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# School Experiences of Siblings of Children with Chronic Illness: A Systematic Literature Review

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## ABSTRACT

**Problem:** Siblings of children with chronic illness have unique experiences that can affect their school functioning, such that they may miss ongoing periods of school, experience difficulties with schoolwork or experience changes in their peer and teacher interactions. This review provides an overview of these siblings' school experiences. **Eligibility criteria:** Six databases (Medline, PsychINFO, CINAHL, ERIC, Embase and The Cochrane Library) were systematically searched for studies examining the school experiences and peer relationships of siblings of children with chronic illness, as well as school-based interventions for these siblings. Studies were included if they were published in or after 2000 and were published in English.

**Sample:** We identified 2137 articles upon initial search. From these, we identified 28 eligible studies examining the school experiences of >1470 siblings of children with chronic illness.

**Results:** Three key themes were identified throughout the reviewed articles. The literature described 1) the psychological impact on siblings at school; 2) decreases in school attendance and academic functioning, and; 3) changes or perceived differences in peer and teacher interactions. Siblings value teacher and peer support, and this support may contribute to better sibling school functioning.

**Conclusions:** Many siblings are socially resilient, yet overlooked, members of the family who may present with psychological, academic and peer related difficulties at school following diagnosis of a brother or sister with chronic illness.

**Implications:** Future research is needed to further delineate the sibling school experience to better facilitate the development of targeted sibling support interventions within the school environment.

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Chronic serious illness in children confers long-term care requirements that have an ongoing impact on the affected child. Chronic medical conditions in children (aged 0–18 years of age) can be defined as lasting longer than three months, or occurring three or more times in the past year and being likely to recur (Mokkink, Lee, Grootenhuys, Offringa, & Heymans, 2008). Chronic conditions adversely affect the child's quality of life due to treatment-related side effects, disruption to normal daily routine and extended hospitalization rates (O'Halloran, Miller, & Britt, 2004). Families of children diagnosed with chronic illness also experience many emotional stresses such as fear associated with the child's diagnosis and prognosis, and the challenging adjustments required to cope with daily changes in family life (Alderfer et al., 2010). Families may experience changes in family routines and roles, reduced amount of time spent together, and the increased care duties or attention that the ill child may need (Alderfer et al., 2010; Gerhardt, Salley, & Lehmann, 2016; Knecht, Hellmers, & Metzging, 2015). The daily routine and psychological functioning of the siblings of the ill child are also directly affected by these changes (Alderfer et al., 2010).

Siblings have long been described as the 'forgotten' members of the family even though they may experience as many changes to their everyday function as the affected child (Cassady, 1982; Sidhu, Passmore, & Baker, 2005). Increased responsibilities at home and regular visits to the ill sibling in hospital are all daily factors that can contribute to stress and anxiety in siblings. Parents tend to focus on the needs of the ill child and may thereby provide less attention and emotional support to the siblings (Alderfer & Hodges, 2010). The loss of the companionship of the affected child means that siblings' feelings of neglect and loneliness can be compounded (Sloper, 2000). The combination of changes to the family structure and sibling relationship can result in siblings modifying their behavior, for example hiding emotions, in an attempt to reduce any potential burden placed on their parents (Vermaes, Van Susante, & Van Bakel, 2012).

The consequences of being a sibling of a child with a chronic illness may extend to the sibling's school experiences. School experiences are integral to a child's academic and social development (Roeser, Eccles, & Sameroff, 2000). Connectedness to school and peers has a significant contribution to a child's overall psychosocial adjustment (Law, Cuskelly, & Carroll, 2013). However, siblings of chronically ill children may struggle to keep up with their schoolwork, and have poorer social functioning as a result of missing regular school attendance (Alderfer et al., 2010). Changes to attendance and engagement with school as a result of their sibling's illness and associated treatment may mean that healthy siblings do not experience the 'normalcy' that a regular school routine contributes to their lives (Gerhardt, Lehmann, Long, & Alderfer, 2015). Understanding the influence of a child's peer group and school environment on their adjustment and emotional functioning can improve our capacity to identify and support the needs of siblings (Law et al., 2013; Roeser et al., 2000).

Reviews in the last decade have examined the psychosocial functioning of siblings of children with chronic serious illness and have generally shown increased negative mood states, internalizing problems and somatic symptoms, lower scores in quality of life measures and qualitative descriptions of maladjustment in siblings following their brother or sister's diagnosis (Alderfer et al., 2010; Incledon, 2015; Knecht et al., 2015; O'Brien, Duffy, & Nicholl, 2009; Vermaes et al., 2012). Yet despite the importance of school attendance in child development, no reviews to date have specifically focused on siblings' school experiences. Therefore, this systematic review sought to examine past research investigating the school experiences of siblings of children with chronic illness and attempt to provide a unique and holistic overview of the sibling school experience in the context of the sibling's

wider psychological functioning. In reviewing the educational experiences of siblings, we considered both academic and psychosocial outcomes at school. We aimed to investigate current school-based interventions and school related support that can help promote healthy sibling adjustment in schools.

We aimed to answer two key research questions:

1. What are the school experiences of siblings of children with chronic illness?
2. What interventions are available that provide educational support for siblings of children with chronic illness?

## Method

We used six databases to locate articles: Medline, PsycINFO, Cumulative Index to Nursing & Allied Health Literature (CINAHL), Educational Resources Information Center (ERIC), EMBASE and The Cochrane Library. We manually searched the references of eligible papers, as well as searching citations of eligible papers in Web of Science and Scopus. We used search terms that fit into three categories: study participant, illness, and school (see Table 1). PRISMA methodology was used to guide this review (Liberati et al., 2009; Moher, Liberati, Tetzlaff, & Altman, 2009).

## Selection Criteria

We included peer-reviewed journal articles relating to the sibling school or peer related experience, and those that focused on specific school based interventions for siblings. Searches were limited to articles published after January 2000 until the 9th of March 2016 (when searches were completed) and to those published in English. We reviewed articles that examined school outcomes from the perspective of families, parents, teachers, and siblings themselves. We excluded articles focusing on children with developmental, cognitive or intellectual disabilities, rare illnesses, and articles focusing solely on bereaved siblings, adult siblings, and articles where there was no general sibling control population. However, three articles were included which examined the retrospective experiences of siblings who had already completed their schooling at the time of study participation. Dissertations, commentaries, abstracts and conference abstracts were excluded from this review.

## Quality Appraisal

We assessed the quality of the included articles using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Lee, & Cook, 2004). Articles received a maximum score of 2 for each of the 14 checklist criteria for quantitative studies and 10 criteria for qualitative studies; with an overall maximum total score that varied depending on the relevance of each criteria to the different studies. Mixed methods studies were assessed using both quantitative and qualitative checklists. Two reviewers (LG and BN) assessed each review separately and disagreements were resolved

**Table 1**  
Search terms.

Search category	Search terms
Study participant	"Sibling", "siblings", "brother", "sister"
Illness	"Chronic disease", "chronic illness", "neoplasm", "cancer"
School	"School", "classroom", "peer", "education", "learning", "absenteeism", "social", "psychosocial"

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