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Daily life situations and participation of siblings of children with childhood-onset disabilities: a scoping review

Johanna Linimayr ,[1,2] Judith Graser ,[3,4] Selina Gredig ,[5,6,7] Hubertus J A van Hedel ,[3,4] Anne Tscherter ,[5] Sebastian Grunt ,[6] Christina Schulze [1]

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For numbered affiliations see end of article.

Correspondence to
Johanna Linimayr; lini@zhaw.ch

ABSTRACT

Background Siblings of children with disabilities or childhood-onset chronic conditions (eg, autism, cerebral palsy or congenital heart disease) often face challenges in mental health, quality of life and psychosocial adjustment. However, comprehensive knowledge of their participation in daily activities remains limited. Understanding their participation patterns and potential restrictions can help clarify their needs.

Aims and methods This scoping review aims to summarise current research on the participation of siblings of children with childhood-onset chronic conditions. Following the Joanna Briggs Institute methodology, we systematically searched MEDLINE, CINAHL, AMED, PsycINFO and ERIC for peer-reviewed studies published in English between 2001 and 2024. Eligible studies focused on siblings of children with disabilities or early-onset chronic conditions (population) and their participation, including attendance and involvement in daily activities (concept) across children's homes, communities and schools (context). The review adheres to the Preferred Reporting Items for Scoping Reviews guidelines.

Results A total of 62 articles met the inclusion criteria: 45 qualitative (73%) and 7 quantitative (11%) studies, 7 reviews (11%) and 3 meta-studies (5%). The studies covered various chronic conditions (eg, cancer, chronic kidney disease and Down syndrome), with autism being the most common (22 studies). Key participation themes identified include family life, home participation, school involvement, leisure activities, social interactions with peers, information-seeking and continuous meaning-making. Factors such as normalcy, advocacy, identity, gender, age, culture and socioeconomic status were found to intersect with participation.

Conclusions This review provides a comprehensive overview of current research and contributes to our understanding of how participation in daily activities has been studied so far in the population of siblings of children with disabilities. It reveals a gap in research specifically measuring participation among siblings. The identified themes enhance our understanding of potential participation restrictions in this population.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Siblings of children with childhood-onset chronic conditions may face participation restrictions, but existing evidence is limited.

WHAT THIS STUDY ADDS

⇒ Highlights the impact of childhood-onset chronic conditions on siblings' participation in daily life.
⇒ Reviews how research has addressed siblings' participation and related aspects to date.
⇒ Enhances understanding of siblings' attendance, involvement and experiences in daily situations, including key factors influencing participation.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This review can inform research, practice and policy by identifying crucial questions regarding siblings' participation and guiding the selection of appropriate methods to address knowledge gaps.

INTRODUCTION

Siblings of children or youth with childhood-onset disability or chronic conditions have received limited attention over the years. While they play important roles in the family, such as being their siblings' playmates, teachers, advocates or even primary caregivers,[1 2] there is often an asymmetry in these relationships from early childhood onward.[3] Some siblings begin sharing responsibilities with parents or even assume primary caregiving roles.[4] These 'young carers' can face significant limitations in their participation, particularly in school activities, especially when they lack adequate support.[5]

Research indicates that siblings of children with long-term conditions are at risk of health issues.[6–8] For example, siblings of children with cancer may experience heightened post-traumatic stress,[9] those with autistic siblings may report lower family quality of life[10] and siblings of children with Duchenne muscular dystrophy may face higher risks of psychological problems.[11] However, these studies are difficult to generalise due to variations in target populations, methods, sample sizes and

outcome measures. Moreover, potential health risks do not necessarily reflect the siblings' daily activities, desires or participation challenges.

Participation, as a concept defined by the International Classification of Functioning, Disability and Health (ICF) as 'involvement in a life situation',[12 13] has become a key goal and outcome measure in rehabilitation and research. Despite this, effectively measuring participation remains challenging due to the evolving and often unclear language surrounding the concept.[14] The ICF lacks a clear distinction between activity and participation and does not define 'life situations'. Coster and Khetani[15] addressed this by defining life situations as 'organised sequences of activities directed towards a personally or socially meaningful goal'. Yet, participation has been interpreted inconsistently within the research community, leading to confusion and imprecise terminology.[14] Imms *et al*[14 16] identified two core elements of participation: attendance, meaning physical or virtual presence, and involvement, meaning the subjective experience during attendance. These are distinct from participation-related constructs, which can be intrinsic (eg, preferences, sense of self, activity competence) or extrinsic (eg, context and environment).[16]

Despite the evolving concept, researchers have attempted to quantify participation and developed several measures within the context of childhood disability.[17 18] While this supported the detection of participation restrictions for children with disabilities,[19–21] information on their siblings' participation is yet sparse. Some studies have explored aspects of participation such as time use, attendance in specific activities or subjective experiences in settings like home, school and community, for instance, siblings of children with chronic illness reported limited opportunities to participate in peer activities due to family needs,[22] and siblings of children with complex care needs faced participation restrictions due to time constraints, financial limitations or accessibility issues in certain situations (eg, travelling).[23] In contrast, participation in blog writing on Canadian sibling support websites was found to be supportive for siblings of children with chronic health conditions,[24] and being the sibling of a child with autism was not generally associated with participation restrictions, though the severity of autism symptoms did correlate with fewer extracurricular activities.[25] These studies present a rather fragmented picture of siblings' participation in daily life.

While family life and childhood disability are recognised as complex and interconnected,[6 21 26] leading to increased interest in children's and parents' perspectives, siblings are often overlooked.[26] Given the fragmented knowledge of siblings' participation and its potential relevance for healthcare, family research and community services, an initial examination of the scope and nature of research in this area is necessary to identify gaps and future directions. A preliminary search found no current or ongoing reviews summarising literature on this topic. Thus, this study aims to collate existing evidence on the participation of siblings of children with childhood-onset chronic conditions, with a scoping review identified as the most suitable method.[27 28]

The objectives of this scoping review are to (a) summarise the extent and type of available evidence and (b) synthesise research findings on the daily life participation of siblings of children and youths with childhood-onset chronic conditions.

METHODS

This scoping review adhered to the Joanna Briggs Institute (JBI) methodology for scoping reviews[28–30] and was reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews.[31]

Protocol and registration

The review protocol was registered on the Open Science Framework on 12 July 2023.[32] Any deviations are noted in this article.

Eligibility criteria

Eligibility criteria were outlined in the protocol[32] and refined during screening to specify exclusion criteria (table 1). Articles were included if they met the criteria for population, concept and context. Both primary and secondary research studies from peer-reviewed journals were eligible, regardless of study design. Unpublished manuscripts, conference abstracts and grey literature were excluded. Studies published in English and German were included for feasibility. Studies published before 2001 were excluded, using the WHO's 2001 definition of participation as a reference.[12]

Information sources

Searches were conducted in databases covering health (MEDLINE, CINAHL, AMED), psychology (PsycINFO) and education/social sciences (ERIC).

Search strategy

A three-step search strategy was implemented[28]: (1) Initial search: A preliminary search in CINAHL identified relevant articles. Keywords and index terms from these articles informed the full search strategy.[33] (2) Database search: In August 2023, searches were conducted across five databases, with the last update on 29 August 2024. (3) Reference list screening: Reference lists of all included studies were screened for additional relevant articles.

Selection of sources

The PRISMA flow chart outlines the selection process (figure 1): All identified articles (n=9570) were uploaded to Covidence systematic review software, and duplicates were removed. Titles and abstracts were screened independently by two reviewers in two rounds: (1) Initial screening against inclusion criteria, with 'conflict' cases discussed and criteria refined to focus on core participation constructs and (2) Refined criteria were applied to

Table 1 Eligibility criteria, population, concept, context

	Included	Excluded
Population	Siblings of children or youth with childhood-onset chronic conditions between the ages of 0 and 18 years	Adults (only)
	Siblings are defined as brothers, sisters, adopted siblings or siblings-in-law, living in the same household as the child or youth with childhood-onset chronic condition	Other family members or not further specified
	Childhood-onset chronic conditions are defined as early-onset congenital or acquired disabilities or chronic conditions due to an impairment of the brain and/or neuromuscular system or other physical illness that may create long-term functional limitations and/or participation restrictions, conditions characterised as permanent or long-lasting and non-communicable	Psychiatric disorders (eg, anorexia nervosa), diabetes, obesity, trauma (eg, refugee experience), sexual abuse, drug abuse, communicable diseases (eg, HIV)
Concept	Participation, attendance or involvement	Other concepts only (eg, genetic exposure, blood pressure, mental health, social inclusion, well-being, quality of life, relationship quality, attitudes towards disability, psychosocial adjustment, transplant donor)
	Siblings' participation is assessed using participation measures, attendance or involvement	Measuring only intrinsic participation-related constructs (preferences, sense of self, activity competence) or extrinsic participation-related constructs (context, environment)*
	Siblings' participation experiences	Siblings' emotional status, relationship quality or psychological problems (eg, anxiety, stress, rivalry, loneliness)
	Participation in daily life activities	Siblings' functional levels, skills or performance (eg, body functions, school functioning, eating skills, joint attention, academic performance, family functioning, self-esteem, psychosocial characteristics, psychosocial functioning, coping skills)
Context	Childhood and youth	Adulthood (only)

*Refinement of eligibility criteria after the first round of title abstract screening.

the remaining titles and abstracts, which resulted in 83 articles being assessed for eligibility in full text. Again, full-text articles were assessed independently by 2 reviewers, resulting in 21 articles being excluded. Reasons for exclusion were documented. Disagreements were resolved through discussion. In parallel, the first author manually screened reference lists of included articles for further relevant literature and screened for eligibility with inclusion confirmed by a second reviewer (citation searching, n=15).

Data charting process

Using the JBI template for evidence extraction,[28] a data extraction tool was developed to capture details on participants, concepts, contexts, study methods and key findings. The tool was refined after piloting on nine studies (16%).[34] Data extraction was performed by the first author, with 33% checked for consistency by a second reviewer. Discrepancies were resolved through discussion.

Synthesis of results

Extracted data are presented in tables, summarising the extent and type of available evidence. Most studies addressed participation indirectly, focusing on aspects like time use and activity types, with only one study directly defining participation.[25] Consequently, the findings needed to be related to the core aspects of participation, attendance and involvement. To summarise relevant issues on siblings' participation in daily life, first, information from the results section of included studies was listed and categorised; second, categories were linked to attendance and/or involvement; and third, results were synthesised in tables, accompanied by a short descriptive narrative.

Patient and public involvement

Parents of children with and without cerebral palsy contributed to the discussion and interpretation of findings. Family partners will support the creation of a knowledge translation product to be publicly available on the project website (https://www.parti-cp.ch).

RESULTS

Description of included sources

62 studies met the inclusion criteria, including 45 qualitative (73%) and 7 quantitative (11%) studies, 7 reviews (11%) and 3 meta-studies (5%). Most studies focused on siblings of children or youth with one specific diagnosis including autism spectrum disorder in 22 studies,[25 35–55] cancer in 9 studies,[9 56–63] acquired brain injury,[64] chronic kidney disease,[65] congenital heart disease,[66] cystic

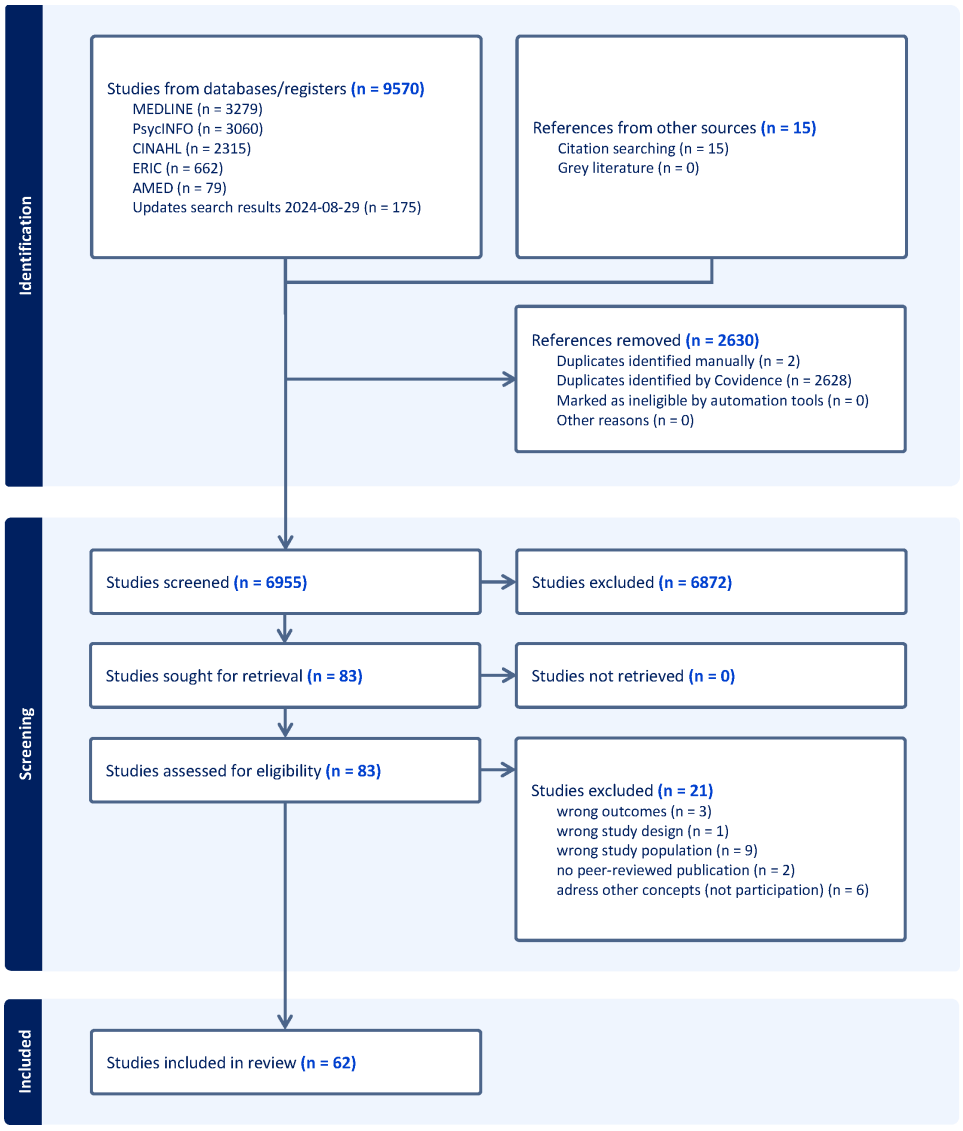

Figure 1 PRISMA flow chart. This flow chart illustrates the study selection process following the PRISMA extension for scoping reviews. The initial search identified 9570 records across 5 electronic databases, an additional 15 records from other sources, including references from citation searching, and additional records resulting from the last search update on 29 August 2024. After removing 2630 duplicates, 6955 unique records were screened based on titles and abstracts, resulting in the exclusion of 6872 records that did not meet eligibility criteria. The full texts of the remaining 83 articles were assessed for eligibility, with 21 articles excluded due to wrong outcomes, study design, population, lack of peer revision or focus on other concepts than participation. 62 studies were included in the final review. The flow chart provides a transparent overview of each stage in the study selection process, from initial identification to final inclusion.

fibrosis,[67] cerebral palsy,[68] hearing disabilities,[69] Down syndrome,[70] epilepsy,[71] juvenile idiopathic arthritis,[72] profound intellectual and multiple disabilities,[73] spina bifida,[74] and visual impairments.[75] Different diagnosis types were studied together in 18 studies,[23 76–92] and 1 study did not further specify diagnoses but labelled all as chronic illnesses.[61]

Siblings' participation was studied in diverse countries and continents: Most studies were conducted in Europe (25 studies, 40%), followed by North America (23 studies, 37%), Australia (7 studies, 11%), Asia (6 studies, 10%), and 1 cross-continental study (1 study, 2%). No studies were found from South America or the African continent (table 2).

Siblings' participation in daily life

We identified six broad categories (see also table 3) of siblings' participation from the results sections of included studies: (1) family life and home, with seven subcategories: (a) daily routines, (b) sibling activities, (c) caregiving activities, (d) receiving care from parents and substitutes, (e) participation in public spaces, (f) waiting and (g) sleep; (2) school participation; (3) leisure participation; (4) social situations with peers; (5) information seeking and (6) continuous meaning-making. These categories, reflecting both challenges and supports, relate to core participation constructs of attendance and involvement, though continuous meaning-making was viewed as a distinct aspect not covered by these constructs.

Table 2 Description of sources

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Sharpe and Rossiter 2002[76]	Canada	To review the literature on siblings of children with a chronic illness and evaluate effect size statistics	Meta-analysis	Searches in databases between 1976 and 2000	N=unclear, 2–20 (M=10.8, SD=2.1)	Chronic illnesses (cancer, cardiac, diabetes, cystic fibrosis, anaemia, bowel, kidney, seizure, hearing, spina bifida)
Wilkins and Woodgate 2005[62]	Canada	To identify the contributions of qualitative research in advancing the understanding of the childhood cancer experience from the perspective of siblings	Review of qualitative research	Searches in databases between 1979 and 2005	N=2–254 (range), 5–40 (majority 7–18)	Cancer
Baumann *et al*, 2005[77]	USA	To explore the meaning of being a sibling of children with cleft lip palate or Down Syndrome	Qualitative study (descriptive)	Open interviews, use of art and drawings to facilitate interviews	N=12, 5–15 (M=10.17s)	Cleft lip and palate, Down Syndrome
Mascha and Boucher 2006[35]	UK	To explore the subjective experiences and feelings of typically developing siblings with a brother or sister with autism	Qualitative study	Semistructured interviews	N=14, 11–18 (M=14.73, SD=2.25)	Autism spectrum disorder
Nolbris *et al*, 2007[61]	Sweden	To understand the experience in everyday life of being a sibling when a brother or sister is receiving treatment for a cancer disease or has completed treatment	Qualitative study (phenomenological-hermeneutic approach)	Interviews	N=10, 10–36 (majority <18)	Cancer (leukaemia, brain tumour)
Benderix and Sivberg 2007[36]	Sweden	To describe siblings' present and past experiences of having a brother or sister with autism and moderate to profound mental retardation	Case study	Semistructured interviews	N=14, 5–29 (majority <18)	Autism spectrum disorder and mental retardation
Waite-Jones and Madill 2008[72]	UK	To understand the experiences of having a sibling with juvenile idiopathic arthritis	Qualitative study (grounded theory)	Semistructured interviews	N=8, 9–24 (half <18)	Juvenile idiopathic arthritis
Bellin *et al*, 2008[74]	USA	To investigate the influence of spina bifida in the lives of adolescent siblings	Mixed-methods study	Questionnaires	N=155, 11–18 (M=13.83; SD=2.26)	Spina bifida
Mulroy *et al*, 2008[78]	Australia	To describe the impact of having a sibling with Down syndrome or Rett syndrome	Cross-sectional survey	Questionnaire	N=unclear (>327), unclear (childhood context)	Down syndrome, Rett syndrome
Petalas *et al*, 2009[37]	UK	To investigate the perceptions and lived experiences of typically developing siblings, in middle childhood, who were growing up with a brother with autism	Qualitative study (interpretative phenomenological analysis)	Semistructured interviews	N=8, 9–12 (M=11.19, SD=1.32)	Autism spectrum disorder
Barak-Levy *et al*, 2010[38]	Israel	To assess the social and emotional adjustment of siblings of children with autism	Cross-sectional study	Child Behaviour Checklist (CBCL)	N=27, 6–18 (M=12.51, SD=4.02)	Autism spectrum disorder

Continued

Table 2 Continued

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Hwang and Charnley 2010a*[39]	South Korea	To explore siblings' perspectives of living with an autistic sibling in South Korea	Qualitative study (visual ethnography)	Visual ethnographic methods (diary entries, personal dialogues, movies, video elicitation, interviews)	N=9, 7–15	Autism spectrum disorder
Hwang and Charnley 2010b*[40]	South Korea	To explore the role of culture and siblings' understanding of caregiving for their sibling with autism	Qualitative study (visual ethnography)	Visual ethnographic methods (video diaries, home movies), interview	N=9, 7–15	Autism spectrum disorder
Barr and McLeod 2010[79]	Australia	To determine what siblings of children with disabilities tell about their lives, describe siblings' interactions with strangers, friends and family and explain the effect of these interactions on siblings	Qualitative study (inductive thematic analysis)	Responses collected from public sibling support websites and contributions (from October 2006 to July 2008)	N=unclear (childhood context)	Intellectual impairment, Down syndrome, Asperger's syndrome, autism, cerebral palsy, attention deficit hyperactivity disorder, cystic fibrosis, epilepsy, muscular dystrophy, spina bifida, physical impairment, and anorexia nervosa
O'Shea *et al*, 2012[60]	USA	To capture the views of paediatric oncology nurses concerning the needs of siblings of children with cancer	Qualitative study (descriptive)	Semistructured individual interviews, focus group	N=unclear (childhood context)	Cancer
Kao *et al*, 2012[80]	USA	To explore the experiences of Latino siblings of children with developmental disabilities through sibling and parent interviews	Qualitative study	Semistructured interviews	N=17, 8–14 years (M=10.4)	Intellectual disability or developmental delay, physical disability such as cerebral palsy or neurological disorder such as seizure disorder
Graff *et al*, 2012[70]	USA	To explore the experiences of adolescent siblings of children with Down syndrome and additional health problems requiring increased caregiving	Qualitative study (descriptive)	Interviews	N=21, 12–19 (M=16, SD=2.15)	Down syndrome with additional health problems acquiring increased caregiving (including congenital heart defect, gastrointestinal disorders, endocrine disorders)
Petalas *et al*, 2012[41]	UK	To explore how adolescent siblings grow up with a brother with autism and make sense of their experiences	Qualitative study (interpretative phenomenological analysis)	Semistructured interviews	N=12, 14–17 (M=15.71, SD=1.55)	Autism spectrum disorder
Angell *et al*, 2012[55]	USA	To explore the experiences of siblings of individuals with autism and identify their support needs	Qualitative collective case study (cross-case analyses)	Semistructured interviews	N=12, 7–15	Autism spectrum disorder
Latta *et al*, 2013[42]	USA	To capture perspectives of siblings living with a child with autism	Qualitative study (descriptive)	Photo elicitation interviews	N=14, 8–16 (M=10.79, SD=2.29)	Autism spectrum disorder

Continued

Table 2 Continued

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Mazurek and Wenstrup 2013[43]	USA	To characterise the amount and intensity of television, video games and social media use among children with autism as compared with typically developing children	Cross-sectional study	Questionnaire	N=179, 8–18 (M=12.5, SD=2.6)	Autism spectrum disorder
Chan and Goh 2014[44]	Singapore	To explore the impacts of autism on the relationship and coping of neuro-typical children of autistic siblings	Qualitative study	Semistructured interviews	N=5, 9–13 (M=10.8)	Autism spectrum disorder
Driscoll *et al*, 2015[69]	USA	To examine the effect of familial involvement in music of children with CIs and their normal-hearing siblings	Cross-sectional study	Questionnaire (adapted music engagement questionnaire (MEQ-P/E)	N=28, 3–13	Hearing disability
Bitsika *et al*. 2015[45]	Australia	To investigate the experiences of child and adolescent non-autism participants who had a sibling with an autism	Cross-sectional study	Questionnaire	N=75, 8–18 (M=11.87, SD=2.93)	Autism spectrum disorder
Long *et al*, 2015[116]	USA	To elucidate how siblings experience a brother's or sister's cancer	Qualitative study (grounded theory)	Interviews	N=30, 10–17	Cancer
Mandleco and Webb 2015[81]	USA	To examine sibling perceptions when living with a young person with autism or Down syndrome	Integrated review	Searches in databases between 2000 and 2014	N=2–205 (range), 4–21	Autism spectrum disorder, Down syndrome
Cridland *et al*, 2016[46]	Australia	To investigate adolescent sisters' roles from the perspectives of multiple family members	Qualitative study	Interviews	N=3, 16–17	Autism spectrum disorder
Samson *et al*. 2016[59]	USA	To examine how siblings of children with cancer perceive childhood cancer to have influenced their lives at school, in extracurricular activities, and with friends	Qualitative study (modified grounded theory)	Interviews	N=33, 8–15 (M=11.6, SD=1.9)	Cancer
Yang *et al*, 2016[58]	Taiwan	To understand the nature of the experiences of siblings who have a brother or sister with childhood cancer	Systematic review	Searches in databases between (1960 and 2013)	N=1–94 (range), 6–20	Cancer
Luijkx *et al*, 2016[73]	Netherlands	To describe both positive and negative aspects of having a sibling with profound intellectual and multiple disabilities	Qualitative study	Photo elicitation interviews	N=18, 6–13 (M=9.1, SD=2.1)	Profound intellectual and multiple disabilities
Woodgate *et al*, 2016[23]	Canada	To understand how siblings of children with complex care needs view and experience participation in everyday life	Qualitative study (ethnography)	Interviews, ecomap drawing, photovoice	N=16, 7–23 (M=14)	Developmental disabilities, cerebral palsy, congenital disorders, genetic disorders, chronic lung disease
Wigston *et al*, 2017[25]	Australia	To compare the number, frequency, enjoyment and performance in extracurricular activities of siblings of children with autism to their typically developing peers, and to identify participation differences	Case–control study	Questionnaires (paediatric interest profiles and self-developed questionnaire)	N=30, 8–17	Autism spectrum disorder

Continued

Table 2 Continued

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Corsano *et al*, 2017[47]	Italy	To explore the experience of growing up with a sibling with autism in typically developing adolescents	Qualitative study	Semistructured interviews	N=14, 12–20, (M=16.07 years, SD=2.46)	Autism spectrum disorder
Webster 2018[71]	UK	To explore the caring roles and responsibilities of siblings	Qualitative study	Interviews	N=14, 6–16	Epilepsy
Gan *et al*, 2018[82]	Australia	To investigate parents' perceptions of siblings' school experiences and school support	Qualitative study	Semistructured telephone interviews	N=31, 4–25 (M=13.65, SD=5.19)	Cancer, persistent asthma, heart disease, gastrointestinal disease, kidney disease and cystic fibrosis
Deavin *et al*, 2018[83]	UK	To investigate the experiences of siblings of children with a chronic and non-communicable physical health condition	Meta-synthesis of qualitative research	Searches in databases from inception to April 2016	N=7–155 (range), 4–22	Spina bifida, life-limiting conditions, chronic illnesses, diabetes, Fanconi anaemia, mucopolysaccharidoses and Batten disease, 22q11.2 deletion syndrome, Duchenne muscular dystrophy
Tsai *et al*, 2018[48]	Taiwan and UK	To describe the experiences of mothers and typically developing siblings of children with autism in two cultural contexts	Qualitative study (interpretative phenomenological analysis)	Semistructured interviews	N=14, 9–17	Autism spectrum disorder
Van Schoors *et al*, 2019[57]	Belgium	To gain an increased understanding of how siblings experience their everyday family life postdiagnosis	Qualitative study (interpretative phenomenological analysis)	Semistructured interviews	N=10, 10–16	Cancer (acute lymphoblastic leukaemia, acute myeloid leukaemia, chronic myeloid leukaemia, non-Hodgkin's lymphoma)
Pavlopoulou and Dimitriou 2019[49]	UK	To explore how sisters make sense of their everyday experience of growing up with an autistic brother or sister	Qualitative study (interpretative phenomenological analysis)	Interviews	N=9, 12–14 (M=13, SD=0.86)	Autism spectrum disorder and learning disability
Nabors *et al*, 2019[117]	USA	To describe family perspectives of coping with the child with a chronic illness	Qualitative study	Interviews	N=12, 5–13 (M=8.25)	Chronic illnesses (not specified)
Lostelius *et al*, 2019[68]	Sweden	To elucidate the experience of being a sibling in a family that includes a child with both cerebral palsy	Qualitative study	Interviews	N=7, 15–20 (majority <18)	Cerebral palsy and pain
Israelsson-Skogsberg *et al*, 2019[92]	Sweden	To illuminate the everyday life experiences of siblings of home mechanical ventilation-assisted children	Qualitative study	Narrative interviews	N=10, 7–17	Home mechanical ventilation (caused by diverse long-term medical diseases with extensive functional disabilities and a need for comprehensive support)

Continued

Table 2 Continued

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Løkkeberg *et al*. 2020[56]	Norway	To explore the experiences of adolescents with a sibling suffering from cancer	Qualitative study	Semistructured interviews	N=7, 13–17	Cancer
Pavlopoulou and Dimitriou 2020[50]	Greece	To study typically developing sisters' experiences, needs and perspectives in their local communities	Qualitative study (modified photovoice)	Modified photovoice, dialogue around photos with SHOWed technique	N=11, 13–14 (M=14.27, SD=1.33)	Autism spectrum disorder with additional learning disability
Molinaro *et al*, 2020[51]	Canada	To explore the experiences of family members living with a child with autism	Qualitative study (phenomenological case study)	Semistructured interviews	N=3, 9–10	Autism spectrum disorder
Parker *et al*, 2020[66]	UK	To investigate the impact of having a sibling with congenital heart disease	Literature review	Search in databases (1967–2018)	N=unclear, (childhood context)	Congenital heart disease
Kale and Sığirtmaç 2021[84]	Turkey	To describe the roles and responsibilities taken on by the elder siblings for their siblings with special needs	Qualitative study (case study)	Semistructured interview	N=6, 8–12	Down syndrome, congenital visual disability, orthopaedic inadequacy
Lee *et al*, 2021[85]	USA	To investigate the cross-cultural experiences of siblings of individuals with intellectual and developmental disabilities	Scoping Review	Search in databases (date unclear)	N=648, 8–46 (majority <18)	Intellectual and developmental disabilities
Schmeer *et al*, 2021[52]	USA	To explore how having a sibling with autism impacts the siblings within a family systems framework	Qualitative study	Interviews	N=15, 7–17 (M=12.9)	Autism spectrum disorder
Alrø *et al*, 2021[86]	Denmark	To explore the perspectives of parents of a child with Home Mechanical Ventilation on well siblings' lives	Qualitative study (phenomenological, secondary analysis)	Semistructured interviews (individual, couple and family interviews)	N=12, 0–18, (M=8.58, SD 5.84)	Chronic respiratory insufficiency and different diseases; neuromuscular diseases, lung diseases such as tracheomalacia and bronchopulmonary dysplasia, central apnoeas and facial anomalies
Watson *et al*, 2021[53]	UK	To summarise qualitative studies that focused on the experience of being a sibling of a child with autism	Systematic review	Searches in databases until 26 October 2020	N=164, 5–29 (half <18)	Autism spectrum disorder
Milo *et al*, 2021[67]	Italy	To understand the experiences of siblings of children with cystic fibrosis*	Qualitative study (grounded theory approach)	Focus groups	N=8, 14–35 (M=20.9) (half <18)	Cystic fibrosis
Vella Gera *et al*, 2021[91]	Malta	To examine the experiences of siblings of disabled children living in Malta	Qualitative study	Semistructured interviews	N=7; 8–12	Disabilities including cerebral palsy, Down syndrome, attention deficit hyperactivity disorder and autism spectrum disorder

Continued

Table 2 Continued

Study ID	Country	Study aim	Type of methodology	Data collection methods	Siblings' age range (M, SD) in years	Diagnosis of childhood-onset chronic condition
Agerskov *et al*, 2021[65]	Denmark	To explore experiences of everyday life among siblings of children with chronic kidney disease	Qualitative study (phenomenological–hermeneutical approach)	Interviews	N=7, 7–13	Chronic kidney disease
Kelada *et al*, 2022[87]	Australia	To assess the inter-relationships between siblings' self-reported caring responsibilities, psychosocial functioning, coping, and familial relationships	Cross-sectional study	Questionnaires	N=45, 12–24 (M=15.40, SD=3.31)	Cancer, cystic fibrosis, kidney disease, a non-cancer blood disorder, epilepsy, gastrointestinal disorder, and others (eg, Wiskott-Aldrich Syndrome)
Heaton *et al*, 2023[88]	Canada	To explore the experiences of adolescents of siblings with a rare genetic condition	Qualitative study	Semistructured interviews	N=10, 14–20 (childhood context)	Rare genetic condition (ie, a definite or probable diagnosis from genome-wide sequencing)
Vallee *et al*, 2023[64]	France	To analyse the extent and nature of the research available on the impact of childhood-acquired brain injury on siblings	Scoping review	Searches in databases up to August 2022	N=267, unclear (childhood as inclusion criteria)	Acquired brain injury
Burnham Riosa *et al*, 2023[54]	Canada	To explore the lived experiences of siblings of children and youth on the autism spectrum	Qualitative study (interpretative phenomenological analysis)	Semistructured interviews	N=9, 8–17 (M=12.2 years, SD=3.45)	Autism spectrum disorder
Nygård *et al*, 2023[89]	Norway	To synthesise and interpret existing qualitative research on experiences of siblings of children with complex care needs	Interpretive meta-ethnography	Searches in databases until November 2022	N=239, 5–20 years (majority <18)	Long-term physical illness with complex care needs including cancer, acquired brain injury, cerebral palsy, Duchenne muscular dystrophy, spinal cord injury, epilepsy
Reimers *et al*, 2023[90]	USA	To explore the adaptation for adolescents who had a younger sibling with an intellectual disability and physical or mental health disorders	Qualitative study (phenomenological approach)	Daily check-in journals, photo-elicitation interviews, observations	N=5, 13–17	Intellectual disability and either autism spectrum disorder, another disorder, or serious health conditions
Wawrzynski *et al*, 2023[63]	USA	To explore the technology use of adolescent siblings of children with cancer	Qualitative study	Interviews, ecomaps	N=24, 12–17 (M=14.2)	Cancer
Battistin *et al*, 2024[75]	Italy	To explore the topic of relationships in siblings of children with visual impairments	Qualitative study	Semistructured interviews	N=33, 7–22 (majority <18)	Visual impairments

*Both studies, Hwang 2010a and Hwang 2010b, are investigating the same participant group with different research questions. The articles were based on the doctoral thesis of the first author. Information was provided during email correspondence.

Table 3 Siblings' participation in daily life

Categories	Descriptions	References
(1) Family life situations and home participation	Siblings experience numerous situations shared with other family members, both at home and within the community. They spend time with family members (including parents, siblings and extended family) and derive meaning from engaging in activities or simply being together as a family. Seven subcategories were identified: (a) daily routines, (b) sibling activities, (c) caregiving activities, (d) receiving care from parents and substitutes, (e) participation in public spaces, (f) waiting and (g) sleep.	
	(a) Daily routines: Siblings value time spent with family and appreciate shared routines, interests and memories. However, they often face disruptions in family life, such as postponed holidays and less spontaneity, leading to a loss of activities and routines. They also experience inequality due to different treatment and rules, which can make them feel marginalised within their own family. This can result in a sense of disconnection, loss of relationships and withdrawal from previously cherished activities.	23 35 42 47 52–54 56–58 60–62 64–66 68 69 74 78–81 83 86 88–90 92 116
	(b) Sibling activities Siblings engage in various activities with their brother or sister who has a chronic condition, finding both enjoyment and challenges in these interactions. They may struggle with communication, conflict or limitations imposed by the sibling's condition and external factors like hospital rules. Siblings also express the need for personal breaks and time away, feeling exhausted by constantly adapting to others' needs. They often experience inequality in their relationship, feel a lack of involvement in joint activities or losing cherished activities as their sibling's condition worsens.	35–37 41 42 46–55 61 62 64 67 68 70 72–75 78 80 81 86 89 90 117
	(c) Caregiving activities Siblings often take on significant caregiving roles for their brother or sister with a chronic condition, including practical, personal, emotional and educational support, as well as ensuring their sibling's safety and social participation. They also assist with medical care and keep their sibling company. While siblings find it rewarding to help, they often feel burdened by the heavy expectations placed on them. Additionally, they support their parents by sharing household responsibilities and helping them cope, sometimes taking on extra tasks to ease their parents' struggles.	23 35–37 39 40 44–49 51–55 57 60–62 64–68 70–75 78–90 116 117
	(d) Receiving care from parents and substitutes Siblings seek more time, attention, emotional availability and support from their parents, particularly during recreational activities. While one-on-one time with a parent can compensate for limited attention, siblings often experience reduced communication with their parents. They spend more time with extended family or non-family members, who provide emotional and practical support. This reliance on others fosters increased independence and maturity but can also lead to suppressing their own needs and feelings of loneliness.	42 44–46 51 52 54 56 58 60 62–65 67 68 72 73 75 79–83 92 116 117
	(e) Participation in public spaces Siblings often desire more family activities outside the home but face challenges in public settings, such as discomfort from being stared at. This can make society feel unsafe and discouraging. However, they also appreciate certain benefits, like free parking or discounts at amusement parks offered due to their sibling's condition. Siblings frequently find themselves explaining their brother's or sister's behaviour to others, anticipating ignorance and prejudice, and often become accustomed to addressing these situations.	35 37 40 41 45 49 55 70 72–74 78–81 83 85 88
	(f) Waiting Siblings of children with chronic conditions often spend considerable time waiting in hospitals or at home, leading to boredom and anxiety. They struggle with the emotional challenges of being separated from both their sibling and parents due to hospital stays and medical treatments.	56–58 60 62 64 72 78 86 92 117
	(g) Sleep Siblings sometimes share sleep routines and a bedroom with a brother or sister who has a chronic condition. They may develop sleep difficulties due to being awakened by their sibling or due to worrying about their family.	37 39 49 50 56 92
(2) Participation in school	Siblings' learning can be disrupted by worries about their sibling or increased responsibilities at home, leading to difficulties like learning challenges, school absences and insufficient homework time. Their social involvement at school may also suffer, as they might face teasing or bullying due to their sibling's condition or exhibit misbehaviour themselves. School can be either a source of stability or a place of insecurity. Additionally, siblings often take on a protective role at school, safeguarding their sibling with a chronic condition from bullying or monitoring their health.	46 47 49 50 55 58 59 65 66 71 72 82 83 88 89 116
(3) Participation in leisure	Siblings often face restrictions in activities like socialising, private time and travel due to family or their sibling's needs. They may feel compelled to prioritise family over their own interests, which include gaming, reading, physical activities and other hobbies. Additionally, they frequently lack the support needed to engage in their preferred leisure activities fully.	23 25 37–40 42 43 45 49 50 54 56 59 62 63 65 68 70 74 78 88 89 116
(4) Social situations with peers	Siblings spend less time with friends, experiencing fewer visits, playdates and opportunities to meet in the neighbourhood compared with peers or their own expectations. They feel ambivalent about friendships; while enjoying the distraction and connection, they may withdraw due to social stigma, fear of negative reactions, or a preference for family time. Some siblings also choose friends based on their attitudes toward their sibling with a chronic condition. Technology use (such as texting and video calls) seems to facilitate staying in contact with friends when not being able to meet in person.	23 36 37 40 41 47–53 55 56 58 59 63 64 66 72–86 88 89 92 116

Continued

Table 3 Continued

Categories	Descriptions	References
(5) Information seeking	Siblings seek information through parents, the internet, observation or by asking health professionals, but they sometimes struggle to access necessary information or services. Their experiences with support groups vary: Some are unaware, uninterested or have limited experience, while others value meeting peers, benefit from discussions and express a need for more peer support. Parents often recognise the need for increased peer support. Support from school staff, both academic and psychological, can also be beneficial.	37 47–49 55 56 60 62 63 68 73–75 80–83 86 88–90
(6) Continuous meaning-making	Siblings continuously create meaning and make sense of their sibling's chronic condition while engaging in shared everyday situations. They are emotionally and mentally engaged and often acutely aware of their sibling's activities and state of being. They develop understanding and empathy, witness instances of bullying, pain and injustice, and constantly interpret and find meaning in these experiences.	41 47 58 64 68 70 72–75 88 90 92 116

Intersecting factors such as normalcy, advocacy, identity, gender, age, culture and socioeconomics, though not participation categories, impact siblings' participation. A summary of these factors is provided in table 4.

DISCUSSION

To our knowledge, this review is the first to compile and summarise the available evidence on the participation of siblings of children with childhood-onset chronic conditions. We identified six key participation themes and seven intersecting factors from 62 studies. The findings are descriptive, aiming to provide a concise overview.

The diverse range of diagnoses included in the review reflects our intention to capture siblings of children with various childhood-onset conditions. Despite these differences, siblings appear to face similar everyday life challenges. Notably, most studies focused on siblings of children with autism. Autism research has shown particular interest in siblings, possibly due to early diagnostic efforts; younger siblings of children on the autism

Table 4 Intersecting factors in siblings' participation

Factor	Description	References
Normalcy	Siblings compare their lives to those of others and express a desire for their family to conform to societal norms that value normalcy. They perceive being different as negative and feel frustration about their sibling's disability or illness and its lack of social acceptance. Over time, they become accustomed to these disparities. Engaging in social media can provoke a positive perceived normalcy or also the opposite due to a negative comparison with friends.	39–42 47 48 53 55 61–63 65 70 72 73 75 88–90 117
Advocacy	Siblings demonstrate empathy towards their siblings with chronic conditions. Their experiences have taught them to appreciate life and their unique situations. This empathy influences their attitudes towards people with disabilities, often leading to an explicit appreciation for social inclusion and inclusive environments, as well as active advocacy for individuals with disabilities or chronic conditions, beyond just their own sibling.	50 55 73 74 80 88
Identity	Siblings view their relationship as a core aspect of their identity. The mutual dependence and support create a sense of meaning. Siblings feel a need and desire to be 'good siblings', which can create pressure to conform or adjust. They also contemplate and worry about the future, particularly about expected caregiving responsibilities and their sibling's well-being after their parents are no longer present. They often feel uncertain about the availability of support services and perceive themselves as responsible because of their sibling identity.	35 39 41 45 47–50 61 70 77 78 80 81 83 85 88 89 116
Gender	Gender differences are evident in siblings' caregiving roles: Sisters are often expected to help more, and girls are more likely to provide personal care. Gender influences cultural expectations of caregiving responsibilities, both in the present and future. Family support is predominantly provided by grandmothers. Gender differences also affect siblings' activity preferences, such as gaming.	39 43 46 66 67 71 72 88
Age	Different participation needs are reported based on siblings' age: Toddlers mainly seek to be with their parents; school-aged children want to spend time with their siblings; and adolescent siblings seek more knowledge and understanding about their sibling's condition. Adolescence is often associated with increased difficulties and dissatisfaction. Adolescent siblings are also more likely to provide care or assume parental roles.	35 46 58 60 62 64 67 71 72 75 81 87 90
Culture	The environment and cultural attitudes can impact siblings' participation, such as placing additional burdens on ethnic minority groups. The extent of caregiving responsibilities may be influenced by cultural expectations, which can also lead to increased school absences due to prioritising family needs.	48 85
Socioeconomics	Limited financial resources can affect siblings' opportunities, such as the ability to go on holidays or participate in recreational and educational activities.	78 85

spectrum are increasingly screened for early detection.[93 94] This focus may have spurred broader research into siblings, including their participation. Interestingly, no participation themes were found to be specific to any diagnosis. However, further differentiation was not pursued, and siblings of children with conditions excluded from this review (eg, depression)[95] may experience similar issues.

This study may enhance our understanding of the concept of participation and could encourage further development of the concept and refinement of related instruments. Most studies were qualitative, likely due to the exploratory nature of sibling participation research, which currently shows a low level of clinical evidence.[96] Additionally, the complexity of siblings' life situations may pose challenges for quantitative research. Although comprehensive quantitative participation measures have been developed in recent years, most quantitative studies focus on attendance—tracking activity frequency and categories—while often neglecting or struggling to quantify involvement.[18] Measures such as levels of enjoyment, engagement, cooperation, humour and language have been used interchangeably to assess involvement.[18] Only the Participation and Environment Measure for Children and Youth (PEM-CY)[97] and the Young Children's Participation and Environment Measure (YC-PEM)[98] aim to quantify involvement by assessing 'how much' a child is involved.[18] The inherently subjective nature of a child's experience in life situations often necessitates qualitative approaches.[99] Some participation topics identified in this review, such as involvement in family routines or school participation, could potentially be measured using existing quantitative tools like the PEM-CY. However, this review also reveals a research gap in applying quantitative participation measures to siblings of children with childhood-onset chronic conditions, being unable to find a single study using a defined participation measure. Other themes, such as daily sleep or the potential burden of waiting for other family members, may require further exploration and possibly incorporation into future participation instruments.

While this study focused on participation, other research has examined related topics in this population, such as siblings' relationships,[100] perceived social support,[101 102] psychosocial functioning[103] or occurring parentification of siblings.[104 105] The study findings underscore the clinical relevance of siblings' challenges for future research and practice while offering a new perspective on siblings' daily lives. However, this study may also challenge current approaches to redirect assessment towards the complexity of the daily life of these siblings, which may lack adequate evaluation. The inter-relatedness between siblings' daily life experiences and their participation in life situations might be specifically valuable for further exploration.

Constant meaning-making emerged as a distinct aspect of participation, not fitting into categories of attendance or involvement. We suggest further investigating siblings' experiences in making sense of their participation in daily life. This meaning-making can be viewed as an active participation process shown in siblings' descriptions of spending time thinking about and interpreting daily experiences, of being alert and ready to help out or of witnessing their family members' involvement. Meaning-making may also influence their present and future choices in life situations. The importance of siblings' retrospective and prospective meaning-making is supported by, but not limited to, previous research on their future planning,[106 107] expressed information needs[108] or fear of bullying.[109]

The identified intersecting factors—normalcy, advocacy, identity, gender, age, culture and socioeconomics—can influence siblings' participation. Several studies in families of children with childhood-onset disabilities show that gender appears to have an impact on siblings' participation in caregiving and the types of caregiving activities.[46 88] Based on these findings, female siblings may need different or more support as they appear to have greater caring responsibilities. However, more research is required to explore these participation dynamics and their mechanisms. Identity was identified as another factor influencing participation. Some siblings seem to think and worry about their future caregiving roles,[47 85] showing that their identity can be characterised by their role as a sibling and their attitudes towards family belonging. However, siblings are often not or only little involved in a family's future planning discussions and decision-making.[106] Notably, aspects of culture and socioeconomics receive little attention in the included literature, despite previous research suggesting their importance.[110 111]

Strengths and limitations

This review adds to the limited evidence on the participation of siblings of children with childhood-onset disabilities. A comprehensive search strategy was used across multiple databases, and the review process was guided by a predeveloped protocol, with all steps conducted collaboratively by at least two reviewers, enhancing the study's credibility. However, the review was limited to peer-reviewed articles written in English or German, excluding other potentially valuable sources. As a scoping review, it lacks a quality assessment,[30] leading to moderate evidence due to study heterogeneity and limited generalisability. The review also focused on childhood and youth, excluding research on adult siblings, despite the potential lifelong impact[112] of, for example, caregiving responsibilities.[113–115] The findings may also be relevant for siblings of children with severe acute illnesses. However, this population was not included. Nevertheless, this study advances our understanding of siblings' participation, highlights existing research gaps and emphasises the need for comprehensive, high-quality quantitative studies.

Implications

The participation themes identified in this review can help healthcare providers initiate discussions with families about sibling participation. These themes can be assessed with siblings, caregivers or teachers, and while they may not apply to every individual, they are relevant across various childhood-onset chronic conditions. This review also provides a foundation for further research, guiding the development and selection of assessments to identify potential participation restrictions in siblings. It is crucial to provide resources and support for siblings of children with disabilities to ensure their needs are not overlooked. Healthcare providers should proactively address sibling needs, and parents should be encouraged to support them. The findings suggest that childhood-onset disability impacts many daily life situations of siblings during childhood and adolescence such as home, school or peer communities, and these may change over time throughout adulthood. Given that siblings often assume caregiving responsibilities into adulthood, they should be involved in discussions and planning from an early age. Family-centred care practices must consider the changing life situations of siblings and develop, evaluate and refine support strategies fitting the different and changing participation situations. Further research is needed to better understand the lifelong perspectives of siblings when growing up with and caring for a brother or sister with a disability.

CONCLUSIONS

This scoping review identified existing research on the participation of siblings of children with childhood-onset chronic conditions. It summarised key participation topics, including siblings' involvement at home, school and in the community. While siblings often seek information about their brother's or sister's condition, their engagement in continuous meaning-making was found as an additional aspect of their participation. The results depict the complexity and interrelatedness of siblings' daily life experiences, their participation and intersecting factors such as gender, age or normalcy. Challenges were found across all aspects of daily life, regardless of diagnosis type. These findings are relevant to any child with a sibling who has a disability or chronic condition, making them important for all healthcare providers working with children.

Author affiliations
[1]Institute of Occupational Therapy, School of Health Sciences, Zurich University of Applied Sciences, Winterthur, Switzerland
[2]Faculty of Medicine, University of Zurich, Zurich, Switzerland
[3]Research Department, Swiss Children's Rehab, University Children's Hospital Zurich, Affoltern a. Albis, Switzerland
[4]Children's Research Center, University Children's Hospital Zurich, University of Zurich, Zurich, Switzerland
[5]Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland
[6]Division of Neuropediatrics, Development and Rehabilitation, Department of Pediatrics, Inselspital, Bern University Hospital, University of Bern, Bern, Switzerland
[7]Graduate School for Health Sciences, University of Bern, Bern, Switzerland

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ORCID iDs
Johanna Linimayr http://orcid.org/0009-0001-1302-4074
Judith Graser http://orcid.org/0000-0002-9921-8581
Selina Gredig http://orcid.org/0009-0005-7942-6120
Hubertus J A van Hedel http://orcid.org/0000-0002-9577-5049
Anne Tscherter http://orcid.org/0000-0002-6972-482X
Sebastian Grunt http://orcid.org/0000-0003-2820-9650
Christina Schulze http://orcid.org/0000-0002-5662-5347

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