

# Children's Perspectives on Living With a Sibling With a Chronic Illness

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## abstract

**CONTEXT:** Clinical guidance emphasizes the importance of considering the whole family when caring for a child with a pediatric chronic illness (PCI). However, there is a lack of research specific to sibling experience. Parental accounts are used in studies to examine family experiences; consequently, the direct voices of siblings are neglected.

**OBJECTIVE:** The meta-synthesis was used to explore the experiences of siblings of children with PCIs to understand their perspectives; in particular, we observed what they feel had influenced their emotional well-being, to target interventions.

**DATA SOURCES:** We searched PsychInfo, Cumulative Index to Nursing and Allied Health Literature, PubMed, and Academic Search Complete databases from inception to April 2016.

**STUDY SELECTION:** We selected qualitative articles used to examine children's perspectives of living with a sibling with a PCI. Twelve articles were reviewed.

**DATA EXTRACTION:** We observed participants' characteristics, qualitative methodology, analysis, and themes.

**RESULTS:** The thematic synthesis identified 2 overarching themes providing new insights. The first theme, "changing relationships," had 2 subthemes: "changing family relationships" and "changing relationship to self." The second theme, "managing changes," had 3 subthemes: "coping and acceptance," "support from friends, peers, and support groups," and "negative reactions from others."

**LIMITATIONS:** Studies were often descriptive with little explicit qualitative analysis.

**CONCLUSIONS:** The findings are used to outline how changes in family relationships often result in reduced communication and a suppression of healthy siblings' needs. Siblings develop strategies to help them cope with and accept their circumstances, including finding new prosocial ways of meeting their needs in the form of skills and roles they develop.

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Dr Deavin conceptualized and designed the study, conducted the synthesis, and drafted the initial manuscript; Drs Greasley and Dixon reviewed the initial concept, data collection, and analysis and critically reviewed and edited the manuscript; and all authors and approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

**DOI:** <https://doi.org/10.1542/peds.2017-4151>

Accepted for publication May 24, 2018

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** No external funding.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

**To cite:** Deavin A, Greasley P, Dixon C. Children's Perspectives on Living With a Sibling With a Chronic Illness. *Pediatrics*. 2018;142(2):e20174151

**TABLE 1** Search Terms Used for Meta-synthesis

Search Terms	Boolean Terms: “OR” Used Within Row and “AND” Used Across Rows
Sibling	Brother, sister, kin
Experience	Experien*, cop*, resilien*, manage*, deal*, respon*, adapt*, adjust, understand*, impact, well-being, wellbeing, effect*, thought, think, feel, perspective
Chronic	Chronic health condition, chronic physical health condition, chronic disease, muscular dystrophy, cancer, neoplasm, asthma, cystic
noncommunicable	fibrosis, diabetes, arthritis, life-limiting, fatal, terminal, congenital, genetic, non-communicable, organic disease, non-infectious
physical health condition	disease, autoimmune disease, kidney disease, heritable, patient, palliative
Qualitative	Qualitative, interview, IPA, grounded theory, subjective, quot*, narrative*, them*, audio, discourse, phenomenon*
Not to be included	Autism, ASC, psychosis, psychotic, schizophrenia, bipolar, alzheimer, attention deficit disorder, ADHD, anorexia, bulimia, HIV, drug

ADHD, attention-deficit/hyperactivity disorder; ASC, autism spectrum condition; IPA, interpretative phenomenological analysis.

There is an emotional toll that families experience from living with a child who has a pediatric chronic illness (PCI) and may frequently be unwell, in pain, or struggling to adjust to their condition.<sup>1,2</sup> These experiences impact the quality of life of the individuals who have the illness and family members.<sup>3</sup> This is recognized in professional guidance for recommendations of family-based care and interventions, in which the needs of each family member are considered and supported.<sup>4,5</sup> However, within these guidelines, the discussion of siblings is marginal. This is also true of the representation of siblings in research, which is generally focused on overall family experiences or is used to prioritize parental accounts of sibling experiences.<sup>6–16</sup> Consequently, the voices of siblings are overlooked. It has been commented that the effect on siblings has received little attention,<sup>1</sup> and it is difficult to make clinical recommendations on the basis of available research.<sup>17</sup>

Authors of studies suggest increased levels of sibling distress compared with peers<sup>12</sup>; however, results have often been mixed with contradictory findings. In their review from 2002, Sharpe and Rossiter<sup>11</sup> reiterate Cuskelly’s<sup>18</sup> statement of how previous research into psychological adjustment of healthy siblings leaves the reader with “...the overwhelming impression of contradiction and confusion.” Contradictions may reflect the difficulty in consolidating data for different samples (eg, age,

pediatric condition), differing data sources (sibling, parent, teacher), and the wide range of psychosocial constructs used to determine the current psychological state of the well sibling.

Qualitative research has been used to understand siblings’ experiences, but this has mostly been from a whole family perspective, in which all family members are interviewed together. This approach has been used to explore treatment demands,<sup>19</sup> family dynamics,<sup>20</sup> perceptions toward genetic testing,<sup>21</sup> and general psychosocial impacts.<sup>16</sup> Although this may help to provide an understanding of family perspectives, siblings’ views may be influenced by other members of the family therefore failing to identify the distinct voices of the siblings. Many studies include siblings of younger ages<sup>16</sup> and, although having an adult present and/or their perspective included in the research ensures initial insights into a difficult-to-engage sample, this may mean that siblings provide socially desirable responses.<sup>20</sup> The benefit of this approach is that siblings at least have a partial voice, which has provided insight into reactions on diagnosis, education on the chronic illness, siblings’ involvement in care, sibling relationships, fears, and the overall impact of the disease on the sibling.<sup>16</sup>

To further advocate siblings’ experiences, this synthesis is focused on siblings’ direct reports. For some specific diseases, such as pediatric cancer, the sibling experience is

investigated with siblings directly and is generally better documented and understood as demonstrated by 3 reviews.<sup>22–24</sup> However, it has been argued that a non–diagnosis-based review could focus on the psychosocial commonalities that would help to improve care for families.<sup>1</sup> A more generic review with the intention of unifying siblings’ voices across diseases has not yet been undertaken. Thus, our aim with this meta-synthesis of qualitative research was to fill this gap and address the following research question: What are the experiences of siblings of children with a chronic and noncommunicable physical health condition?

## METHODS

### Database Searches

The following 4 databases were searched: PsychInfo, Cumulative Index to Nursing and Allied Health Literature, PubMed, and Academic Search Complete. Search terms were generated from recommended vocabulary from the American Psychological Association, each database’s specified term generator, key words from relevant articles, and reviews of search terms with the research team (Table 1).

### Inclusion Criteria

- The PCI that affected the unwell sibling must have been physical, chronic, noncommunicable, incurable, and require ongoing care.

- Authors of studies had to report a qualitative approach that elicited firsthand accounts in the form of interviews or written responses (eg, open-ended questionnaires), in which the sibling's experiences could be identified independently in the findings (ie, as a separate theme).
- The content of the interview had to include discussion of the siblings' experiences as children (under the age of 20 years old to account for all childhood experiences).
- Studies must have been published in English before April 2016.

### Exclusions

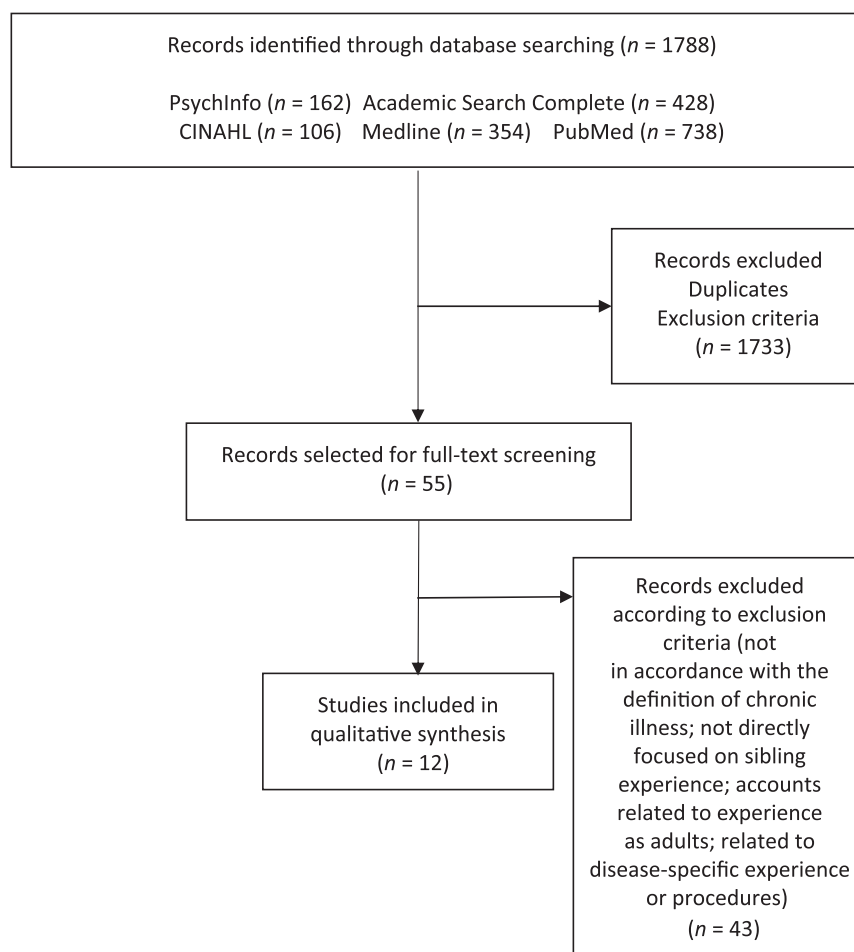
- Articles in which authors targeted disease-specific experiences or procedures (eg, being a donor for a hematopoietic stem cell transplant)<sup>25</sup> as part of the research question were excluded.
- Experiences relating to physical injury (eg, brain injury), mental health, or addiction were not included.
- Articles relating to cancer were excluded. Some forms of cancer are recognized as being acute (eg, acute leukemia), and treatment in other forms can lead to long-term remission of the symptoms, which was felt to make this disease sufficiently different from the sample to exclude childhood cancer from this review.

### Selection Process

Articles were identified, screened, and selected by using the inclusion and exclusion criteria as outlined in Fig 1. This produced the final sample of 12 articles. Summaries of the aims, key features, and themes of the final sample are provided in Table 2.

### Quality and Critical Appraisal

The Critical Appraisal Skills Program (CASP)<sup>38</sup> qualitative checklist was used for quality appraisal of the studies (Table 3). CASP provides



**FIGURE 1**

PRISMA flowchart. CINAHL, Cumulative Index to Nursing and Allied Health Literature.

10 questions relevant to appraising qualitative studies (eg, Was the data analysis sufficiently rigorous?), to which a rating of 0 (no evidence present), 1 (some evidence), 2 (good evidence), or 3 (very good evidence) was applied, with a maximum score of 30 for each article. Scores were assessed independently by the first author and a colleague, both experienced in qualitative research, and then averaged to provide a guide to the quality of the reported studies. With Table 3, we can see that there were no significantly weak studies, with ratings ranging from 13 to 23.5 (mean: 18.9).

### Meta-synthesis

The thematic synthesis<sup>39</sup> followed 3 main stages of (1) identifying codes

directly from the data in the studies, (2) using these codes to generate initial categories and themes, and (3) using these codes, categories, and themes to generate the analytical themes and subthemes represented in the overarching model of the synthesis (Fig 2). The benefits of this approach are that the analysis remains faithful to the original articles, while allowing a transparent deconstruction (coding), synthesis of the data (descriptive themes), and translation of the concepts (analytical themes).<sup>39</sup> The discussion sections were also reviewed to check for new information; however, codes were only included when it was grounded in the data rather than conceptual interpretations.

**TABLE 2** Summary of Key Features of Selected Articles

Author (Date)	Title	Methodology	Participants	Age Range or Average of Healthy Siblings (Unwell Siblings)	Type of Illness	Setting and Country
Bellin et al <sup>26</sup> (2008)	Risk and protective influences in the lives of siblings of youths with spina bifida	Data reported from larger mixed-method study. One open ended question was posed in posted study packet; written responses returned by post. Thematic content analysis. Mixed methods and semistructured interviews. Grounded theory.	155 siblings	13-83	Spina bifida	Social work; United States
Brennan et al <sup>27</sup> (2013)	Paediatric life-limiting conditions: coping and adjustment in siblings	Semistructured telephone interviews and questionnaires to siblings and parents	31 siblings	9-9	Life-limiting conditions	Health psychology; United Kingdom
Derouin and Jessee <sup>28</sup> (1996)	Impact of a chronic illness in childhood: siblings' perceptions	Part of a larger study. Structured interview with results categorized according to questions.	15 siblings; 14 parents	8-17	Chronic illnesses	United States
Gallo et al <sup>29</sup> (1991)	Stigma in childhood chronic illness: a well sibling perspective	Semistructured interviews focusing on rewards and costs of having a sibling with diabetes, developed according to social exchange theory. Template analysis.	27 siblings	6-14	Chronic illnesses	Nursing; United States
Herrman <sup>30</sup> (2010)	Siblings' perceptions of the costs and rewards of diabetes and its treatment	Semistructured interviews focusing on rewards and costs of having a sibling with diabetes, developed according to social exchange theory. Template analysis.	20 Siblings	4-16	Diabetes	Nursing; United States
Hollidge <sup>31</sup> (2001)	Psychological adjustment of siblings to a child with diabetes	Mixed methods and/or semistructured interviews. References not given for qualitative part of analysis.	28 siblings	8-12	Diabetes	Social work; Canada
Hutson and Alter <sup>32</sup> (2007)	Experiences of siblings of patients with Fanconi anemia	Semistructured interviews. Reported by using qualitative description and content analysis.	9 siblings	11-21	Fanconi anemia	Nursing; United States
Malcolm et al <sup>33</sup> (2014)	A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study	Mixed methods study. Qualitative section used interviews facilitated by card sorting technique. Analysis was informed by grounded theory.	8 siblings	7-12	Mucopolysaccharidoses and Batten disease	Nursing; United Kingdom
Okashah et al <sup>34</sup> (2015)	Parental communication and experiences and knowledge of adolescent siblings of children with 22q11.2 deletion syndrome	Mixed methods and an online survey with 2 open ended questions. Reported by using content analysis.	29 siblings	12-16	22q11.2 deletion syndrome	Genetic counseling; United States
Read et al <sup>35</sup> (2011)	Siblings of young people with Duchenne muscular dystrophy—a qualitative study of impact and coping	Semistructured interviews using thematic analysis and the thematic framework approach for analysis	35 siblings	11-18 (5-22)	Duchenne muscular dystrophy	Neurology; United Kingdom
Velleman et al <sup>36</sup> (2016)	Psychological wellbeing and quality-of-life among siblings of paediatric CFS/ME patients: a mixed-methods study	Mixed methods and semistructured interviews; analyzed by using thematic analysis	9 siblings	12-17 (8-18; 13.8 mean)	CFS and/or ME	Clinical psychology and psychiatry; United Kingdom
Wennick and Huus <sup>37</sup> (2012)	What it is like being a sibling of a child newly diagnosed with type 1 diabetes: an interview study	Semistructured interviews and content analysis	7 siblings	10-17 (8-13; 9.5 median)	Diabetes	Nursing; Sweden

CFS, chronic fatigue syndrome; ME, myalgic encephalomyelitis.

**TABLE 3** CASP Quality Appraisal

Articles	Are Clear Research Aims Present?	Is Qualitative Approach Appropriate?	Is Design Appropriate for Aims?	Is Recruitment Strategy Appropriate?	Does Data Collection Address the Research Issue?	Is the Reflection on Researcher and Participant Relationship Present?	Are Ethical Issues Considered?	Is Data Analysis Rigorous?	Is Statement of Finding Clear?	Does Research Add Value?	Total Score Out of 30
Bellin et al <sup>26</sup>	3	2.5	1.5	1.5	2	1	1.5	2.5	2.5	3	21
Brennan et al <sup>27</sup>	3	2.5	3	2	3	0	2	2.5	2.5	2	22.5
Derouin and Jessee <sup>28</sup>	3	2.5	1.5	2	1.5	1	1.5	1	2	2	18
Gallo et al <sup>29</sup>	3	2.5	1	1	2	0	0	1	1.5	1.5	13.5
Herrman <sup>30</sup>	3	2.5	3	2	3	0.5	1.5	2	2	2	21.5
Hollidge <sup>31</sup>	2.5	2.5	1.5	2	1	0	0	1	1.5	2	14
Hutson and Alter <sup>32</sup>	2.5	2.5	3	2.5	3	1	2.5	2	2	2.5	23.5
Malcolm et al <sup>33</sup>	3	2.5	3	2.5	2.5	0.5	2	1.5	2.5	1.5	21.5
Okashah et al <sup>34</sup>	2.5	2	1	1.5	1.5	1	1	1	1	1	13
Read et al <sup>35</sup>	3	2.5	2	2	2.5	0.5	2	2	2.5	1.5	20.5
Velleman et al <sup>36</sup>	3	2	1.5	2	1.5	1	1.5	1.5	2	2	17.5
Wennick and Huus <sup>37</sup>	2.5	2.5	2.5	2	2	0.5	2.5	1.5	2	1.5	19.5

## Findings

With Fig 2, we can see that the systematic review yielded 2 major themes of “changing relationships” and “managing changes.” “Changing family relationships” occurred between all members of the family as a result of their changing circumstances and their own emotional responses. This led to a “changing relationship to self” for siblings as a result of meeting the changing needs of the family and consequently acquiring new roles, skills, and responsibilities that frequently became part of their long-term identity. Managing these practical and psychological changes (theme 2) requires siblings to develop ways of coping, accepting, and adjusting, which is often influenced by external support or their fear of negative reactions from others.

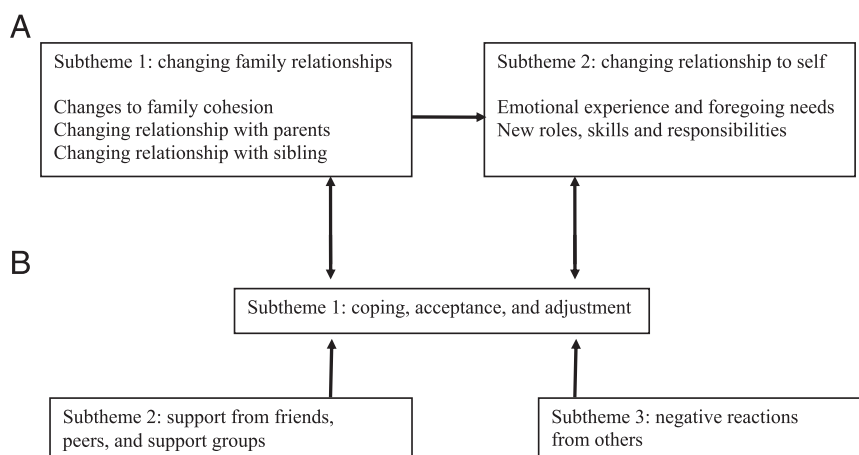
### Theme 1: Changing Relationships

#### *Subtheme 1: Changing Family Relationships*

This subtheme is used to outline siblings’ perceptions of changes to family cohesion, changes to their relationships with their parents, and with their unwell sibling.

An altered sense of family cohesion since the onset and diagnosis of the disease was reported in 5 articles. Siblings expressed views representing both a sense of increased and decreased family cohesion. When positive experiences were reported, siblings described a united family environment,<sup>26,37</sup> with the whole family contributing to their unwell sibling’s care.<sup>35,37</sup> They felt as though this brought them closer,<sup>37</sup> giving the family something in common,<sup>30</sup> which they shared and talked about together.<sup>35</sup> Participants felt this level of closeness and bonding was different from that of other families that did not have to manage a PCI.<sup>26,30</sup> Findings from 10 articles were used to address the changing relationship between





**FIGURE 2**  
Themes and connections. A, Theme 1: changing relationships. B, Theme 2: managing changes.

parents and their healthy children. These reveal changes in the amount and quality of parental attention given to each of the children,<sup>28–32,34,36,37</sup> the perceived change in parental expectations of the healthy sibling (eg, helping to care for the unwell sibling),<sup>26,32</sup> and a reduced level of communication with their parents.<sup>32,34,37</sup> Authors of the majority of reports from healthy children describe a shift of parental attention to their sibling. They often felt jealous and resentful of the amount of time, protection, and “special treatment” parents bestowed on their siblings,<sup>28,30,36</sup> especially when their sibling appeared to be “doing well”<sup>32</sup>; however, they acknowledged the increased attention was necessary.<sup>28</sup>

Healthy siblings from 2 studies described what has been termed as “parental silence,” whereby parents do not talk to them about the illness to protect them from the difficult aspects of the disease.<sup>32,33</sup> This meant parents sometimes did not know how much siblings knew about the illness.<sup>33</sup> Participants in the study by Wennick and Huus<sup>37</sup> discussed how siblings would return the silence because their parents had “enough to worry about.” This resulted in a reciprocal silence between parents and the healthy sibling,<sup>32</sup> which is potentially problematic for family relationships because some

participants reflected that openness might provide the antidote to family breakdown.<sup>36</sup>

The relationship between siblings appeared to be equally complex, eliciting a range of emotional responses. For example, the increased time spent together meant some had a closer relationship,<sup>35</sup> but it was found in 6 studies that healthy siblings recognized negative changes in their sibling relationship, describing it as a loss<sup>30</sup> or distancing.<sup>35</sup> These were associated with changes in their unwell sibling,<sup>28,36</sup> for example, becoming more prone to mood swings.<sup>37</sup>

Families hold varying beliefs about how to view and approach illness as a unit and as individuals.<sup>14</sup> For some, the illness is all but ignored in attempts to create a sense of self that is unaffected, but for others, they incorporate the illness in the new family identity to the point in which it may become the sole focus, causing the family to define themselves on the basis of providing care.<sup>40</sup> The sense of increased family cohesion some children mentioned may therefore result from identifying with the family system’s roles and agendas, causing them to feel included. However, this presumptive allocation of roles has repercussions for siblings who do not fit with

the “acceptable” assumptions of the family system. For example, 1 common and potentially damaging issue is the reciprocal silence that occurs when familial beliefs promote a lack of discussion about the illness to protect others or because it is too painful. This causes siblings who want to discuss their emotions to feel as if they are threatening the family, perhaps becoming a burden, forcing them to become isolated and unable to address their needs. These internal system boundaries,<sup>40</sup> set up to protect each other, consequently reduce communication and cause members to become distant at times when they need each other the most. Given that the structure and hierarchy of the system is also governed by parental beliefs, it is important to remember that not all members have equal power and voice. With healthy siblings being both children and perceived of as being in less urgent need, their voices may often be ignored and suppressed by the adults around them.

#### *Subtheme 2: Changing Relationship to Self*

As a result of the changes in the family, healthy siblings became more aware of their role within the family and felt forced to change. The authors of all the articles acknowledged the changes occurring within the family had an impact on the emotional experiences of healthy siblings. Authors of 2 studies<sup>26,28</sup> noted there were positive impacts, including a positive sense of self and life experiences, but the majority of authors discussed the overwhelming sense of negativity. In Derouin and Jessee’s<sup>28</sup> article, some siblings went so far as to cite themselves as the “most unhappy member of the family.” Their empathy with their sibling often led to sadness that their sibling had the disease or anger when others bullied their sibling because of the disabilities arising from the PCI.<sup>26,32,36</sup>

Worrying about their sibling's health and well-being was pervasive.<sup>28,30,32,33,36</sup> Some recognized that worrying had begun to interfere with other areas of their life, particularly causing problems with concentration at school.<sup>33</sup> Siblings also worried about the uncertainty of their future.<sup>36</sup> Dependent on the type of illness their sibling was diagnosed with, participants reported anxiety about the development and transmission of the illness, specifically how it might affect their health<sup>30,31</sup> and whether they would be a carrier for their children.<sup>32,35</sup> Other emotions reported in the literature were feelings of "survivor guilt,"<sup>26,31,36</sup> loneliness resulting from familial and peer isolation,<sup>26,32,33,36</sup> and jealousy due to the reduced level of parental attention.<sup>31,35</sup>

Findings from Read et al<sup>35</sup> were used to describe the difficulties participants experienced in balancing home demands, including parental and sibling expectations, while their own needs were often overlooked. Given siblings' perceptions that their needs were not as important as their ill siblings, it is not surprising participants in 5 articles stated they did not discuss their feelings with their family for fear of their parents becoming angry, increasing their parents' worry,<sup>31</sup> and adding to their burden.<sup>33</sup> In addition, siblings discussed avoiding conflict<sup>27,32</sup> and pleasing family members to gain approval.<sup>32</sup> The desire to balance the needs of the family, leading to avoidance of communicating their emotions, appears to provide the foundation of siblings' experiences of not recognizing,<sup>32</sup> deprioritizing,<sup>27,31</sup> and suppressing their own needs, with a desire to be emotionally self-sufficient.<sup>27</sup> Bradford's<sup>2</sup> hypothesis of "sibling self-sustainability" due to reduced parental attention is synonymous with this sense of emotional self-sufficiency. "Self-sufficiency" is thought to be promoted by reduced communication

from parents to protect the sibling. Furthermore, siblings regularly do not have direct contact with a health professional, compounding the lack of communication and need to be self-sustaining.<sup>41</sup>

In all of the articles, healthy children described the new roles and skills they had developed since the onset of their sibling's condition. Participants described how this felt like a role transfer and found themselves embodying roles associated with older adolescents or adults.<sup>35,36</sup> Their new experiences provided them with specialist knowledge of the condition, and the responsibilities placed on them caused them to develop a caring role, which became a part of their identity.<sup>26,36,37</sup> These skills and tasks ranged from general caring for the family (eg, housekeeping, supervising their sibling,<sup>30,37</sup> helping with leisure activities<sup>35</sup>) to identifying, assessing, and managing their sibling's symptoms.<sup>29,33,35</sup> The findings of Brennan et al<sup>27</sup> reveal the extent to which the caring persona was internalized and supported by others, revealed by friends calling the healthy sibling "mum." One sibling noted how their experience had made them more compassionate toward other people generally.<sup>34</sup> Siblings described their caring role with pride, noting the acceptance that came with the role but also recognizing the limitations.<sup>33,36</sup> The caring role was discussed as increasing over time,<sup>35</sup> with few breaks,<sup>32</sup> and some discussed the shame they experienced when they did not meet their own expectations of the role.<sup>31</sup>

The acquisition of specialist knowledge, skills, and internalized positive roles appears to have provided siblings with an identity that makes them feel unique and special<sup>30</sup>; some acknowledged their experiences shaped their career choices (eg, becoming a family support worker or nurse).<sup>35</sup>

## Theme 2: Managing Changes

This theme is used to outline how healthy siblings cope with and accept the changes that result from their sibling's disease. It consists of the following 3 subthemes: "coping, acceptance, and adjustment," "support from friends, peers, and support groups" and "negative reactions from others."

### *Subtheme 1: Coping, Acceptance, and Adjustment*

Adjustment over time was a factor described in 5 articles as having an influence on coping and acceptance. Siblings described the impact of the illness as getting easier over time.<sup>30</sup> They commented that it was harder when their sibling was first diagnosed,<sup>26</sup> but when there was a slow progress of the disease, this allowed coping and acceptance.<sup>35</sup> Time was felt to create space to make sense,<sup>26</sup> allowing the process of accommodating to their sibling's decline.<sup>33</sup>

Participants described the evolving process of accruing information<sup>35</sup> and the importance of providing siblings with information about the disease.<sup>32,35</sup> Some commented that a lack of information, particularly relating to symptom management, led to fear.<sup>37</sup> Parents were noted as the main source of information<sup>35</sup>; however, when they were unwilling to discuss the disease, siblings would find alternatives such as support groups or the internet.<sup>32,35</sup>

When siblings had access to information, they started changing their attitudes toward the disease and its impacts.<sup>36</sup> Siblings described how they developed insight and understanding of the broader situation<sup>28</sup> and empathy for their family members' experiences.<sup>29,30,33,35</sup> Understanding sometimes helped them to cope with the imbalance of attention between themselves and their sibling.<sup>37</sup> For others, they still felt jealousy or neglect but could

tolerate and accept the necessity of the situation.<sup>35</sup>

It is suggested in these findings that siblings would prefer to have increased levels of information earlier, relating to the disease and its impacts, which may help build their understanding and empathy, helping them to tolerate and accept the situation and their feelings. This is supported by findings revealing strong associations among increased sibling illness knowledge, positive sibling attitude toward the illness, and sibling behavior.<sup>42</sup> However, it is important to note that this depends on the age of the sibling, with older children having more illness knowledge.<sup>42</sup>

Authors of many articles presented findings relating to behavioral and cognitive strategies that allowed healthy children to cope with and/or accept having a sibling with a PCI. These appear to be either distancing or integrating techniques. Distancing techniques included avoidance,<sup>35</sup> distraction,<sup>28</sup> and physical and temporal compartmentalization.<sup>27,32</sup> These were often described as “getting on with it,” “focussing on the day-to-day,” “living in the present,” and removing themselves from difficult situations by pursuing external interests<sup>36</sup> to keep their home and “other” life separate and maintain some level of “normality.” Bellin et al<sup>26</sup> noted how siblings deemed “normalising” as a step toward acceptance and integration of the disease into their lives.

Little is documented on the specific coping strategies used by siblings; however, the techniques identified in this meta-synthesis are comparable to those used by children with PCIs. With a narrative review, Compas et al<sup>43</sup> categorize strategies into the following 3 types: active, accommodative, or passive coping. Active coping is an individual’s attempts to directly influence or change the source of stress. Accommodative coping is

an attempt to adapt to the source of stress through “...reappraisal, positive thinking, acceptance or distraction.”<sup>43</sup> Passive coping includes cognitive and physical avoidance of the stressor. The authors of the review found accommodative coping to be the most effective form of coping, with mixed findings for active coping and poorer outcomes for those who use passive coping techniques.

#### *Subtheme 2: Support From Friends, Peers, and Support Groups*

Support came from family, friends, teachers, and support groups.<sup>33,35</sup> Findings from Gallo et al<sup>29</sup> detail the internal conflict healthy siblings have when telling other people about their sibling’s illness and seeking support; some felt comfortable revealing the illness to others (although some would be selective), but some did not want people to know. Friendships were discussed in 5 of the articles<sup>26,29,32,33,35</sup> and were often supportive, mature, and inclusive,<sup>26</sup> providing both practical and emotional support, although participants from the study by Hutson and Alter<sup>32</sup> feared that their friends would reject or ignore them because of their siblings. Support groups were mentioned as a form of support used to help them overcome their isolation and aid their adaptation,<sup>35</sup> allowing them to share their experiences and knowledge with each other.<sup>28</sup> Such groups enabled connections to others with shared experiences, expanding their social network and offering them more opportunities to make sympathetic friends.<sup>30</sup>

#### *Subtheme 3: Negative Reactions From Others*

Findings from 7 studies were used to identify the reactions of others to their chronically ill brother or sister as a worry.<sup>33</sup> Siblings were worried their ill brother or sister might be teased or rejected by others and become upset,<sup>26,29,35</sup> even so far

as for them to be concerned about prejudice from the community.<sup>33</sup> They described becoming embarrassed by the treatment of their brother or sister in public<sup>30</sup> identifying ignorance as a rationale for their negative behavior<sup>33</sup>; they wished others would be more accepting and tolerant.<sup>33</sup>

## **DISCUSSION**

With our synthesis, we found that siblings alter their behavior to meet their own needs and those of the family, taking on tasks and skills that include them in the current caring goals of the family. With time and positive feedback, the behaviors that are reinforced become roles within the family and an internalized positive characteristic of their identity. These characteristics are synonymous with prosocial characteristics listed in the clinical and research literature.<sup>2,27,40,44,45</sup>

However, this combination of emotional self-sufficiency and increase in prosocial behaviors may lead parents and professionals to perceive the sibling as functioning and thriving. Parents underestimate the emotional responses and needs of healthy siblings,<sup>2</sup> which may explain why healthy siblings are frequently overlooked, and why there is a lack of professional guidance regarding the treatment of siblings through the care process.<sup>41,46</sup> For example, the policy statement from the American Association of Pediatrics highlighted the importance of patient- and family-centered care but did not mention specific risks or recommendations for siblings.<sup>4</sup> Although siblings adapt their behavior to become more prosocial, they are still experiencing high levels of distress; in a meta-analysis, Vermaes et al<sup>12</sup> found that siblings had significantly higher levels of internalizing problems (eg, depression and anxiety) than comparisons.



Siblings have many strategies and resources they use to manage the changes that result from their sibling's disease. Paramount was the access to relevant and timely information, which led to greater understanding and empathy toward family members and helped them to manage and tolerate their own emotions, in particular their sense of jealousy regarding the imbalance of parental attention. They used a variety of cognitive and behavioral techniques identified in the pediatric patient literature. With our review's findings, we suggest that, although siblings use active and accommodative coping strategies, many also rely more on passive coping (eg, distancing), which has been linked to poorer outcomes. Sharing their experiences with others could be helpful, but they also expressed the fear of being rejected because of their sibling's illness. Support groups were seen as helpful but infrequent. Supportive relationships have been helpful for siblings of children with cancer, allowing them to access information to help them make sense of the situation, provide opportunities to communicate how they feel, seek reassurance, receive attention to feel valued, and maintain self-esteem and a sense of self independent of the illness.<sup>47</sup>

These findings are comparable to those of children with a sibling with pediatric cancer.<sup>22,23,48</sup> Authors of mixed methodology reviews found that, although siblings as a whole did not report significantly higher levels of psychiatric disorders, a subset experienced strong negative emotional reactions, and their experiences impacted their emotional and social well-being. More specifically, it was reported that siblings experienced greater distress closer to the time of diagnosis, and there were often school difficulties within 2 years of the diagnosis. Younger siblings

often reported somatic complaints, whereas concerns for teenagers were psychosocial. The qualitative elements of these reviews similarly highlighted the importance of changing family dynamics and routines, siblings' experiences of intense feelings, the development of some positive self-attributes, and recognition of their unmet needs. However, with our review, we help to explain the complex interaction between family dynamics, emotional experiences, and changes to the siblings' identity to meet their needs. These previously obscured links can be used to identify the family's ability and need to reduce communication, which often leads to siblings not expressing their needs and conversely appearing to be doing well, which subsequently may explain some of the confusion in research outcomes.

Current good practice guidelines identify the need to consider the entire family when working with families with a PCI.<sup>4</sup> However, there is little guidance as to how this should be implemented with siblings.<sup>4,5</sup> With this synthesis, we point to several areas for family-centered clinical intervention. The findings reveal siblings' desire and ability to conceal their needs and emotions, so professionals should be mindful of their needs and monitor the levels of communication or avenues for support available to the sibling. This could be explicitly addressed by inviting siblings to a hospital appointment in which they would have access to a health professional. The professional could answer their questions, discuss age appropriate inclusion of the sibling in caring duties, promote family discussion about the disease, and directly discuss the subjective needs of the sibling, which may reduce anxiety regarding treatments and their uncertainties about the future.

Age-appropriate leaflets could also be used to normalize the experience

for the family. When possible, families should be encouraged to speak together about the illness with siblings and allow them a forum to express their concerns to help them understand and feel heard and included. Keeping channels of communication open would also allow parents to problem solve when necessary. Support groups and other positive events, such as charity work or sibling days,<sup>44</sup> were also found to be helpful but were often too far away for siblings to access regularly. It may be that more online resources and ways of communicating could be developed and encouraged (eg, sibling forums, buddy systems, or Web sites) such as [www.sibs.org.uk](http://www.sibs.org.uk).

Although siblings are proficient at creating a positive prosocial identity, their ability to identify other positive self-attributes are lower than that of siblings of healthy children.<sup>12</sup> Consequently, families and professionals should liaise to ensure that siblings have space and support to develop a positive identity outside of the caring role. At home, this could be implemented by ensuring that children are encouraged to have interests, and their independent achievements are recognized. More broadly, this could be supported by actions used to reduce negative reactions within the general population due to a lack of understanding, such as providing education days at school about chronic illnesses.

## CONCLUSIONS

With this review, we give voice to healthy siblings' concerns regarding their inability to disclose their emotions and the necessity to develop skills and roles to meet their own needs by constructing a positive identity that is concordant with the family's needs. Expressing their feelings and needs is hampered by the widening gaps in communication with their support systems, perhaps leading to

the clinical symptoms often reported as maladjustment (ie, mood changes, rebellion, attention seeking, and somatic complaints).<sup>14,16,19,49,50</sup> Although there is some evidence of considering the clinical importance of siblings' experiences,<sup>2,40,44</sup> it has been recognized that those experiences have been overlooked within the research literature.<sup>1,17</sup> This may be as a result of siblings appearing to be functioning well and in a desired manner to parents and professionals, combined with their fear of expressing how they feel.

#### ABBREVIATIONS

CASP: Critical Appraisal Skills Program  
PCI: pediatric chronic illness

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*Pediatrics* 2018;142;

DOI: 10.1542/peds.2017-4151 originally published online July 26, 2018;

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