater knowledge of their sibling's long-term condition which in turn was associated with greater sibling adjustment, emotional/behavioural functioning, problem solving and coping strategies (Haukeland et al., 2020; Vatne et al., 2019; Wolff et al., 2023), which are similar to the findings of this

umbrella review. Unfortunately, healthy siblings in Taiwan experienced distress when parents expected them to have knowledge of their ill sibling's condition without being provided support, which was a direct contrast for siblings in the United Kingdom, demonstrating culture as an influencing factor (Tsai et al., 2018).

In this review, healthy siblings wanted to support their ill sibling by being present in hospital, caring for them and being involved, yet also needed ongoing formal social and emotional support from their parents, healthcare professionals, friends, and teachers (Deavin et al., 2018; Long et al., 2018; Piotrowski et al., 2022; Weiner & Woodley, 2018). Nabors et al. (2018) reported that mothers perceived their healthy siblings were a primary support for their ill sibling by protecting them, providing instrumental emotional support, creating Facebook pages, undertaking fundraising activities and providing physical/emotional comfort through hugs and staying in hospital with their sibling during admissions yet support offered to the healthy sibling was not represented in the mothers' voices (Nabors et al., 2018). On an important note, Guidotti et al. (2021) reported siblings (healthy and ill) had a close relationship characterised by affection, warmth, and perception of similarity as evident in the siblings' drawings based on Pictorial Assessment of Interpersonal Relationships methodology. Close sibling bonds and relationships were highlighted in this review as well as the wider literature (Chudleigh et al., 2019; Deavin et al., 2018; Tay et al., 2021; Wolff et al., 2023).

Overall, the evidence confirms that growing up with a sibling with a LTC has both positive and negative effects. For some children and young people growing up with a sibling with a LTC may be a strength, creating empathy and building resiliency, whereas others may feel strong negative emotions and experience psychological and mental health challenges (Chan & Shorey, 2022; Chudleigh et al., 2019; Long et al., 2018; Martinez et al., 2022; Quintana Mariñez et al., 2022). This means that siblings are not impacted in the same way, with potential for some to fare better than others. For example, the impact on the quality of life for healthy siblings varied depending on the nature of the LTC, with those whose siblings had cancer, experiencing worse outcomes (Long et al., 2018), while siblings of children with attention deficit hyperactivity disorder reported lower life satisfaction, and greater mortality was observed among siblings with conduct and foetal alcohol spectrum disorders (Martinez et al., 2022; Orm & Fjermestad, 2021). Other reviews and meta-analysis have similarly noted a variation in impact based on the nature of the long-term condition, including the type, severity and prognosis (Dinleyici et al., 2019; Levkovich & Labes, 2023; Watson et al., 2021).

This umbrella review confirmed that siblings living with a sibling with a LTC frequently experienced isolation, and loneliness, felt neglected and emotionally burdened by the situation, and sometimes developed somatic symptoms such as difficulty sleeping and pain (Chudleigh et al., 2019; Long et al., 2018; Tay et al., 2021; Weiner & Woodley, 2018). A recent systematic review found mixed results regarding the relationship between having a sibling with long term illness and somatic symptoms where most studies focused on siblings of children with cancer (Elliott et al., 2020). Despite these mixed results the fact that some siblings do develop somatic symptoms is important as it points to the need for prevention and early intervention.

The siblings in our umbrella review valued the opportunity to connect with peers and friends. They viewed this as a welcome distraction and source of support, but their social activities were often curtailed, leading to changes in their friendships, which could either be strengthened or weakened due to their altered ability to spend time with and relate to friends (Deavin et al., 2018; Long et al., 2018; Piotrowski et al., 2022). Peer related social adjustments and problems are reported in previous literature (Berbis et al., 2015; Hanvey et al., 2022; Niedbalski, 2023), and highlight how important peer relationships are in terms of coping and overall quality of life.

The healthy siblings of children with LTCs frequently underwent multiple role transitions as the dynamics of the household shifted.

Healthy siblings often found themselves shouldering new responsibilities, sometimes having to juggle seemingly contradictory roles, such as caregiver and child, concurrently. This umbrella review showed that healthy siblings often felt more mature than their peers due to the responsibilities and caregiver roles they had to take on, which is in line with sibling-focused parentification theory (Levante et al., 2023). According to the parentification theory, children sometimes take on pseudo-parent roles long before they are cognitively and physiologically ready for it leading to potentially positive outcomes but also an increased risk for negative outcomes more often occurring when the children are forced to take on a pseudo-parent role (Dariotis et al., 2023). A recent study by Kelada et al. (2022) suggests that when a healthy sibling takes on an active role in caring for their unwell sibling, it results in a beneficial sense of engagement and empowerment, which agrees with increased autonomy, empathy, and improved communication skills found in our umbrella review (Chudleigh et al., 2019; Long et al., 2018; Piotrowski et al., 2022).

Conversely, the negative outcomes of parentification have been associated with suboptimal mental health and internalising or externalising behavioural problems (Dariotis et al., 2023). The umbrella review showed that siblings taking on caregiver roles often had concerns about their sibling's health and the family's well-being, prioritizing their sibling's needs ahead of their own (Deavin et al., 2018; Piotrowski et al., 2022; Tay et al., 2021). This is in keeping with other research which suggests that the obligation to safeguard and look after their unwell sibling may result in healthy siblings experiencing a sense of responsibility for their siblings care (Agerskov et al., 2021; Milo et al., 2021), which eventually could lead to suboptimal health for themselves unless they have optimal support. Social support, distress, coping skills, and resilience are examples of mediating concepts that can play pivotal roles for the outcome of parentification (Dariotis et al., 2023; Elhabashy et al., 2023; Kelada et al., 2022; Levante et al., 2023). It is reported that extra attention should be paid to children experiencing parentification when their cognitive and emotional systems are still immature (Dariotis et al., 2023). Furthermore, guiding families to redirect their focus towards the positive aspects of raising a child with a LTC is crucial. Recent research underscores benefits such as siblings cultivating heightened empathy, families strengthening their bonds, and all members undergoing valuable growth experiences that might not have occurred under different circumstances (Kelada et al., 2022).

Strengths and Limitations. The main strength of this review was the inclusion of reviews where the focus was on siblings' voices, rather than parents as proxy. In addition, the reviews covered a range of LTCs. We systematically followed the JBI guidelines to describe the findings of the included studies and thus ensured reproducible methods. In addition, quality assessment, data extraction and synthesis were undertaken by a robust process of peer consensus among all authors at each stage.

However, there are limitations to this study that warrant consideration. We limited our inclusion criteria to reviews published in English which may have caused language and cultural bias. Engaging in an umbrella review, as a developing methodology, presents numerous challenges, with the most notable one being that the evidence is an additional step removed from the primary source. The reviews we identified included qualitative and mixed methods and the findings from these reviews used a variety of synthesis methods, with some not indicating the synthesis method used. The umbrella review method is dependent on the findings provided by those who conducted the reviews and the language they elected to use to present them. Despite these limitations the procedure undertaken by the authors in this review was rigorous and followed a systematic process.

Implications for practice

This umbrella review has demonstrated an array of psychosocial impacts on siblings of children with LTCs, both positive and negative.

Acknowledgment that healthy siblings themselves may experience diverse and far-ranging effects beyond the child with the LTC supports the need to implement a range of child and family-oriented interventions to address their unique requirements. Healthy siblings call for information, and desire to be involved in the care and management decisions regarding their sibling, points to the need for the development of age-appropriate condition specific resources for siblings. Educational interventions have been shown to not only improve understanding of the LTC but also improve perception of social support and psychological well-being (Dinleyici et al., 2019). Some community and hospital based interventions that have been effective in supporting healthy siblings and their families include support groups, summer camps, and child health programs where siblings and family report increased self-esteem, behaviour, attitudes, coping strategies, resiliency and knowledge (Committee On Hospital Care and Child Life Council et al., 2014; Lummer-Aikey & Goldstein, 2021; McKenzie Smith et al., 2018; The Hole in the Wall Gang, 2024).

Child health nurses are well positioned to support healthy siblings during periods of hospitalisation. Given these siblings may feel marginalised and neglected, nurses can include them by discussing appropriate strategies for coping, promoting hope, positive adjustment (encouraging them to help participate in care), and providing age-appropriate resources (puppets, pictures, for younger children and health education materials for older children), as well as opportunities to have fun (Hovén et al., 2023; Porteous et al., 2019; Yang et al., 2016). However, it is important that healthy siblings' involvement should be on their own terms and means with children's rights being honoured as indicated in the UNCRC (Hovén et al., 2023; United Nations Convention on the Rights of the Child, 1989).

Better understanding of healthy sibling coping may be enhanced with screening for family cohesion/functioning. Screening can include family conflict, cohesion, flexibility, communication, and problem solving in order to identify risk and protective factors (Psihogios et al., 2019). Deavin et al. (2018) found that increased family cohesion from healthy siblings was experienced when the family united as a whole, contributing to the care of the unwell sibling, as this brought them closer together with a shared purpose. Here a FCC approach is vital to include the whole family and identify family system's roles, siblings' perspectives, agendas, communication, protective and risk factors to facilitate a family based strength approach, as family members provide an important source of strength and support for one another (Abela et al., 2022; Gill, 2020; Woodgate et al., 2016).

Parental involvement through open age-appropriate conversations and allowing siblings to visit and accompany the child with LTC is important in assisting healthy siblings' adjustment to changed family dynamics and to promote autonomy, understanding, emotional security, sibling warmth and confidence (Biswas, 2022; Gill, 2020; Pickering et al., 2023; Yang et al., 2016). An integrative review on parenting interventions with healthy siblings reported improvement in children's behavioural and emotional adjustment and health condition knowledge post intervention; however, all six included studies combined four parent and child-directed intervention components (the ISEE: Intervention for Sibling Experience Enhancement (ISSEE) and Modified Intervention for Sibling Experience Enhancement (M-ISSEE); SibLink; Sibstars; and SIBS), making it difficult to evaluate which component resulted in change (Mitchell et al., 2021). Haukeland et al. (2020) and Fjermestad et al. (2021) reported similar findings with a parent-sibling five-session intervention that improved quality of parent-sibling communication; sibling emotional and behavioural problems; sibling adaptation; and knowledge (Haukeland et al., 2020) with improvement in parent mental health; and mental health for siblings (parent proxy); but no change in mental health or family communication (sibling proxy) (Fjermestad et al., 2021).

It is recommended to raise parental, public, and school awareness of the impact on healthy siblings, available support networks, resources, and interventions (Porteous et al., 2019). School nurses and teachers

need to pay particular attention to siblings' academic performance, absenteeism, coping strategies, support networks and peer interactions (Gan et al., 2017; Hovén et al., 2023; Yang et al., 2016) as healthy siblings need support to reach their academic, social, and vocational potential (Tsimicalis et al., 2018).

Children and young people growing up with a sibling with an LTC desire more contact with peers and greater support for managing their own emotions and responses to their sibling's condition. There is need for more sibling specific support groups and opportunity to cultivate heightened awareness and acknowledgment of sibling support within the domains of medicine, health, and social care (Joosten et al., 2019; Meltzer, 2021b; Nguyen et al., 2023). Healthcare workers and parents, therefore, need to be aware of what sibling support entails (Meltzer, 2021b) and recognise how good support, communication, understanding, and protection can help empower and normalise siblings' feelings and behaviour (Meltzer, 2021a).

Implications for research

Future research recommendations as informed by this review include: the need to gain a greater awareness of both the continuity and the challenges within family life that siblings are confronted with; to focus on siblings of children and young people that have high morbidity and high mortality conditions as these may act as significant moderating factors; develop sibling specific screening tools; undertake prospective longitudinal research to map change over time especially with younger healthy siblings; explore ways to best promote positive family relationships and cohesion; identify protective/risk factors to detect siblings at high risk of developing psychological distress; conduct participatory research with healthy siblings to develop strategies, guidelines, and interventions and explore the role salient contextual factors (e.g., age, sex, family factors, illness type, order in family, culture, length of illness) have on healthy siblings' well-being.

Conclusion

It was evident in this review and the wider literature that siblings experienced both positive and negative experiences, like a double-edged sword. As healthcare professionals and researchers, it is important to honour siblings' voices and focus on participatory individualised problem response as opposed to the problem itself (sibling's LTC). Professionals, organisations, and policy makers must continue to engage in dialogue with sibling representation through age-appropriate child-friendly means, educating ourselves and others, to ensure that siblings' voices are heard and actions/interventions put in place in a way that are empowering, respectful, and effective for siblings. The clinical and research implications generated from this review will inform future practice, policy, and research.

Disclosure

Mandie Foster is the editor-in-chief and Julie Blamires is an assistant editor for JPN. As authors of this paper, they did not participate in any editorial process or decision-making, which was handled by another editor.

CRedit authorship contribution statement

Julie Blamires: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation. **Mandie Foster:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Shayne Rasmussen:** Writing – review & editing, Methodology, Formal analysis. **Maggie Zgambo:** Writing – review & editing, Formal analysis. **Evalotte Mörelus:** Writing – review & editing, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2024.03.022>.

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