Exploring the Impact of Childhood Chronic Health Conditions on Siblings:

A Systematic Review and Qualitative Study
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Declaration of Originality

I, Kathryn Hales, hereby certify that this thesis is my own original work. Any ideas, text or research referred to in this thesis which are not my own have been appropriately referenced. I also declare that this thesis has not been previously submitted for assessment.

Kathryn Hales
07.10.2015
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I would like to thank the seven families who gave up their time to participate in the current study. I would also like to acknowledge the courage of both participating parents and children in openly discussing sensitive natured topics.

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Abstract

**Systematic review:** To address a gap in the literature, a systematic review of research evaluating parenting interventions to support siblings of chronically ill children was performed. An electronic database search was executed using a liberal criteria, due to the paucity of research in the field. Data extraction was conducted and a risk of bias assessment was executed where relevant. Five papers were included in the review, evaluating three separate intervention programs. Two papers assessed randomised control trials and the remaining were one-group, pre- and post-test studies. The primary findings suggest that interventions for siblings have the potential to benefit illness knowledge, reduce negative attitudes, decrease stress, and increase sibling reported mood. Parent-reports propose that some treatments may reduce sibling emotional and behavioural problems.

**Qualitative study:** A qualitative study was also undertaken to explore the impact of childhood chronic illness on siblings, from both parent and sibling perspectives. A descriptive study design was utilised to interview the seven parent-sibling dyads from families with a chronically ill child. A convenience sample was recruited using a non-categorical approach to diagnosis specification, and face-to-face interviews were conducted using a pre-determined semi-structured schedule. Thematic analysis and NVivo version 10 were adopted to analyse the interview transcripts. Analysis revealed five themes and four sub-themes. Themes focused broadly on the individual differences of siblings, the sibling relationship, lifestyle variances, wanting more from family life, negative illness impact, and family adaptability.

**Conclusions:** Limitations of both studies are noted. Findings propose that there is insufficient research within this field, and parenting interventions may provide promising opportunity for future family support.
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Introduction

Childhood chronic illness can be broadly defined as a long-term medically diagnosed health condition affecting pre-adolescent children, which is usually incurable or has persistent symptoms (Limbers & Skipper, 2014; Morawska, Calam, & Fraser, 2014). Examples of common chronic illnesses affecting Australian children include asthma, eczema, diabetes, arthritis, and epilepsy. Subsequently, the combination of illness symptoms and treatment demands can severely restrict daily functioning for the diagnosed child, their parents, and siblings (Limbers & Skipper, 2014). The negative psychological and physical impact of chronic health conditions on the family unit has been well documented; however, there are a multitude of variables that influence this relationship.

As opposed to being restricted to particular diagnostic groups, the effect of chronic health conditions on family functioning, adjustment, and treatment compliance has been found to greatly depend on the severity of the illness (Morawska et al., 2014; Rodrigues & Patterson, 2007), and whether it is life threatening, unpredictable, or has an intrusive treatment regimen (Stein & Jessop, 1982). Family features, the home environment, and individual child and parent characteristics have also been proposed to predict adjustment outcomes (Perrin, Ayoub, & Willett, 1993). Evidence suggests that it is these variables and not specific disease symptomatology that predict family functioning (Stein & Jessop, 1982; Williams et al., 2009). Therefore, this research will take a non-categorical approach (Stein & Jessop, 1982; Williams et al., 2009) and will assess chronic health conditions more holistically. Stein and Jessop (1982) propose that this perspective facilitates for the design and implementation of all-inclusive treatment interventions, catering for a greater and more diverse population.
Impact on the Family

Chronic health conditions directly impact the child with the diagnosis; however, they also indirectly affect the entire family unit (Feeman & Hagen, 1990). Families often undergo vast lifestyle adjustments to cater for illness management responsibilities, subsequently disrupting family role dynamics and daily functioning (Bellin & Kovacs, 2006; Brown et al., 2008; Cohen, 1999). These alterations usually demand a change in the family schedule to accommodate treatment practices, doctors’ visits, specialist appointments, and hospitalisations (Bellin & Kovacs, 2006). Hence, the presence of a childhood illness can enforce strict confines on family time and finances (Bellin & Kovacs, 2006; Brown et al., 2008), impacting on social, community, and school interactions (Brown et al., 2008). In addition, parents must redirect extra physical and emotional resources towards condition treatment, consequently reducing parental availability (Bellin & Kovacs, 2006; Feeman & Hagen, 1990). Maintaining a positive balanced environment in the midst of chronic illness predicts not only treatment compliance, but also long-term family health outcomes (Brown et al., 2008; Cohen, 1999).

Adjusting to and coping with childhood chronic health conditions has been suggested to have a negative impact on all family members (Compas, Jaser, Dunn, & Rodriguez, 2012; Morawska et al., 2014; Rodrigues & Patterson, 2007). Existing research proposes that chronic illness management responsibilities contribute to family stress (Bellin & Kovacs, 2006; Compas et al., 2012; Rodrigues & Patterson, 2007), which has also been found to adversely impact illness compliance and symptom severity (Compas et al., 2012). Another negative consequence of childhood health conditions for all family members is the experience of anxiety, fear, and uncertainty (Feeman & Hagen, 1990). Evidence proposes that family anxiety predicts varying degrees of emotional and behavioural problems for the ill child and
their siblings (Compas et al., 2012). All psychological family variables can impact on treatment practices and illness symptom severity (Blackman, Gurka, Gurka, & Oliver, 2011; Compas et al., 2012).

Importantly, however, some research has suggested that the presence of a childhood chronic illness can cause some families to become stronger and more resourceful (Walsh, 2002). Bellin and Kovacs (2006) refer to this concept as family resilience, which has been defined as positive adaptation in response to challenges. This ability for a family to adapt and cope with illness demands has been identified to have a positive effect on family health outcomes (Barlow, Harrison, & Shaw, 1998; Bellin & Kovacs, 2006).

Sustaining family well-being while managing a chronic health condition is demanding and can have both negative and positive psychological ramifications for the entire family unit. However, these consequences interact with illness severity and treatment, substantiating the impact of childhood chronic health conditions on all family members and justifying the importance of this area of research (Cohen, 1999).

**Impact on the Diagnosed Child**

The chronically ill child is affected by disease pathology, treatment, consequent side effects, and lifestyle condition requirements; for example physical therapy (Brown et al., 2008). Children with chronic health conditions are at risk of a multitude of physical and psychological problems, which can severely impact their individual health condition and family well-being. Research suggests that emotional issues or internalising problems, such as anxiety and depressive symptoms, are the most prevalent problems in children with chronic health conditions (Bennett, 1994; Blackman & Conaway, 2012; Blackman et al., 2011; Hysing et al., 2007; Hysing, Elgen, Gillberg, & Lundervold, 2009; Morawska et al., 2014; Pinquart & Shen, 2011). Internalising problems may arise from a lack of illness control and side effects,
upsetting symptoms, physical pain, reduced independence and autonomy, restriction of activities and social interactions, and even peer rejection (Pinquart & Shen, 2011). These emotional issues have been found to be associated with poor treatment compliance and diminished well-being (Blackman & Conaway, 2012).

In addition, evidence has been established for the occurrence of externalising behaviour problems in chronically ill children, for example; fighting, arguing, and acting out (Blackman & Conaway, 2012; Blackman et al., 2011; Hysing et al., 2007; Hysing et al., 2009; Morawska et al., 2014; Pinquart & Shen, 2011). Pinquart and Shen (2011) have proposed that externalising behaviours can occur in response to illness and treatment frustrations; for instance, being teased by peers.

Chronically ill children have also been found to experience developmental difficulties, such as problems with learning, attention, and communication (Blackman & Conaway, 2012; Blackman et al., 2011); report somatic complaints other than defined illness symptoms (Feeman & Hagen, 1990); have decreased school attendance and academic performance (Feeman & Hagen, 1990); and show increased social difficulties due to reduced opportunities for developing peer relationships (Feeman & Hagen, 1990). Finally, research has suggested that children with chronic conditions are at a greater risk for physical and emotional abuse (Svensson et al., 2011).

The severity of the illness and the intrusiveness of treatment are recognised as risk factors that substantially predict emotional, behavioural, and developmental functioning in children with health conditions (Rodrigues & Patterson, 2007). Evidence proposes that greater illness severity and impairments are associated with overall poorer family well-being and functioning (Blackman et al., 2011; Hysing et al., 2009; Rodrigues & Patterson, 2007; Timko, Stovel, & Moos, 1992).
Impact on the Parents

Parents and caregivers of chronically ill children are also affected by their child’s symptomatology and illness management regimens (Barlow et al., 1998). Parents are responsible for time consuming and often complex treatment demands, such as managing medication compliance, continual supervision, committing to clinic appointments, hospital visits, physical therapy, and adhering to specialised diets (Barlow et al., 1998; Bellin & Kovacs, 2006; Brown et al., 2008; Morawska et al., 2014). Parents must also sustain work commitments, ensure financial stability, and maintain a healthy, social, and educational environment for all children within the family unit (Barlow et al., 1998; Bellin & Kovacs, 2006; Brown et al., 2008; Morawska et al., 2014). Once a child has a diagnosis, parents must also come to accept that their child possesses an often incurable illness, that they may have limited life expectancy, suffer severe pain, have consequent psychological and developmental problems, and face restricted social and lifestyle opportunities (Barlow et al., 1998). Many parents report lacking confidence with regards to parenting and raising an ill child (Feeman & Hagen, 1990), often resulting in parental anxiety, depressive symptoms, stress, feelings of hopelessness, loss of control, and guilt (Barlow et al., 1998; Brown et al., 2008; Wood, Sherman, Hamiwka, Blackman, & Wirrell, 2008), all of which may negatively impact the marital relationship (Brown et al., 2008). Some parents also report a feeling of heavy burden and may decide not to have any more children as a consequence of illness management strain (Barlow et al., 1998). Furthermore, research proposes that this parental distress has been associated with an increase in emotional and behavioural problems in all children within the family home (Cohen, 1999; Tritt & Esses, 1988).
Impact on the Siblings

**Negative effects.** Childhood chronic health conditions have been found to have an overall negative impact on the siblings within the family unit (Vermaes, van Susante, & van Bakel, 2012). While research suggests that this adverse impact is lesser than that on the ill child, siblings tend to experience greater difficulties compared to children living with healthy siblings (Vermaes et al., 2012). Siblings are often required to change their usual routines and take on additional daily caregiving and household responsibilities (Vermaes et al., 2012; Wood et al., 2008), and may experience differential parental treatment (Vermaes et al., 2012). As a result of this, siblings of chronically ill children often endure vast consequences that shape their future behaviour and development.

Evidence suggests that siblings of children with chronic illnesses are at a greater risk of internalising problems (Hollidge, 2001; Knecht, Hellmers, & Metzing, 2015; Sharpe & Rossiter, 2002; Tritt & Esses, 1988; Vermaes et al., 2012). It has been suggested that regardless of diagnosis type, siblings often experience anxiety and depressive symptoms as a result of negative emotional manifestations (Hollidge, 2001; Vermaes et al., 2012; Williams et al., 2009). Siblings often feel scared or worried about their family’s well-being, and may also be concerned about their own health status (Hollidge, 2001; Williams et al., 2009). Siblings may also feel angry, jealous, and resentful, possibly due to family sacrifice, increased responsibilities, and lack of parental attention (Bellin & Kovacs, 2006; Hollidge, 2001; Kiburz, 1994; Strohm, 2001; Vermaes et al., 2012; Williams et al., 2009). They also often report feeling guilty, either because they are frustrated with lifestyle changes, or perhaps because they were spared from the illness (Bellin & Kovacs, 2006; Hollidge, 2001; Strohm, 2001). Finally, some siblings experience a pervasive degree of loneliness and isolation, perhaps from reduced parental availability and social experiences
Evidence suggests that these siblings experience a pressure to behave and quietly achieve with the intent of protecting their parents from extra burden (Bellin & Kovacs, 2006; Strohm, 2001). Which may explain why siblings are more likely to internalise their problems, withdraw from others, and not openly share their grievances with their parents (Hollidge, 2001; Tritt & Esses, 1988).

Siblings of chronically ill children may also experience externalising behaviour problems (Tritt & Esses, 1988), such as aggressive reactions (Sharpe & Rossiter, 2002; Vermaes et al., 2012), fighting, delinquency (Vermaes et al., 2012), or antisocial behaviour (Ferrari, 1984). However, it has been advocated that emotional difficulties are more prevalent and associated with greater negative effects than externalising problems (Sharpe & Rossiter, 2002; Vermaes et al., 2012). Vermaes and colleagues (2012) believe that this could be due to siblings not wishing to overburden their parents, or that siblings have learnt that behavioural reactions are ineffective at gaining parents’ attention.

Moreover, research has found that siblings of chronically ill children may experience poorer self-esteem and self-attributes, than siblings of healthy children (Hollidge, 2001; Vermaes et al., 2012; Williams et al., 2009). Siblings also often face school problems, decreased levels of academic performance (Feeman & Hagen, 1990; Limbers & Skipper, 2014; Williams et al., 2009), and reduced cognitive development and ability (Feeman & Hagen, 1990; Sharpe & Rossiter, 2002). Furthermore, Williams (1997) found evidence that some siblings have lower social competence than siblings of healthy children, which can lead to reduced and unfulfilling peer relationships. Finally, siblings of chronically ill children are more likely to report somatic complaints than siblings of healthy children (Feeman &
Hagen, 1990; Hollidge, 2001), for instance; sleep disturbances, enuresis, eating problems, headaches, and abdominal pains (Knecht et al., 2015; Williams, 1997).

**Positive effects.** In addition to siblings often experiencing the negative consequences of living with a chronically ill child, there is also evidence for a range of positive side effects and resilience (Bellin & Kovacs, 2006). For instance, research has found that siblings are often more empathetic (Bellin & Kovacs, 2006; Kiburz, 1994; Strohm, 2001; Vermaes et al., 2012; Williams et al., 1997), compassionate (Bellin & Kovacs, 2006; Kiburz, 1994; Strohm, 2001), patient, sensitive (Bellin & Kovacs, 2006; Tritt & Esses, 1988), tolerant, mature, and appreciative (Strohm, 2001), than siblings of healthy children. Sharpe and Rossiter (2002) believe that these positive responses enhance the sibling relationship and promote family closeness.

**Risk and protective factors.** The severity of the chronic condition and the degree to which it is life-threatening has been found to greatly influence sibling well-being. Evidence suggests that greater illness severity and threat is associated with increased psychological distress in siblings (Limbers & Skipper, 2014; Vermaes et al., 2012). Alternative researchers advise that the degree of illness impact on daily family functioning, serves as a risk factor for sibling adjustment (Sharpe & Rossiter, 2002). Regardless, more recent diagnoses appear to be associated with increased family stress, usually a result of disease management adjustments and parental uncertainty (Ferrari, 1984; Wu, Follansbee-Junger, Rausch, & Modi, 2014).

The age of the sibling in relation to the child with the illness has also been found to serve as either a risk or protective factor. Siblings younger than the child with the condition tend to display more resilience than older siblings (Vermaes et al., 2012). Limbers and Skipper (2014) believe that parents may be less inclined to disclose negative illness information to their younger children, and that they may be
less cognitively capable of fully understanding disease consequences. Conversely, older siblings may be at risk for greater negative outcomes, because they are often delegated more daily responsibilities, and may be more informed and understand adverse illness outcomes (Limbers & Skipper, 2014; Vermaes et al., 2012).

Evidence regarding the sex of the sibling as a risk or protective factor is less definitive. Ferrari (1984) proposes that siblings of the same sex as the chronically ill child experience an increased risk for negative outcomes, however overall females exhibit slightly more positive adjustment. Consistently there is also evidence that male siblings exhibit greater anxiety and decreased self-concept than female siblings (Hollidge, 2001). Alternatively, other research suggests no sex difference in overall sibling functioning (Bellin & Kovacs, 2006; Vermaes et al., 2012).

Informant limitations. Informant type is perhaps one of the greatest discrepancies in the literature with regards to understanding sibling adjustment in families with chronic illness. There seems to be a vast disconnect between parent-reports of sibling outcomes and the siblings own self-reports (Eiser & Morse, 2001; Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010), especially with regards to less observable domains, like emotional functioning (Eiser & Morse, 2001). Evidence suggests that parents tend to rate sibling well-being and functioning as better, and less impacted by the illness, than siblings report for themselves (Knafl & Zoeller, 2000; Van Roy et al., 2010). For instance, Limbers and Skipper (2014) found that parents rated sibling physical, psychological, and school functioning outcomes more positively than sibling-reports. The authors proposed that sibling outcomes may be overlooked by parents, due to preoccupation with the ill child (Limbers & Skipper, 2014). As mentioned earlier, it has been suggested that siblings are less likely to share their problems with their parents so to not overburden them; parents may therefore be unaware of the severity of sibling distress (Eiser & Morse, 2001;
Hollidge, 2001). In contrast, it has been found that some parents do, in fact, report greater negative impact on sibling adjustment than sibling self-reports (Sharpe & Rossiter, 2002). Researchers (Sharpe & Rossiter, 2002; Wood et al., 2008), believe that parents may actually be more sensitive to sibling outcomes, because they are aware that they are more involved with the ill child, and therefore feel guilty and perceive siblings to be functioning more poorly. It is also possible that overprotective parents may report sibling outcomes as worse compared to less protective parents (Sharpe & Rossiter, 2002). Vermaes and colleagues (2012) found that parents rated sibling self-attributes as poorer than sibling-reports, however they suggest no informant difference regarding internalising and externalising problems. Finally, Ferrari (1984) found insignificant differences in reports of sibling functioning irrespective of informant type.

**Interventions for Siblings and the Role of Parenting Support**

In response to the growing body of literature pertaining to the adverse effects of chronic health conditions on siblings, treatment intervention research has promptly expanded. To date, the majority of interventions have focused on sibling-directed illness- and psycho-education, often provided in the context of therapeutic support groups and recreational programs (Hartling et al., 2014; Incledon et al., 2013). However, considering the influence of childhood chronic conditions on the entire family unit, directing treatment interventions purely at the affected sibling may not be the most efficient or effective method for initiating positive and long-term change.

In contrast, parenting interventions provide an opportunity for all family members to be positively influenced by a treatment program, and are one promising avenue that may help families better adapt to childhood illness demands (Morawska et al., 2014). Parenting interventions are based on the principle that parenting style and techniques contribute to the onset and maintenance of childhood emotional and
behavioural problems (Lundahl, Risser, & Lovejoy, 2006). Theoretically, parenting interventions are founded in social learning theory, which suggests that children learn from their social experience defining their behaviour (O'Connor, Matias, Futh, Tantam, & Scott, 2013). As a result of this, children often directly and indirectly learn their life strategies from their family relationships (O'Connor et al., 2013), for instance stress, conflict, and emotion management. Hence, parenting interventions are constructed to improve confidence and to directly teach parents empirical strategies to apply to their own child’s behavioural and emotional problems; such as learning more efficient ways to manage childhood anxiety, helping parents to teach their children to problem-solve, build skills for future development, and foster strong family relationships. There is an association between childhood behavioural and emotional adjustment and the use of ineffective parenting strategies, family stress, and the overall family environment (Lundahl et al., 2006; Morawska et al., 2014; Perrin et al., 1993; Timko et al., 1992; Wu et al., 2014).

There is evidence for the efficacy of parenting interventions aimed to reduce the emotional and behavioural problems of chronically ill children. For instance, randomised controlled trials assessing these interventions, have been found to improve parenting skills, decrease stress (Sassmann, de Hair, Danne, & Lange, 2012), reduce diagnosis-related family conflict (Doherty, Calam, & Sanders, 2013), and ease childhood internalising and externalising behaviours (Westrupp, Northam, Lee, Scratch, & Cameron, 2014). It is anticipated that siblings may also be positively influenced by parenting interventions, however to date, very few programs have targeted siblings directly and measured sibling health outcomes. Therefore, it is useful to explore the efficacy of parenting interventions at reducing negative adjustment outcomes in siblings of chronically ill children.
Although a systematic review has been conducted to evaluate the effects of sibling-directed interventions (Hartling et al., 2014), no published systematic review could be sourced focusing on parenting interventions to support siblings of children with chronic health conditions. To address this important gap in the literature, a systematic review of literature evaluating parenting interventions to support siblings of chronically ill children was undertaken (Study 1). In addition, a qualitative study (Study 2) was also conducted to explore the impact of childhood chronic health conditions on siblings, from the perspective of both siblings and their parents. Current perspectives on child and family research stress the importance of including both child and parent opinions, in effectively understanding the impact of chronic health conditions on siblings (Eiser & Morse, 2001; Knecht et al., 2015). This multi-informant approach was applied to the current study, whereby both parents and siblings of children with chronic health conditions were interviewed. Similarly, Sanders and Kirby (2012) promote the importance of a consumer-focused perspective with regards to parenting intervention design; on this basis, including parent and sibling perceptions can be considered valuable to informing the development of future interventions for this population.

**Study 1: Systematic Review**

**Method**

**Search Strategy**

A systematic electronic database search was conducted for both published and non-published literature in PubMed, CINAHL, Scopus, PsycINFO, Web of Science, and Google Scholar. No beginning limits were specified for publication date and the search was resolved in July 2015. The search strategy included combinations, synonyms, and varied spellings of the following terms: ‘chronic health condition’, ‘sibling’, ‘family’, ‘child’, and ‘parenting intervention’. Searching techniques
such as truncation were applied for more efficient results, and reference lists were also hand searched to ensure all relevant articles were located. Refer to search information and terms per database (Appendix A).

**Inclusion and Exclusion Criteria**

A liberal criteria was applied to this review to capture the maximum range of articles, as past literature suggests a paucity of research within this area. The following inclusion criteria were applied prior to searching: studies available in English only, both published and grey literature, and interventions that included any type of chronic health condition (but not limited to), with at least one intervention component designed to support parents in their parenting role with siblings. No limitations were specified for study design (for example, randomised control trials), child and sibling age, or year of publication. Non-English articles have been excluded from the present review.

**Data Extraction**

Titles and abstracts of the recovered articles were screened and the above minimal criteria applied. Full-text versions of the relevant articles were retrieved and checked for suitability by two separate reviewers. Any disagreements were resolved though discussion. The process of systematic data extraction was performed for all suitable studies, which included participant characteristics, study design, characteristics of the parenting intervention or component, and the outcomes assessed.

**Risk of Bias Assessment**

The Cochrane Risk of Bias tool (Higgins & Green, 2008) was adopted to evaluate the quality of the eligible randomised trials, covering the following six domains: sequence generation, allocation concealment, blinding, incomplete outcome data, selective reporting and other sources of bias. Each relevant study
was assigned an overall risk assessment score (low, unclear, or high risk of bias). A brief risk of bias discussion will be included concerning the non-randomised studies. However, the included non-randomised studies only measure one group (at pre- and post-intervention), meaning that the results must be interpreted with extreme caution. These findings are likely to have a high risk of bias, as there is no comparison group to determine whether the differences at pre- and post-test can be directly attributed to the treatment interventions.

**Contributions**

The initial idea of performing a systematic review focusing on siblings of chronically ill children was proposed by the supervisor to the student. Progression and consensus of the present research question was influenced by both the supervisor and student. Search terms and strategies were designed by the student, however checked and revised by the supervisor and a faculty librarian. Searching, criteria application, data extraction, and bias assessment, were conducted by the student and checked by the supervisor.

**Results**

The initial search yielded 2,023 titles (refer to Figure 1). However, a further one paper (Giallo & Gavidia-Payne, 2008) was added to this total, which was not recovered through searching, but discovered during preliminary readings. In all, 168 duplicate papers were removed, leaving 1,856. Based on title and abstract screening, an additional 1,824 were excluded as they did not meet the current inclusion criteria (either based on general child health - not interventions, or they did not focus on chronic illness or childhood chronic illness). Full-text versions of the remaining 32 papers were retrieved. Of these, nine were not published in English, and 14 were interventions for the ill child or family, which did not include sibling outcomes, and were thus excluded. Finally, an additional four papers were excluded
as they were not parenting interventions or did not have any parenting component. Reference lists were also searched for other relevant papers, however no supplementary titles were retrieved. Overall, a total of five papers remained, evaluating three separate intervention programs: Sibstars (Giallo & Gavidia-Payne, 2008), SibLink (Lobato & Kao, 2002, 2005), and the ISEE: Intervention for Siblings – Experience Enhancement (Williams et al., 1997; Williams et al., 2003).

Figure 1. PRISMA flow diagram of search results.

Studies and Participants

All participating families were recruited through advertising in paediatric speciality clinics, and health service providers, specialising in children with chronic illness and disability. The ages of participating siblings ranged from 7- to 16-years, with the exception of Lobato and Kao (2005) who focused on younger siblings aged 4- to 7-years old. The diagnosed children ranged from 1- to 21-years of age. The majority of authors reported their participating family ethnicity as Caucasian, although...
Giallo and Gavidia-Payne (2008) failed to report ethnicity, their study was conducted in Australia. Study sample sizes ranged from approximately 20 families (Giallo & Gavidia-Payne, 2008; Williams et al., 1997), to 40 families (Lobato & Kao, 2002, 2005), and finally Williams and colleagues (2003) sampled 252 families. All included studies adopted a non-categorical approach to diagnosis categorisation, including chronic illness, and intellectual, sensory, physical, and developmental disabilities. Four of the interventions were delivered in group settings either in a medical centre, or a children’s hospital. Only Giallo and Gavidia-Payne (2008) conducted face-to-face sessions to individual families (location not mentioned), and provided follow-up home telephone support for families. Refer to the data extraction table (Appendix B) for a summary of all study and participant details.

**Intervention Types**

Three interventions have a one group, pre- and post-test design: a pilot evaluation for the *ISEE program* (Williams et al., 1997), a preliminary evaluation for *SibLink* (Lobato & Kao, 2002), and a preliminary evaluation of a downward extension of *SibLink* for younger siblings (Lobato & Kao, 2005). The fourth intervention is a randomised three-group (repeated measures) design of the *ISEE program*: full intervention, partial intervention, and a wait-list control (Williams et al., 2003). The final intervention is a randomised controlled trial of the *Sibstars* program, which has also been compared to a wait-list control group (Giallo & Gavidia-Payne, 2008).

All programs included a psycho-educational parenting component, where parents were taught strategies to manage: children’s behaviour (Giallo & Gavidia-Payne, 2008; Williams et al., 2003), family stress, family routines, communication, family problems (Giallo & Gavidia-Payne, 2008), and sibling needs and emotions (Lobato & Kao, 2002, 2005; Williams et al., 1997; Williams et al., 2003). However, the duration of intervention delivery varied widely among programs. The parenting
component of the *SibLink* program ran concurrently with the sibling treatment consisting of six sessions (90 minutes) over approximately eight weeks (Lobato & Kao, 2002, 2005). The *ISEE* pilot program (Williams et al., 1997) was comprised of only one parenting session (three hours). While the Williams and colleagues (2003) *ISEE* program was a five-day summer camp, which included one parenting session (two hours) prior to the recreational camp, and two booster sessions (two hours each) at four and nine months post-camp. The partial intervention consisted of the summer camp only, with no additional parenting component (Williams et al., 2003).

Finally, the *Sibstars* program comprised one face-to-face and six telephone parent sessions (all approximately 30 minutes each), with a total duration of six weeks (Giallo & Gavidia-Payne, 2008). All programs included psycho-educational training for siblings, and additionally, both *ISEE* programs incorporated social and recreational components. The parenting components of these programs were delivered by either paediatric clinical nurses, clinical psychologists, or clinicians with postgraduate training in psychology or paediatric nursing.

**Risk of Bias Assessment for Randomised Trials**

**Sequence generation.** Both of the controlled trials reported randomising participants either into a treatment or wait-list control group (Giallo & Gavidia-Payne, 2008), or full treatment, partial treatment, or wait-list control (Williams et al., 2003). Williams and colleagues (2003) did not report randomisation procedures, therefore risk of bias is unclear. However, Giallo and Gavidia-Payne (2008) utilised a computer generated allocation sequence program, thus the risk of bias is low.

**Allocation concealment.** The first study (Giallo & Gavidia-Payne, 2008) recruited and allocated participants using a central allocation procedure, suggesting a low risk of bias. Risk of bias is unclear for the second paper, due to insufficient reporting of procedures (Williams et al., 2003).
Blinding. In both studies, participants and personnel were not blind to the treatment conditions, as a result of the intervention delivery procedure and the included wait-list control. Thus, risk of bias assessment is unclear for blinding of outcome measures, as insufficient information has been provided.

Incomplete outcome data. Giallo and Gavidia-Payne (2008) reported attrition: one wait-list family withdrew (poor availability), and two failed to complete post-treatment measures. No other incomplete or missing data was reported, therefore risk of bias is low. Williams and colleagues (2003) reported attrition (reasons not provided) and exclusion; seven withdrawals, due to inconsistent parent accompaniment to sessions. However, authors reported no significant differences between withdrawn and remaining participants, and withdrawal was approximately equal over conditions (14%). Due to similar attrition and exclusion across groups, the incomplete outcome data risk is low.

Selective reporting. Both studies reported on all outcome measures regardless of significance, suggesting a low risk of bias regarding selective outcome reporting.

Other sources of bias. Both studies reported no significant differences between treatment and control groups at baseline. Giallo and Gavidia-Payne (2008) had a small sample size ($n = 21$), restricting the generalisability of results. Williams and colleagues (2003) recruited a large sample ($n = 252$), although siblings attended the summer camp free of charge, and parents were compensated $40 each for every data collection session. Overall, both randomised studies can be considered relatively free of bias on all assessed domains.

Randomised Intervention Outcomes for Siblings
Knowledge about illness. One study assessed sibling illness knowledge and found a significant increase from baseline over all time-points in the treatment condition, compared to the partial and control groups (Williams et al., 2003).

Emotional adjustment and mood. Giallo and Gavidia-Payne (2008) found that at post-intervention, siblings in the treatment group had significantly lower emotional symptoms (parent-reported), compared to the wait-list control group. They also found that siblings in the treatment group reported significantly lower perceived intensity of daily stress hassles (relating to the child with the illness) than the wait-list group at post-test (Giallo & Gavidia-Payne, 2008). Non-significant results were associated with sibling-reported internalising, externalising, frequency of daily hassles, and the frequency and intensity of uplifts (positive affect associated with the chronically ill child) (Giallo & Gavidia-Payne, 2008). In the alternative study, self-reported sibling mood significantly improved from baseline, at nine and 12 months in the full treatment condition, compared to the partial and control groups (Williams et al., 2003). Additionally, sibling-reported negative attitudes decreased in both conditions, however this effect was significantly larger in the treatment condition, compared to the partial and control groups (Williams et al., 2003).

Behavioural adjustment. Williams and colleagues (2003) found a significant decrease in parent-reported sibling behavioural problems in the treatment group at nine and 12 months, compared to the partial and control groups. The second study measured parent-reported conduct problems, hyperactivity, peer issues, and level of pro-social sibling behaviour, and discovered no significant differences between groups (Giallo & Gavidia-Payne, 2008).

Social support. Williams and colleagues (2003) found an increase in sibling-reported social support in all treatment groups from baseline, with the partial intervention group yielding a significantly higher degree of support. In contrast, Giallo
and Gavidia-Payne (2008) utilised an alternative scale and found no significant difference in sibling-reported social support between the treatment and control groups.

**Self-esteem.** One study assessed sibling-reported self-esteem and found a significant increase from baseline, in the partial and full treatment conditions (Williams et al., 2003).

**Coping.** Giallo and Gavidia-Payne (2008) found that siblings in the treatment group reported using significantly less distance coping than the wait-list control. They also measured sibling-reported problem solving skills and found no significant differences between groups (Giallo & Gavidia-Payne, 2008).

**Total difficulties.** Finally, Giallo and Gavidia-Payne (2008) assessed sibling overall total difficulties (including emotional symptoms, conduct problems, hyperactivity, peer problems, and pro-social behaviour) as reported by parents, and discovered no significant differences between treatment and wait-list control groups.

**Randomised Intervention Outcomes for Parents and Families**

**Parent and family resilience factors.** In one study, at post-intervention parents in the treatment group reported that they engaged in significantly more family time and routine activities, than the wait-list control (Giallo & Gavidia-Payne, 2008). Parent perceived stress, parenting behaviour, family problem-solving communication, and family hardiness was also measured in the same study, although no significant effects were found (Giallo & Gavidia-Payne, 2008). Williams et al. (2003) assessed no parent or family outcomes.

**Risk of Bias Assessment for Non-randomised Trials**

No formal risk of bias assessment tool was applied to the three reviewed non-randomised trials, as a result of their methodological insufficiency. The Williams and colleagues (1997) paper reports on a pilot study of the *ISEE* program, which has been
evaluated in the afore-mentioned randomised trial summarised above (Williams et al., 2003). However, the results of the one-group pilot study present a high risk of bias and must be treated with caution. Similarly, both of the papers which evaluate the SibLink intervention are one-group pre- and post-test studies (Lobato & Kao, 2002, 2005), suggesting that the results present a high risk of bias and must be cautiously considered. All three of these studies may be subject to confounds which are creating and (or) contributing to all of the following presented results, regardless of the potential effectiveness of the interventions.

**Non-randomised Intervention Outcomes for Siblings**

**Knowledge about illness.** All three studies assessed sibling illness knowledge, although Williams and colleagues (1997) used a 30-item true or false test, compared to the SibLink studies, which utilised structured interviews (Lobato & Kao, 2002, 2005). All studies found a significant increase in illness knowledge from pre- to post-test (Lobato & Kao, 2002, 2005; Williams et al., 1997).

**Adjustment to illness.** One study measured sibling-reported negative illness adjustment and found a significant decrease from pre- to post-test, however parents’ reports were non-significant from pre- to post-test (Lobato & Kao, 2002).

**Global behaviour functioning and connectedness.** Both of the SibLink studies assessed global child behaviour and sibling connectedness using the same scale (Lobato & Kao, 2002, 2005). Lobato and Kao (2005) which sampled younger siblings (4- to 7-year-olds), found no significant differences in global behaviour functioning from pre- to post-intervention and at follow-up. Although, the authors (Lobato & Kao, 2005) found that both sibling and parent-reported connectedness significantly increased from pre-test to post-test, however only parent-reports were significantly maintained. Lobato and Kao (2002) tested older siblings (8- to 13-year-olds) and found significantly less internalising and externalising from pre- to post-test,
which was maintained at follow-up. Additionally, parent and sibling-reported connectedness significantly increased from pre- to post-test, and was sustained at follow-up (Lobato & Kao, 2002).

**Discussion**

This review provides a novel contribution to the literature, by presenting a synthesis of research focusing on parenting interventions to support siblings of chronically ill children. Data extraction was performed on five studies: two of which were randomised controlled trials (Giallo & Gavidia-Payne, 2008; Williams et al., 2003), and the remaining were one-group, pre- and post-test studies (Lobato & Kao, 2002, 2005; Williams et al., 1997). Due to the paucity of parenting intervention research in this field, all reviewed studies included a sibling-directed and parenting component. An accurate comparison of outcomes was difficult to achieve, due to the studies inconsistent research designs. Similarly, there is a disparity between intervention treatment methods, procedures, and number of sampled families. Both randomised trials revealed a relatively low risk of bias, however certain domains in Williams and colleagues (2003) were not thoroughly reported. All three non-randomised trials have a high risk of bias, due to the nature of their insufficient methodological design.

The key findings from the randomised studies suggest that interventions for siblings can benefit illness knowledge, reduce negative attitudes (Williams et al., 2003), decrease daily stress (Giallo & Gavidia-Payne, 2008), and increase sibling self-reported mood (Giallo & Gavidia-Payne, 2008; Williams et al., 2003). Based on parent-reports, the results propose some evidence that treatment interventions can help reduce sibling behavioural problems (Williams et al., 2003) and negative emotional adjustment (Giallo & Gavidia-Payne, 2008). Mixed results were found for sibling-reported social support (Giallo & Gavidia-Payne, 2008; Williams et al., 2003),
whereby children’s recreational camps and activities appear to be enhancing social support, compared to alternative intervention techniques. Modest evidence was established for a treatment related increase in sibling self-esteem (Williams et al., 2003), and a slight reduction in distanced coping (Giallo & Gavidia-Payne, 2008). Finally, interventions may help to increase family time and routine activities (Giallo & Gavidia-Payne, 2008).

Consistent with above, the non-randomised studies suggest that interventions may also increase illness knowledge (Lobato & Kao, 2002, 2005; Williams et al., 1997). There is modest evidence that interventions may decrease negative illness adjustment (Lobato & Kao, 2002), and possibly increase sibling connectedness (Lobato & Kao, 2002, 2005). Mixed results were found for global behaviour functioning (Lobato & Kao, 2002, 2005), whereby only one study suggests a decrease in sibling internalising and externalising (Lobato & Kao, 2002). Due to the insufficient design of these studies, further enquiry is necessary to determine the accuracy of the present findings.

**Limitations.** A major constraint of this review is the dearth of available research focusing on parenting interventions (or component), of which measure sibling outcomes. Additionally, the reviewed studies included both parenting and sibling-directed treatment components, meaning that no study was a pure parenting intervention. Suggesting that the origin of the positive intervention effects cannot be definitively established, as they may be resulting from a combination of the two treatment types, or either the parenting or sibling-directed components. Further randomised controlled trials evaluating only parenting treatment interventions are critical to fully determine their efficacy.

Only English research was included in this paper, suggesting that the generalisability of this review may be limited due to a language bias. Similarly, the
majority of the participants within the reviewed studies identified themselves as Caucasian, signifying that these studies may also be limited to a Western population.

**Practical implications.** The results of the current review propose that interventions designed to support siblings of chronically ill children, may be efficacious in reducing negative sibling adjustment. Despite limited evidence, sibling-directed and parenting interventions appear to improve a considerable range of impacted family lifestyle domains. Suggesting that sibling interventions may be a promising treatment avenue, which have the potential to increase the health and well-being of the entire family unit. Past literature proposes that the family environment, stress, conflict, and poor parenting techniques, may predict treatment compliance and illness severity, which influences the family dynamic (Brown et al., 2008; Cohen, 1999; Compas et al., 2012; Feeman & Hagen, 1990). This cycle suggests that parenting interventions may trigger a positive change, indirectly increasing the health and well-being of all children, and even possibly decreasing illness severity. Interventions aimed purely at the siblings may increase sibling well-being temporarily, however the family climate will likely remain as it was.

The current review recommends that interventions for siblings may be easily implemented utilising a non-categorical approach to diagnosis categorisation. Advising that these findings are generalisable over a range of chronic conditions, and that future non-categorical interventions have the potential to be flexible and accommodate a greater population.

**Future research.** There is an extensive gap in the literature concerning pure parenting interventions for siblings of chronically ill children, especially measuring sibling health outcomes. Future researchers should endeavour to design and execute methodologically sufficient research studies, which assess the efficacy of unaccompanied parenting interventions.
The current review provides no insight into family resilience, which appears to be an avenue of interest in past literature (Bellin & Kovacs, 2006). This concept warrants further enquiry as a possible protective factor for siblings and children with chronic illness, by providing fundamental answers to potentially combat negative illness impact.

The reviewed studies did not assess sibling school difficulties, academic performance, cognitive development, and somatic complaints, which appear to be areas of illness impact within past literature (Feeman & Hagen, 1990; Limbers & Skipper, 2014; Sharpe & Rossiter, 2002). All of the above are under-researched areas within this field, and may influence future interventions designed to support all family members affected by chronic illness.

**Study 2: Qualitative Study**

**Method**

A qualitative, descriptive study design was used to investigate the impact of childhood chronic health conditions on the well-being of siblings, using a multi-informant approach which includes the perspectives of parents and the siblings themselves. Parent-child dyads were interviewed face-to-face using a predetermined semi-structured interview schedule. A non-categorical approach to defining chronic illness was applied to this study. Any 5- to 15-year-old child with a diagnosis of a physical chronic illness of which the symptomatology or treatment side-effects impact on daily living to any degree, was to be included. However, mental health conditions and disabilities (for example, autism) were omitted. It was also required that the chronically ill child had been diagnosed for a minimum of two years to ensure a measurable condition impact.

**Research Approach**
A thematic method was employed to analyse the interview data. Thematic analysis offers an accessible and flexible approach to qualitative data analysis that presents a rich understanding of a data-set by identifying patterns and commonalities (Braun & Clarke, 2012). The process employed in the present study was both inductive and deductive, whereby the analysis was open to the exploration of new concepts; however, certain ideas were also been drawn from previous theory and form the foundation of the included semi-structured interview questions.

**Participants**

A convenience sample of parents of chronically ill children, along with one healthy sibling from each family, were recruited to be interviewed. The sample of participants consisted of seven parent-siblings dyads who had a child living within the family home with a chronic health condition. Diagnoses included juvenile idiopathic arthritis, coeliac disease, epilepsy, muscular dystrophy, cerebral palsy, and asthma. Interviewed parents were all mothers with an age range of 36 to 49 (Mdn = 41 years), and all families identified themselves as Caucasian. A total of four parents reported being married, one de-facto, and two divorced. Of the interviewed families two sets of siblings were monozygotic twins, where only one twin had a chronic health condition. See Table 1 for demographic information of the interviewed siblings and the chronically ill children. Of the participating families, four had additional children living within the family home, three of which had a total of three children, and the final family had a total of four children.

Table 1.

*Demographic Information for Sibling Participants and Diagnosed Children*

<table>
<thead>
<tr>
<th>Interviewed sibling</th>
<th>Diagnosed child</th>
<th>Diagnosis duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Age (years)</td>
<td>Sex</td>
</tr>
<tr>
<td>male</td>
<td>11</td>
<td>female</td>
</tr>
<tr>
<td>male</td>
<td>11</td>
<td>male</td>
</tr>
</tbody>
</table>
male  8  female  10  10
male  8  female  10  4
female  12  male  10  5
female  12  female  12  3
female  8  female  5  2

**Materials**

A shortened version of the Family Background Questionnaire (Sanders & Morawska, 2010) was emailed to parents prior to the interview meeting, to collect family demographic information (Appendix C). The schedule of semi-structured interview questions (Appendix D) was generated based on previous research, focusing on the impact of chronic health conditions on the well-being of siblings. Parents and siblings were asked 16 primary questions, examining family functioning, the sibling relationship, the parent-sibling relationship, and sibling emotional and behavioural adjustment. Interview questions were framed depending on the current informant (parent or sibling), sibling age, and diagnosis type. For example, literature suggests that siblings may end up performing additional caregiving and household responsibilities (Vermaes et al., 2012; Wood et al., 2008). Therefore the following question was included for siblings: “Do you think that you have to do more chores and help around the house because [ill child] has [health condition]? What do you do to help out?” And for parents: “How do you think [ill child]’s health has influenced your expectations of [healthy child]? For example, does [healthy child] take on more responsibilities than [he/she] otherwise might?” Time was provided at the conclusion of the interview for parents to make additional comments or share perspectives that were not explored during the interview. All interview questions were independently reviewed by two psychologists with clinical and research expertise in parenting chronically ill children, and revised according to feedback, to establish face validity.

**Procedures**
Participants were recruited through advertisements in local primary school and university newsletters, and by word-of-mouth. As a token of appreciation for participants’ time, all participants were offered the chance to go into a draw to win one of two AUD$50 department store gift vouchers.

Eligible parents received email packs containing written study information and the adapted family background questionnaire for parents to complete prior to the interview date. For families with multiple eligible siblings, the eldest child within the pre-determined age range (6- to 12-years) was selected. All parents and children were informed that participation was voluntary and that they were free to withdraw at any time without further consequence.

Upon meeting, the parent and sibling were asked to read and sign participation consent and assent forms, respectively. The interviews then commenced, lasting approximately 30 minutes with parents and 15 minutes with siblings. All interviews were audio recorded and transferred into written transcripts post-meeting. Once transferred, all audio recordings were erased, and written transcripts, consent forms, and history questionnaires were kept in a secure location.

Data Analysis

Transcripts were written orthographically, whereby all spoken words and sounds were reproduced. The following phases were employed, as per Braun and Clarke's (2012) thematic process guidelines for qualitative analysis: familiarising yourself with the data, generating initial codes, searching for themes, reviewing of potential themes, defining and naming themes, and finally producing the report.

Contributions

The aim and production of this study was initially suggested by the supervisor. Interview questions were designed by supervisor and student, and were revised by two additional psychologists with clinical and research expertise. All procedures
were collectively agreed upon by both the supervisor and student. Data collection and analysis was performed by the student, and reviewed by the supervisor.

Results

A thematic content analysis of interviews was performed to identify and report emerging patterns and themes. All interviews were imported into NVivo version 10, and five primary themes and four sub-themes were confirmed over numerous stages of investigation (Table 2). Quotes are used below to illustrate the identified themes.

Table 2.

*Developed Themes and Subthemes from Interviews*

<table>
<thead>
<tr>
<th>Themes and Sub-themes</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not like other children</td>
<td>Siblings have different lives from other children. They have illness knowledge and appear to be more aware, respectful, and mature.</td>
</tr>
<tr>
<td>Siblings together - but apart</td>
<td>Siblings appear to have healthy relationships and seem to be more protective and empathetic.</td>
</tr>
<tr>
<td><em>Living within limits.</em></td>
<td>Normal sibling relationships – but still different. Some siblings take on illness responsibilities and have different family-life limitations.</td>
</tr>
<tr>
<td>Life is different</td>
<td>Siblings are impacted by routine disruptions, unbalanced parental attention, and different household responsibilities. Some siblings appear to feel jealousy, resentment, and frustration.</td>
</tr>
<tr>
<td><em>Doing what has to be done.</em></td>
<td>Families have to do what is necessary to get by, and siblings are often unaware of life without illness impact.</td>
</tr>
<tr>
<td><em>Wanting more.</em></td>
<td>Families can still do a lot together, although they often wish to be able to partake in more family activities, social interactions, and holidays.</td>
</tr>
<tr>
<td>Living with illness</td>
<td>The unpleasant truth of living with illness - constant family hypervigilance, anxiety, worry, and some guilt.</td>
</tr>
</tbody>
</table>
Seeing and hearing everything.

Real and warranted worries about illness injury, hospitals, emergencies, trauma, and near death experience.

Making the most of it

Families tend to be supportive, understanding, grateful, and adaptable. Learning of valuable lessons and prioritising the important things in life.

Not Like Other Children

Siblings of chronically ill children tend to be aware of their brother or sisters health condition, and have a general diagnosis and treatment understanding. For example, the following sibling descriptions of coeliac disease and asthma:

“It’s a disease where you can’t have gluten, because your intestines don’t work as well” (11-year-old sibling).

“When you get an asthma attack you could go to hospital if it is really bad, and sometimes you might need the puffer and the spacer” (8-year-old sibling).

Parents described that due to their specialised exposure, their healthy children are more aware and considerate of other individuals with illness or disability.

“She has learnt to be very mindful of different people and not to judge someone by the way they look or talk” (Mother of 12-year-old sibling).

“He has seen a lot of kids with disabilities, so he has been very exposed, and I think that makes him very respectful” (Mother of 11-year-old sibling).

A few parents also expressed that their children have learnt valuable life skills from living with a chronically ill sibling.
“We are starting to find that (eldest son) is more mature emotionally for his age” (Mother of 8-year-old sibling).

**siblings Together - But Apart**

Parents and siblings both reported having healthy sibling relationships, and that they enjoy spending time playing together, love, and miss each other when they are apart. Parents expressed that their children also engage in trivial sibling conflict.

“They are just normal brother and sister. They fight like cat and dog, but are best friends the next minute” (Mother of 8-year-old sibling).

“They play really nice together and they love each other, but they can fight as well” (Mother of 8-year-old sibling).

“When they spend time apart they really miss each other” (Mother of 11-year-old sibling).

A few parents reported that their healthy children are protective of their siblings, especially when the sibling was the older of the two children. Similarly, some siblings report watching out for their brother or sister.

“(Healthy child) is definitely more protective of him (ill child)” (Mother of 12-year-old sibling).
“I go to check on her sometimes at night if I hear noises, because my room is next door to hers” (8-year-old brother).

A few parents expressed that their healthy children are empathetic and considerate with regards to their brother or sister’s illness pain or discomfort, and are ever helpful and devoted.

“(Healthy child) is very empathetic when she is in pain” (Mother of 12-year-old sibling).

“Sometimes (healthy child) will go and sleep on the floor next to (ill child), especially if he hasn’t been very well. And they always defend each other if one of them is getting into trouble – they are loyal to each other till they day they die” (Mother of 11-year-old sibling).

It also became apparent that parents were unsure as to whether the sibling relationship would have been any different without illness influence.

“There hasn’t been a clear pre-post, before-after diagnosis. It’s hard to tell” (Mother of 11-year-old sibling).

Alternatively, it was suggested that sibling’s positive behaviours may be due to their innate personality, rather than a consequence of their brother or sisters diagnosis.

“It is hard to tell - because his nature is a bit like that, he is a really kind, thoughtful, sensitive sort of kid” (Mother of 11-year-old sibling).
“I think it’s in her nature to be protective and caring, so I’m not sure if she is more caring because of (ill child)’s condition or if she would have been like that anyways” (Mother of 12-year-old sibling).

**Living within limits.** Some parents and siblings reported that they have taken on illness management and caregiving responsibilities. One parent discussed how her son reminds her about his sister’s medication, and a sibling describes how she helps:

“If I forget her medicine, he’s all like ‘mum have you given (ill child) her medicine?’ and ‘(ill child) have you had your medicine?’” (Mother of 8-year-old sibling).

“Knowing if he has taken his tablets and steroids or not. If he hasn’t - I actually tell mum” (12-year-old sibling).

All parents and siblings expressed that they wish they could interact and spend more family time together. With more severe illness, like epilepsy, parents reported that their children are forced to partake in more sedentary activities. However, even this is often difficult, for instance one mother stated:

“Even if they are sitting playing, like if they are playing cards together or something, we have to make sure that there is padding around (ill child), so if he has a seizure and falls, that he doesn’t hit his head on the furniture and hurt himself - which impacts on where they can play, and how they can play” (Mother of 11-year-old sibling).
In these more severe cases, it is often the simplest things that siblings want for their brother or sister. One child describes the impact of his sister’s severe epilepsy and his corresponding thoughts:

“She can’t walk because she has epilepsy. Umm… she can’t talk because she has epilepsy” (8-year-old sibling).

“If I could (have epilepsy) instead of my sister I guess I would swap with her, so she could live like normal for a while” (8-year-old sibling).

The same sibling also expressed what would happen if his sister were healthy:

“She can walk and talk, and she can do all those nice things. Umm… and we could talk to each other. Umm… that would be the best” (8-year-old sibling).

**Life is Different**

Most parents reported that negative illness impact decreases once a diagnosis and routine has been established. Parents described this diagnosis-adjustment period to be stressful, tiring, and all-consuming. Illness impact on family routine tends to depend on how stable or unpredictable the condition is, for example, seizures can happen with no warning, making it difficult for parents to effectively organise their time. The following are examples of an unpredictable and stable illness impact, respectively:
“Epilepsy has just impacted everyone, in every way” (Mother of 11-year-old sibling).

“Well I think now that it is managed it doesn’t really affect us too much on a daily basis” (Mother of 12-year-old sibling).

Parents and siblings of severe physical conditions discussed having to spend more time at home due to illness limitations, for example, being in a wheelchair.

“We generally keep to home base activities” (Mother of 12-year-old sibling).

“We don’t get to go out a lot because our sister has epilepsy and is in the wheelchair” (8-year-old sibling).

Some parents expect and require their healthy children to perform extra household responsibilities, due to illness management burden.

“The boys really have no choice… yeah so they need to take on more responsibility, so that we can spend more quality time with them” (Mother of 8-year-old sibling).

On the contrary, some parents have purposely lowered their expectations of their healthy children to ensure that they are being fair. Another mother proposed that regardless of her expectations, her older healthy son took it upon himself to perform more household chores. Interestingly, compared to their corresponding parent-
reports, most siblings described that they have greater responsibilities to perform around the house due to their brother or sisters circumstance. For example:

“I know that we both do jobs, but I do the harder jobs because there are things he can’t do. But mine take longer. We have a chart, see *points to chart* and (ill child) has his jobs and I have mine. But sometimes he doesn’t have to do his, and I always have to do mine” (12-year-old sibling).

“I definitely don’t expect her to do anything more than I would if (ill child) was fully healthy, but she thinks I do. She thinks I ask her to do a lot more, and that the jobs are quite unfair between her and (ill child)” (Mother of 12-year-old sibling).

Most parents describe the difficulty in providing a balanced attention divide between all of their children, and the techniques they utilise to manage their children’s associated beliefs.

“I try to explain to her (healthy sibling) that we spend big amounts of time together less often, while my time with (ill child) is a little bit every day, and that it does all even out between them eventually” (Mother of 12-year-old sibling).

“Explaining quality and not quantity. So with the little 3 year old (sibling), he just wants us all the time. So umm… it’s very much managing their expectations” (Mother of 8-year-old sibling).

A few parents have reported that their healthy children can display feelings of jealousy and resentment, as a result of reduced parental attention.
“Because she (healthy child) is not the one getting special attention that she gets a little bit jealous” (Mother of 8-year-old sibling).

Likewise, siblings themselves reported getting frustrated on occasion, as a result of illness burden on the family and wanting more parental attention.

“It would be nice for me to be able to do more things with everyone and not have to worry about it, and mum would have more time, and won’t have to pay for his (ill child)’s stuff, so we would have more money to buy things as well” (12-year-old sibling).

“Sometimes she has asthma and it’s annoying because it wakes me up, or we have to stop what we are doing” (8-year-old sibling).

**Doing what has to be done.** Regardless of illness burden, most parents propose that they strive to provide a healthy environment and lifestyle for their children.

“We made a commitment to each other to just live our lives, and not sort of wait at home for the seizures to get better, so we try and do what we can” (Mother of 11-year-old sibling).

All parents noted that their healthy children are accustomed to living with a chronically ill child, and are rather desensitised to hospital visits, medical equipment, and adverse side-effects. This is anticipated, as siblings younger than the ill child
have never experienced life without the illness, while older siblings may not remember life before the diagnosis.

“She (healthy child) hasn’t been impacted to where she is aware of it – because she doesn’t know life without him (ill child)” (Mother of 12-year-old sibling).

**Wanting more.** All siblings reported wanting their brother or sister to be able to participate in more physical activities and enjoy greater experiences, beyond their capabilities. Parents were also aware of illness limitations, and wished that they could partake in more family leisure activities, social interactions, and holidays together.

“It is limiting lifestyle wise, with what we can do individually and as a family – it’s very demanding” (Mother of 11-year-old sibling).

As above, parents reported a greater illness impact on family activities compared to siblings, possibly because siblings may be unaware of an alternative lifestyle.

**Living with Illness**

Parents of more severe and unpredictable conditions, reported a constant state of hypervigilance and arousal. One parent discussed her daughter’s epilepsy:

“Because her seizures can happen at any time – we have to be ready to go, we are always on call” (Mother of 8-year-old sibling).

All mothers noted that their healthy children have been either anxious, worried, or scared, due to their brother or sisters diagnosis. Although, some parents
and siblings described that this lessened after the diagnosis-adjustment period, after illness-education, and once illness demands were managed. Two siblings provided the following thoughts:

“At first I did (feel worried), because I didn’t really know if she was going to be okay or not. After I learnt a bit more about it, I felt a bit better” (11-year-old sibling).

“Well now we know what it is, she has stopped being sick and she’s like a normal sister” (11-year-old sibling).

Based on parent observations, illness related anxiety seems to be more prevalent in older children, possibly because they have greater knowledge regarding illness consequence. For example, the following account concerning childhood epilepsy:

“It probably effects more our older (18-year-old) son, because he’s been worried now - ‘is she going to end up with brain damage?’” (Mother of 8-year-old-sibling).

Consistent with parent-reports, all interviewed siblings recounted having either felt sad, worried, or scared at some stage due to their sibling’s health and well-being. One brother discloses:

“Whenever like she hurts herself, like when she fell out of her bed. I was scared, because ahh umm of the epilepsy. Umm because she can’t really think where she is and where she has to go… so I was scared” (8-year-old sibling).
On the contrary, one sister reported not being scared, but initially worried:

“I guess worried when mum first told me what it was, because I didn’t really understand and I didn’t really know what it meant. But now I’m okay, I guess I’m not scared, because I mean everyone’s got to die sometime - we are kinda used to it” (12-year-old sibling).

Overall, there seems to be slightly less concern in terms of emotional impact from a sibling perspective, compared to parent-reports. This could be a result of parents hiding illness impact and not wanting to additionally burden their children.

“I try to be very strong in front of them and not… well I break down in private. But in front of them it’s all ‘everything’s fine!’” (Mother of 11-year-old sibling).

It is also possible that some siblings may be doing the same, by trying to hide their true feelings as to not overburden their parents. One mother suggested that her son may sometimes feel pressure to be well-behaved:

“I feel like and it’s really bad, I know… but I feel like - I can’t have two kids with problems, you know… but yeah. So that makes me wonder if he (healthy child) ever feels like he can’t be a problem, because there are already enough problems” (Mother of 11-year-old sibling).

A few parents stated that their healthy children were sometimes resentful towards the illness and consequent limitations.
“(Healthy sibling) would say sometimes ‘I wish I had a normal brother’, you know… that could do the stuff that they can’t do”’ (Mother of 11-year-old sibling).

A couple of parents also proposed that their well-children sometimes feel guilty, as a result of being spared from the illness, or participating in activities that the ill child cannot. One mother suggested:

“He has talked about feeling of guilt – that he was okay and (ill child) wasn’t” (Mother of 11-year-old sibling).

“He feels guilty, really guilty, if or when he can do something that (ill child) can’t” (Mother of 11-year-old sibling).

Interestingly, parent-reported feelings of sibling guilt were only suggested by parents of twin children, while guilt was not mentioned by the siblings themselves.

Seeing and hearing everything. Siblings and parents of chronically ill children both reported vast amounts of sibling anxiety. One mother proclaimed:

“They have been very real sort of worries, and anxieties about safety and health” (Mother of 11-year-old sibling).

These negative psychological responses seem to be greatest with regards to illness injury, for example, falling during seizures, or being unwell after consuming gluten. Consistently, this impact depends on illness severity and unpredictability. For instance, the following seizure experiences accounted by two members of the same family:
“He has seen, (ill child) broken his arm, his tooth, hit his face, so (healthy child)’s been exposed to a lot of trauma and he knows that you need to be careful. He has seen a lot…” (Mother of 11-year-old sibling).

“Sometimes when they (the seizures) went faster, he would hit his head on the ground or hit his head on a cupboard or something, and that would really worry me…” (11-year-old sibling).

Siblings of children with severe chronic illness also appear to be greatly impacted by trauma and unexpected emergencies. For example, one mother provides the following ordeal:

“This day he (ill child) had changed positions in the bath and suddenly had a seizure and fell face down. So (healthy child)’s screaming, trying to lift him and he couldn’t because he is too heavy. So incredibly traumatising, we were in there within seconds, but you know every second is a long time” (Mother of 11-year-old sibling).

Parents also noted that sibling anxiety is often high in hospitals, especially when there is an emergency, and when the sibling not kept updated about their brother or sisters health status. Below are parent and sibling examples, respectively:

“He (healthy child) sees and hears everything, and sometimes he asks why the doctors and nurses do certain things to (ill child). He is pretty protective and likes to know what is going on” (Mother of 11-year-old sibling).
“It’s pretty scary, and really busy (in the hospital). Mostly, I hang outside, but sometimes I will sit with him (ill child), so he knows I’m there” (11-year-old sibling).

Families of children with severe chronic illness are sometimes subject to near death experiences, providing a clear justification for why some siblings exhibit such negative emotional responses. One mother provides an example of her son’s exposure:

“He sat next to (ill child) in hospital when he had a drug reaction, and I thought he was dying, and he was right there where all the doctors were in the middle of crisis” (Mother of 11-year-old sibling).

Compared to sibling self-reports, parents seem to recall greater instances of trauma and negative impact.

**Making the Most of It**

Finally, all parents and siblings noted that their families are supportive, understanding, loving, and fortunate. Additionally, parents reported greater family adaptability, and a few mothers suggested that the illness has taught them a worthwhile lesson regarding life priorities.

“I think we are pretty adaptable as a family… it certainly has made us prioritise as a family about what is actually important” (Mother of 11-year-old sibling).

“It has taught us to value the small things in life” (Mother of 8-year-old sibling).
Discussion

This study explored the impact of chronic health conditions on siblings, from both parent and sibling perspectives, and revealed five primary themes and four smaller sub-themes. All siblings appeared to have some general knowledge of their brother or sister’s health condition, treatment methods, emergency procedures, illness limitations, and the negative consequences of not adhering to an illness management routine. As per parent and sibling-reports, some siblings appear to take on additional caregiving and household responsibilities, which does not seem to depend on sibling age. However, siblings expressed that they perform more tasks, while parents proposed that they would have had these regardless of illness impact. Consistent with Vermaes and colleagues (2012), parents of children with chronic illness appear to have difficulty managing their time equally between all of their children. As a result of this, some parents report sibling jealousy due to reduced parental attention, which seems to be similar across ages. Both siblings and parents equally reported wishing to be able to partake in more family activities, social outings, and holidays. However, parents noted this illness influence to be greater than sibling-reports. In conditions with more a more stable and predictable course, parents reported less illness impact on siblings after the diagnosis-adjustment period, once a family routine was established, and the illness effectively managed.

Congruent with literature, for example Bellin and Kovacs (2006), parents noted some illness-directed sibling resentment, jealousy, and guilt, however most siblings expressed no signs of the these. Research (Bellin & Kovacs, 2006; Hollidge, 2001) suggests that this may be due to children not being able to effectively articulate their feelings. Interestingly, expressions of guilt were only described by parents of twins.
Consistent with Vermaes and colleagues (2012), all parents and siblings reported some degree of sibling internalising problems, for example, anxiety and worry. In accordance with research (Limbers & Skipper, 2014; Vermaes et al., 2012), this seems to be prevalent regardless of illness type, although is likely contingent upon illness severity and stability. Sibling illness anxiety seems to be greater in older children, possibly because they are capable of fully understanding illness consequence. This is consistent with research (Limbers & Skipper, 2014; Vermaes et al., 2012), proposing that siblings younger than the chronically ill child tend to display more resilience. Furthermore, siblings describe less negative emotional concerns than parents, which may be due to limited articulation, or parents hiding illness burden from their healthy children (Sharpe & Rossiter, 2002; Wood et al., 2008). Alternatively, in line with Bellin and Kovacs (2006), it is also possible that some siblings are suppressing their negative emotions, due a pressure to be wellbehaved or not overburden their parents. The current study displays no clear difference in the degree of sibling negative emotional response, as a result of whether or not the siblings were interviewed in the presence or absence of their parent. Finally, parents and siblings report no evidence of internalising problems; concerning their own health status, isolation, or loneliness. In contrast to literature (Sharpe & Rossiter, 2002; Vermaes et al., 2012), parents and siblings proposed no indication of sibling externalising problems. Additionally, inconsistent with Hollidge (2001), no gender differences in sibling-reports of illness burden were apparent.

Parents and siblings both report similar perceptions concerning sibling relationships, although twins and siblings close in age appear to attribute more positive qualities to their relationships. Some parent-reports suggest that siblings older than the chronically ill child, appear to me more protective than siblings younger than the ill child. Consistent with past literature (Bellin & Kovacs, 2006; Vermaes et
al., 2012), parents described their well-children as more empathetic and devoted to their siblings. However, parents appeared to be more inclined to attribute these positive behaviours to the sibling’s innate personality, rather than illness impact. While on the contrary, parents appear to be more likely to attribute their healthy children’s negative behaviours (for example, anxiety) to the illness influence. Consistent with research (Strohm, 2001), some parents reported that their healthy children are more aware, respectful, and more emotionally mature, than siblings of healthy children. Parents also described that siblings are supportive and grateful, which are believed to promote family well-being (Sharpe & Rossiter, 2002).

**Limitations.** A major limitation of this qualitative study is the modest sample size, suggesting that the current results may not be generalisable to a greater population. However, the present enquiry is purely exploratory, and despite the small number of participants provides important preliminary information to help guide future investigation. Also, due to the included families selecting themselves to participate, it is possible that they may be functioning and coping at a greater level than other families with a chronically ill child. Furthermore, result generalisability was also limited by the mother and Caucasian only sample.

The current study utilised a non-categorical inclusion approach, however there appears to be difference in the degree of parent and sibling responses contingent upon illness severity and predictability. This suggests that a program designed for all diagnoses, would be required to provide an extensive range of help to cater for all forms of illness severity and stability.

Finally, this study aimed to focus on the non-consensus between parent and siblings reports, although due to ethical constraints and the nature of home visits, most siblings were interviewed in the presence of their parent. It is possible that siblings were holding back and responding according to their mother’s influence,
which may explain the minimal differences between most sibling and parent responses. Therefore, further research should source a solution to combat this limitation, for example, utilising noise cancelling headphones for parents.

**Practical implications.** Practically the current study contributes valuable research to the development of future parenting interventions. By optimising effective parenting techniques and reducing family stress, these interventions have the potential to positively impact all family members, while promoting a healthier environment. Therefore, it is possible that the chronically ill child may become more compliant with their treatment regime, the illness more manageable, and potentially less severe. The current study provides promise that parenting interventions may be designed to support siblings and chronically ill children together, and has the potential to be flexible, cost effective, and used regardless of age, sex, or diagnosis.

Additionally, the current study used a multi-informant approach and suggests some differences between parent and sibling perspectives, proposing that future research should adopt a consumer-focused perspective (Sanders & Kirby, 2012). The current findings appear to suggest that the diagnosis-adjustment period is a time of great concern for most families, recommending that treatment interventions should aim to provide suitable support during this transition.

**Future research.** Further enquiry should aim to design a parenting intervention that can cater for both chronically ill children and their siblings. This is a valuable area of research, as a program of this nature has the potential to be applied in one combined intervention, positively influencing all family members. The current study suggests, that an exploration should be commenced to determine the efficacy of parenting interventions across varied types of illness severity and stability.

Consistent with the present systematic review, an investigation is necessary to determine sibling health outcomes; concerning school functioning, academic
performance, cognitive ability, social competence, and somatic complaints. Additionally, the current study also provides no insight into sibling self-esteem, and externalising problems.

Conclusions

Families of children with chronic health conditions are at risk of a multitude of negative and positive illness consequences. The current systematic review and qualitative study highlight the paucity of research focusing on sibling health and well-being within this field. The review findings advise that greater investigation into the efficacy of pure parenting interventions is crucial. While the present qualitative study recommends that both parent and sibling perspectives are necessary with designing a suitable treatment program. Lastly, resources ought to be invested in future parenting interventions, as they have the potential to alter family dynamics, and increase the health and well-being of the chronically ill child, their parents, and siblings.
References


Doherty, F. M., Calam, R., & Sanders, M. R. (2013). Positive Parenting Program (Triple P) for families of adolescents with Type 1 Diabetes: a randomized controlled trial of self-directed teen Triple P. *Journal of Pediatric Psychology, 38*(8), 846-858. doi: 10.1093/jpepsy/jsto46


Strohm, K. (2001). Sibling project: A project in South Australia is pioneering the provision of services for siblings of children with disabilities or chronic illness -- a group whose needs are only beginning to be recognised in Australia. *Youth Studies Australia, 20*(4), 48.


### Appendix A

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<td>Authors, country, and study design</td>
<td>Participant characteristics (diagnosis type, sample size, age, gender, ethnicity)</td>
<td>Study aims</td>
<td>Parenting intervention/component characteristics</td>
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<td>Williams, Hanson, Katrin, Riddler, Liebenberg, Olen, Earnard and Tobin-Rutmaneshart (1997) USA</td>
<td>Siblings: n = 22, Age: 8-15yrs (M = not mentioned) Parents: n = 22, Age: Not mentioned (M = 5.5) Diagnosis type: Cancer, cystic fibrosis, diabetes, spina bifida Ethnicity: 92% Caucasian, 13% African-American, remaining 5% not specified</td>
<td>Obtain pilot data to evaluate ISEE (Intervention for Siblings: Experience Enhancement) a. sibling needs b. perceptions of sibling home experiences c. parent session aim to enhance awareness of sibling needs</td>
<td>Description: Structured, educational, and support group intervention with three components: educational, psychosocial, social/recreational Setting: University medical centre Format: Group sessions (parents split into two groups) No. of sessions: Sibling: educational component 5-6hrs, psychosocial component 3-4hrs, social/recreational component 3 x 15-25min (total 1.5hr) Parent: 1 x 3hr group session Duration: Not mentioned</td>
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<td>Lobato and Kao (2002) USA</td>
<td>Siblings: n = 54, Age: 6-13yrs (M = 9.8) Parents: n = 47, Age: 1-16yrs (M = 8.7yrs) Diagnosis type: Intellectual, sensory, physical, or developmental disability and/or a chronic illness – residing at home Ethnicity: 93% Caucasian (remaining not specified)</td>
<td>Obtain preliminary data regarding effectiveness of SibLink a. improving sibling knowledge of illness/disability b. sibling adjustment to chronic illness/disability c. siblings’ sense of connectedness</td>
<td>Description: Parents and siblings attended SibLink concurrent group sessions on the following psychoeducational topics: sibling knowledge, family information exchange, managing siblings’ individual needs, and balancing siblings’ individual needs Setting: Children’s hospital Format: Group sessions – average 6 siblings/group; 5-6 parents/group No. of sessions: 6 x 90 minute psychoeducational sessions Duration: 6-3 weeks</td>
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<td>Williams, Williams, Graff, Hanson, Stanton, Hoffman, Liebenberg</td>
<td>Siblings: n = 252, Age: 7-16yrs (M = 11.1) Parents: n = 252, Age: 1-16yrs (M = 9.5yrs) Diagnosis type: Cancer, cystic fibrosis</td>
<td>Obtain data to evaluate ISEE (Intervention: To increase social support, self-esteem)</td>
<td>Description: Full intervention (n = 79): structured teaching/psychosocial sessions at a 5-day residential summer camp, plus two booster sibling and parent sessions; Partial intervention (n = 71): camp only Setting: Summer camp; medical center for booster sessions</td>
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| Leukenberg, Setter, Ridder, Curry, Barond and Sanders (2003) USA | Diabetes, spina bifida, developmental disabilities
Ethnicity: 88% white; 14% non-white | b. Parent session aim to enhance awareness of sibling needs
c. Booster sessions focused on child behaviour management | c. Self-esteem
d. Mood
e. Behaviour Problems
f. Attitude Towards Illness |
|---|---|---|---|
| Lobato and Kao (2005) USA | Siblings n = 43
Age: 4-7yrs (M = 5.7yrs)
Parents n = 40
III child n = 40
Age: 1-15yrs (M = 6.1yrs)
Diagnosis type: Intellectual, sensory, physical, or developmental disability
and/or a chronic illness
- residing at home
Ethnicity: 100% Caucasian |
| Preliminary evaluation of downward extension of Lobato and Kao (2002) | Obtain preliminary data regarding effectiveness of downward extension of SIBLink on younger siblings
a. Improving sibling knowledge
b. Siblings' sense of connectedness
c. Global functioning |
| One group, pre-posttest design |
| Lobato and Kao (2005) USA | Description: Parents and siblings attended collateral and integrated (sibling-parent) group sessions, covering: sibling knowledge, identifying managing sibling emotions, problem solving, identifying sibling strengths, and balancing needs |
| Setting: Children's hospital |
| Format: Group sessions - 9 groups (averaging 5 sibling/group; 5-8 parents/group) |
| No. of sessions: 9 x 90 minute family-based group sessions |
| Duration: Not mentioned |
| Delivered by: Two doctoral level trainees in psychology (siblings) and clinical licensed psychologist (parents) |
| Control group: None |
| Assessed at baseline (within 2 weeks before) and post-intervention within following two weeks |
| Additional 3 month follow-up available |
| Sibling |
| a. Knowledge of illness/ability |
| b. Sibling Connectedness |
| c. Global Behavioural Functioning |
| Parent |
| a. Sibling Connectedness |
| b. Program Satisfaction |
| Siblings |
| • knowledge of disorder and sibling connectedness increased significantly from pre-post for boys and girls |
| • perceptions of self-competence increased from pre-post |
| • improvements of siblings knowledge and connectedness maintained at follow-up |
| Parents |
| • parent program satisfaction high |
| Giallo and Gavida-Payne (2005) UK | Siblings n = 21
Age: 6-16yrs (M = 11.30)
Parents n = 21
III child n = 21
Age: 3-14yrs (M = 10.5)
Diagnosis type: Non-categorical approach
c. Congenital heart disorders, down syndrome, autism, ADHD, polymicrogyria, Williams syndrome, and multiple illness/disabilities
Ethnicity: Not mentioned |
| Pilot evaluation |
| Randomised controlled trial design |
| Obtain preliminary data regarding effectiveness of a. Strengthening sibling coping, parenting behaviour, family problem-solving communication, family time and routines, and family hardness
d. Decreasing sibling stress, and sibling adjustment problems |
| Description: Family-based psycho-educational Siblings intervention (n = 12), including one face-to-face session, educational written information, and telephone support — simultaneous programs for siblings and parents |
| Setting: face-to-face sessions — location not mentioned, written information and telephone support — at home |
| Format: Individual families |
| No. of sessions: 1 x face-to-face session + 6 x 20-30 minute telephone sessions |
| Duration: 6 weeks |
| Delivered by: Clinician with postgraduate psychology training |
| Control group: Wait-list control group (n = 9) |
| Assessed at baseline and 2 weeks post-intervention Parents |
| a. Parent Strengths/Difficulties |
| b. Perceived Stress |
| c. Parent Behaviour |
| d. Family Hardiness |
| e. Family Problem Solving Communication |
| f. Family Time and Routines |
| g. Socioeconomic Indexes |
| Sibling |
| a. Sibling Daily Hassles and Utopias |
| b. Self-report Coping |
| c. Participant Satisfaction |
| Siblings |
| At post-intervention, the intervention group had significantly:
• lower emotional symptoms scores than the waitlist group |
• lower perceived intensity of daily hassles stress related to the III child than waitlist |
• less use of distancing coping than waitlist |
Parents/family |
| At post-intervention, the intervention group:
• reported that they engaged in more family time and routine activities than waitlist |
• most salient improvements in parent strengths/difficulties, family hardness, family problem-solving communication, reductions in perceived intensity of daily stress for siblings and perceived stress for parents |
Appendix C

The Impact of Childhood Chronic Health Conditions on Siblings

BRIEF FAMILY BACKGROUND QUESTIONNAIRE

1. Parent age (years):

2. Gender of child with chronic illness (male/female):

3. Age of child with chronic illness (years):

4. What chronic illness has your child been diagnosed with (e.g., Asthma, Eczema, etc.)?

5. How long has your child been diagnosed with that illness for (years)?

6. What is your relationship to that child (e.g., mother, father, foster mother, step-mother, etc.)?

7. Your current marital status (e.g., married, single, separated, divorced, etc.):

8. At present who lives at home with your child (e.g., parents, siblings, grandparents, etc.), including yourself? (please answer in table)

<table>
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<tr>
<th>Relationship to the Child with Chronic Illness</th>
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<tbody>
<tr>
<td>1.</td>
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9. Which ethnic of cultural group do you most strongly identify with? (e.g., Caucasian, Indigenous, Asian etc.):

10. Your highest level of education (e.g., primary school or less, trade/technical college qualification, some/completed High School, University Degree, Post-Graduate Degree, etc.):

11. Your partner’s highest level of education (if applicable) (e.g., primary school or less, trade/technical college qualification, some/completed High School, University Degree, Post-Graduate Degree, etc.):

12. What is your profession or area of employment?

13. What is your partner’s profession or area of employment (if applicable)?
Appendix D

Semi-structured Interview questions

PARENT INTERVIEW

Family functioning

- Could you tell me a bit about what life is like having a child with ________ [health condition]?
- Some families find that having a child with a chronic health condition affects other family members, sometimes in a good way and sometimes in a bad way. Other families find there isn’t an impact at all. How do you think ________ [ill child]’s [health condition] has impacted on your family?
- Extra doctors’ appointments, hospital visits, and the time it takes to manage ________ [health condition] can take up time, and disrupt normal family routines. How do you think this has affected your family on a day-to-day basis?
- How does ________ [ill child]’s [health condition] affect what activities your family does, or what sorts of places you can go together for holidays or fun?
- You’ve mentioned some ways that ________ [ill child]’s [health condition] has impacted on your family as a whole. Can you tell me about any other ways that it has impacted on ________ [sibling], in particular?
- (If ill child has been hospitalised in the past): How did ________ [sibling] cope when ________ [ill child] was in hospital?

Sibling relationship

- Can you tell me a bit about the relationship between ________ [ill child] and ________ [sibling]?
- How has ________ [ill child]’s [health condition] impacted on [his/her] relationship with ________ [sibling]? (Prompt: For example, do you think it has led to opportunities for closeness? Do you think it has led to opportunities for conflict?)
- How does ________ [ill child]’s [health condition] impact on the way that they play together, or the types of activities that they can do together?

Parent-sibling relationship

- How do you think ________ [ill child]’s [health condition] has influenced your expectations of ________ [sibling]? (Prompt: For example, does ________ [sibling] take on more responsibilities than [he/she] otherwise might?)
- Caring for a child with a health condition can be time consuming, and parents can find it hard to divide their attention between their children. How have you managed this with ________ [sibling] and [ill child]?

Sibling wellbeing

- Do you think ________ [sibling] ever feels anxious, or worried about ________ [ill child]’s [health condition]?
- As a result of experiencing their brother’s or sister’s health conditions on a daily basis, some siblings start to worry about their own health. Do you ever think that ________ [sibling] is concerned about [his/her] health, or worries about developing an illness [himself/herself]?
- Do you think that ________ [ill child]’s [health condition] has impacted on ________ [sibling]’s emotional adjustment at all? (Prompt: For example, do you ever think that ________ [sibling] is more empathetic, caring or patient, as a result of having a [brother/sister] with [health condition]?)
- (Prompt: Do you ever think that ________ [sibling] is resentful, or feels jealous of ________ [ill child]? Why?)
Conclusion

- What is the best thing about your family?

Thank-you for your time. Is there anything else you’d like to add/share?

SIBLING INTERVIEW

Illness and illness management

- Your [Mum/Dad] told me that ___________ [ill child] has ___________ [health condition]. What is ___________ [health condition]? What does ___________ [ill child] have to do for [his/her] ___________ [health condition]?

- Being ______ [ill child]’s [brother/sister] has made you a real expert on ______ [health condition]. What’s the most important thing I should know about ______ [health condition]?

- What does your Mum/Dad have to do to look after ______ [ill child]’s ___________ [health condition]?

- Do you help to look after (or “watch out” for) ______ [ill child] because of [his/her] ______ [health condition]? What do you do to look after (or “watch out for”) [him/her]?

- Do you think that you have to do more chores and help around the house because ___________ [ill child] has ______ [illness]? What do you do to help out?

Sibling relationship

- What kinds of things do you and ______ [ill child] like to do when you’re playing together?

- When you and __________ [ill child] are playing together, does [his/her] __________ [health condition] ever get in the way of what you are doing/playing? How?

Impact on family functioning/routine

- When Mum/Dad take ______ [ill child] to the doctor or for a visit to the hospital, do you go too? What do you do?

- (If ill child has been hospitalised in the past): Try to remember back to when ___________ [ill child] had to go into hospital because of [his/her] ___________ [health condition]. What was that like?

- Are there any family things that other families do that your family can’t do because of ___________ [ill child]’s ___________ [health condition]? What are they?

Sibling wellbeing

- Does it bother you that ______ [ill child] has ______ [health condition]? What bothers you?

- Do you ever feel sad, or worried, or scared about ___________ [ill child]’s ___________ [health condition]?

- Did you ever worry that you might get ___________ [health condition] too?

- Is there anything good about having ___________ [health condition]?

- Do you ever wish you had ___________ [health condition]? Why?

Conclusion

- Imagine that you had a magic wand, and that you could make ___________ [ill child]’s ___________ [health condition] disappear. What would be the best thing about that?

- What’s the best thing about your family?