The Development of a Psychosocial Intervention that Supports Siblings of Children and Adolescents with Serious Chronic Health Conditions in Aotearoa New Zealand

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ABSTRACT

Due to recent advances in medical care, many childhood chronic health conditions (CHCs) are less likely to be fatal and more able to be successfully managed. This has led to an increase in the prevalence of children living with CHCs, which presents the affected child, their parents, and their siblings with significant long-term consequences and challenges.

Extant literature points to siblings of children with CHCs being a vulnerable population who are at increased risk of developing depression, anxiety, post-traumatic stress symptoms, lower quality of life, and disruption to academic and social functioning. Consequently, there have been calls for the development of sibling support services both in Aotearoa New Zealand (New Zealand) and internationally. Recent needs-based research on siblings of children with cancer and other serious CHCs in New Zealand reported critical unmet needs across the following domains: Information about the illness; Dealing with feelings; Time out and recreation; Support from friends and other young people; Understanding from their family; and Relationship with their affected sibling. These findings emphasise the necessity of a nationwide intervention that provides siblings with support close to the time of their brother's or sister's diagnosis.

The aim of the present study was to develop a needs-based psychosocial intervention for siblings of children with serious CHCs, which protects and promotes the health and wellbeing of this vulnerable population and recognises their existing individual and familial strengths. A literature review was conducted to investigate the impact serious childhood CHCs have on siblings, and to establish whether the commonalities in sibling experiences justify taking a transdiagnostic approach in the development of a sibling intervention. This was followed by a systematised review of existing sibling interventions and an evaluation of their efficacy. Informed by the two major reviews and existing needs-based sibling research, a manualised intervention was developed to meet the self-reported unmet needs of siblings, using a combination of evidence-based therapeutic modalities.

ACKNOWLEDGEMENTS

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My heartfelt appreciation goes to the late Dr. John Williams, Clinical Psychologist, whose care and support when our family was affected by serious illness changed the course of my life and inspired me to pursue a path where I could offer others the same kind of support he offered me.

To my dear friends, thank you for your many kindnesses, your patience, and your encouragement. Our chats, dinners, adventures, and "jalks" have sustained me, and I have loved our celebrations of each and every milestone, no matter how small.

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CHAPTER 1: INTRODUCTION

This introductory chapter describes the background context to this doctoral study and states the research aims and scope. It then describes the theoretical frameworks that provide the broader context of sibling experiences and summarises the sibling research that has been carried out in - Aotearoa New Zealand (New Zealand). The chapter finishes with a brief description of two contrasting approaches to sibling interventions, transdiagnostic and diagnosis-specific, and outlines the structure of the thesis.

Background context to this research

The impetus for this study came from my lived experience as a sibling which has given me a unique perspective on the impact childhood chronic health conditions (CHCs) can have on siblings. My personal experience of receiving the psychological support I needed as a child, and the positive impact it had on my life, motivated me to study psychology. This research project has been a long-term goal through which I hope all siblings who reside in New Zealand will receive the support they need to adjust to the significant life changes the diagnosis of a childhood CHC brings.

CHCs refer to a range of mental, physical, or emotional conditions that are defined by their prolonged duration, interference with normal activities, and where spontaneous resolution does not occur (Compas et al., 2012). The number of children (defined as being below 18-years old) living with these conditions has increased dramatically in recent decades. This is partly due to medical advances in the diagnosis and treatment of paediatric chronic conditions, which has led to increased survivorship of once fatal childhood diseases (Compas et al., 2012; Halfon & Newacheck, 2010; Sawyer et al., 2007), and partly due to an increase in childhood incidences of CHCs (Denny et al., 2014; Sawyer et al., 2007).

While accurate estimates of the prevalence of CHCs are elusive due to differences in the criteria used to define and categorise a CHC, it has been estimated that chronic conditions affect between 10 – 30% of children worldwide (Consolini, 2020). In New Zealand, Denny and colleagues (2014) reported almost 20% of secondary school students live with a CHC and this prevalence is only expected to increase (Compas et al., 2012). These conditions present the affected child, their parents, and their siblings with significant long-term consequences and challenges.

Literature that investigates the impact of childhood CHCs on siblings is compelling. Research has consistently found that the family environment is altered when a child is diagnosed with a CHC; the focus of the family centers on the affected child, which leads to a reduced capacity for meeting the needs of siblings (Cohen et al., 1994; Houtzager, Oort, et al., 2004; Janssens et al., 2010; Long et al., 2018; Murray, 2002; Neville et al., 2016). While there is considerable heterogeneity in methodologies (making it challenging to synthesise findings and draw overarching conclusions), it is clear there is a subgroup of siblings who experience significant psychosocial adjustment problems; in particular, anxiety, depression and post-traumatic stress symptoms (Alderfer et al., 2010; Long, Marsland, et al., 2015; Sharpe & Rossiter, 2002). It is important these negative impacts are reduced as they can lead to long-term mental health problems (Kessler & Wang, 2008) and lower quality of life (Sawyer et al., 2001).

Despite the growing body of evidence pointing toward the potential negative impacts of CHCs on siblings, the needs of siblings are currently inadequately met and seldom addressed. Consequently, there have been calls for the development and delivery of targeted support services that will protect this vulnerable population (Gerhardt et al., 2015; Havermans, 2015; Long, Marsland, et al., 2015).

Following the identification of a gap in psychosocial support available to siblings of children with serious CHCs who reside in New Zealand, the author and her primary supervisor developed a proposal for a two-part research project that addresses this gap.

Research Aim and Scope

The Overarching Research Aim for my Sibling Research is:

To develop a needs-based psychosocial intervention for siblings of children with serious CHCs in Aotearoa New Zealand. This will be completed in two separate studies: a master's thesis (Part 1) and a doctoral thesis (Part 2).

Part 1: Master's thesis (Completed in 2020)

Research Aim:

The aim of the study was to identify the unmet needs of siblings of children with cancer, diabetes mellitus, and cystic fibrosis in New Zealand. This was achieved by conducting a study which produced specific needs-based information in the form of a direct index of the self-reported unmet needs of siblings of children with serious CHCs (Armstrong, 2020). The results of the study emphasised the urgent need to develop targeted support services that aim to protect the health and wellbeing of siblings and provided valuable, needs-based information that will underpin the development of a psychosocial intervention for siblings of children with serious CHCs living in New Zealand. Findings showed:

- high levels of unmet needs across all three health conditions;
- strong similarities across the three health conditions;
- some differences between health conditions, age and gender;
- siblings of children with cancer reported similar types of unmet needs, but higher levels when compared to an Australian study of siblings of children with cancer.

The quantitative analysis detected statistically significant differences in the levels of unmet needs of siblings of children with cancer compared with siblings of children with Cystic Fibrosis (CF) and Type 1 Diabetes Mellitus (T1DM). However, the qualitative results showed the types of unmet needs between the three health conditions had strong similarities, particularly in the areas of needing information and support, the importance of sibling relationships, and the family's ability to understand and support the needs of siblings (Armstrong, 2020).

Findings supported the argument for the development of a transdiagnostic intervention for siblings of children with serious health conditions that are broadly similar in illness severity, illness intrusiveness, and familial burden (Armstrong, 2020).

Part 2: Doctoral thesis (Current study)

Research Aim:

The research aim for the current study was to develop a needs-based psychosocial intervention for siblings of children and adolescents with a serious chronic health condition (CHC) that maps directly onto the self-reported unmet needs identified in the master's thesis. While the applicability of international research to siblings in New Zealand has yet to be established, initial indications suggest siblings in New Zealand experience more problems with negative adjustment than siblings studied in the international literature (Armstrong, 2020; Dobson et al., 2007; Riddick, 2013). The present thesis will develop an intervention that is targeted to the specific needs of siblings within a New Zealand cultural context, with the aim of offering this intervention nationwide.

To achieve this aim, three research questions were asked.

Research Questions:

RQ1: What interventions have been developed internationally for young people who have a sibling with a CHC?

RQ2: Which of these interventions have been evaluated and to what extent were the expected outcomes of the intervention achieved?

RQ3: What information from this review of interventions is important to consider in the development of a psychosocial intervention for siblings who reside in New Zealand?

Methodology/Approach

A two-stage approach was taken to address these questions, comprising a systematised review and the development of a Manualised Sibling Intervention.

A systematised review was conducted to identify interventions that have been developed for siblings of children with serious CHCs. Findings from these studies were evaluated, synthesised, and used to inform the development of a psychosocial sibling intervention for siblings who reside in New Zealand. The intervention draws upon evidence-based therapeutic techniques to meet the self-reported needs of siblings across the following domains: Relationship with their ill sibling; Understanding from their family; Support from friends and other young people; Dealing with feelings; and Information about their sibling's health condition.

The theoretical approach and methodology are detailed in Chapters 5 and 6.

Theoretical Framework

The experiences of family's who live with childhood CHCs need to be considered within their broader sociocultural context. This section discusses key theoretical frameworks that underpin this doctoral research.

Socio-ecological Model

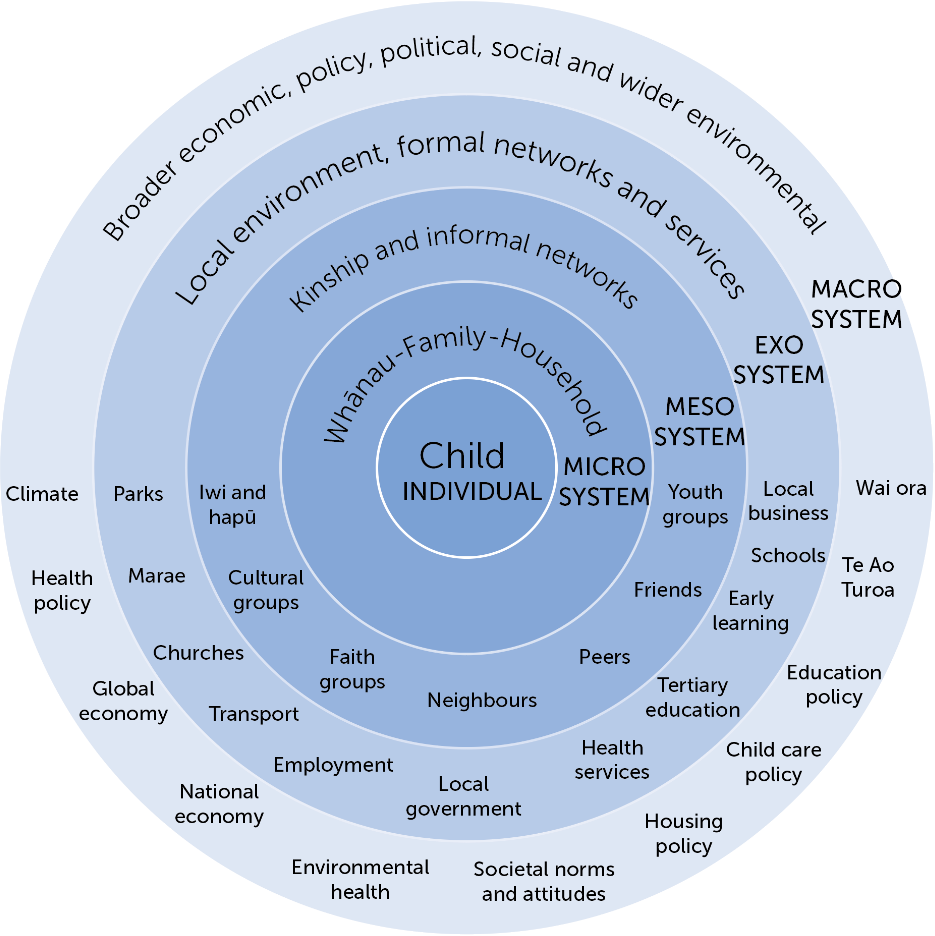
An important consideration when reviewing the literature on siblings of children with CHCs is that the experiences of siblings operate within a broader cultural context. Differences in service provision, cultural norms, and the accessibility and quality of sibling support services mean siblings' experiences are strongly influenced by the country they reside in. Hence, it is important to ensure that the broader influences on siblings are understood and acknowledged within research speaking to this population.

The socio-ecological model enables this by taking a holistic perspective which considers young people within the context of larger, interdependent social systems of influence (Bellin et al., 2009). As illustrated in Figure 1, this model places the child at the centre of concentric circles of influence and captures the impact of multiple layers of child adjustment, highlighting the potential impacts of larger societal and cultural values on the child (Bronfenbrenner & Hickey, 2004).

Understanding risk and protective factors for siblings of children with CHCs requires considering the child's broader context, as these factors span across individual, family, and societal levels (often simultaneously). Framing this research within a socio-ecological model highlights the ongoing interactions among the child, family, and various systems, including medical, educational, and social services (Kazak, 1989).

Figure 1

Socio-ecological Model



Note. Adapted from “Changing to Organize,” by K. Bronfenbrenner & R. Hickey, 2004, in *Rebuilding Labor: Organizing and Organizers in the New Union Movement* (p. 17). Copyright 2004 by Cornell University Press. Licensed under CC BY 4.0.

Additional considerations of the broader influences on siblings’ lives, which can be specific to their cultural context, include: the marginalisation of families with paediatric CHCs (DiNapoli & Murphy, 2002; Futcher, 1988); demographic factors such as lower socio-economic group status and minority group status, which have been associated with greater family needs (Farmer et al., 2004);

and perceived levels of social support which are associated with child health outcomes (Kazak, 2001). The Meihana Model, which is a hauora[1] Māori clinical guide for psychologists (Pitama et al., 2017), highlights the importance of considering the specific cultural context within New Zealand (Figure 2). Siblings who identify as Māori may have different needs than non-Māori siblings due to the different broader influences of colonisation, racism, migration, marginalisation, and cultural and spiritual beliefs (Pitama et al., 2017).

Figure 2

Meihana Model

Note. From "The Meihana Model: A Clinical Assessment Framework*,"* by S. Pitama, T. Huria, & C. Lacey, 2014, *Journal of Primary Health Care, 6*(3), p. 252. Licensed under CC BY-NC 3.0.

Family Systems Theory

The impact of a childhood CHC on siblings can be further understood through the lens of General Systems Theory (Bertalanffy, 1968). Derived from physics and biology, this theory asserts that a system is an interacting set of parts that make up a whole organisation; consequently, each part of the system is affected by what the other parts do (Bertalanffy, 1968). The family systems approach

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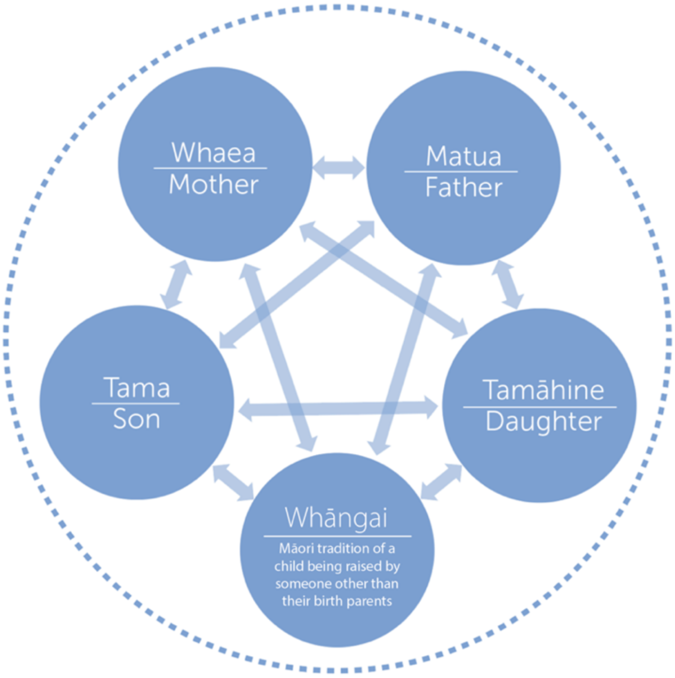
[1] Māori word for health

provides a theoretical framework to investigate family functioning following the diagnosis of a paediatric CHC.

The family is a complex system in which the actions of each family member have the potential to influence each other both directly and indirectly (Gannoni & Shute, 2010; Lamb et al., 2014). A major health crisis (such as the diagnosis of a childhood CHC) is a profoundly stressful experience which impacts every family member individually and can destabilise the structure and functioning of the family. Because family members are interrelated, each individual affects all of the others, and the group as a whole (Figure 3), in an ongoing chain of mutual influence (Rolland, 2018). Naturally, this has major implications for the child with the health condition *and* the sibling/s of that child. The development of significant mental and physical changes in the affected child affects the family unit; in turn, this change in family atmosphere influences the health and therapeutic course of the affected child (Sholevar & Perkel, 1990).

Figure 3

Family Systems Model



Note. Adapted from “General System Theory: Foundations, Development, Applications,” by L. von Bertalanffy, 1968. Copyright 1968 by George Braziller Inc.

Paediatric CHCs have thus been conceptualised as a ‘family affair’ (Knecht et al., 2015). During the course of the condition, family members actively participate in multiple areas of the child’s care including physical, biomedical, social, psychological, institutional, and rehabilitational health domains (Toledano-Toledano & Luna, 2020). This can be all-consuming and particularly challenging when family members vary in their beliefs around how to view and approach illness.

For siblings who align with their family’s approach, this can help them feel included and increase their sense of family cohesion; however, there can be repercussions for siblings who do not fit with their family’s approach (Deavin et al., 2018). For example, in the family that discourages discussion about the illness (often to protect others or because it is too painful), siblings who want information about the health condition, or who wish to address their emotions, can feel isolated and unable to express their needs (Deavin et al., 2018). The hierarchy of the family system is governed by parental beliefs; not all family members have equal power and voice. Siblings who are also children and not perceived as being in urgent need, can find that their voices are ignored and suppressed by the adults around them (Deavin et al., 2018). Hence a family’s ability to adapt its structure, relationships, roles, and communication patterns in response to a child’s CHC is critical to managing the demands and pressures such a diagnosis brings for all members of the family (Branstetter et al., 2008).

Research has recognised that siblings’ sense of responsibility and capacity for active engagement in family coping could potentially be an untapped resource for supporting family adaptation and management (Havill et al., 2019). Programs providing sibling support or family interventions are central to protecting siblings’ emotional wellbeing (Strohm, 2008), and (from a systems theory perspective) can have a positive influence on all family members.

Transdiagnostic versus Diagnosis-specific Approach to Sibling Interventions

Within the field of sibling literature, there has been ongoing discussion about whether paediatric chronic health should take a diagnosis-specific or transdiagnostic approach. The justification for a transdiagnostic approach is that there are multiple commonalities in the experiences of families who have a child with a serious chronic illness such as the burden of care over a long period of time, the impact on the affected child's siblings and parents, and the strain on physical, financial, and emotional resources (Stein & Jessop, 1982). The counter argument is that the illness-specific factors that influence siblings' experiences lead to different needs, and require interventions tailored to meet those needs (Havermans et al., 2015). The review of existing literature, discussed in Chapter 4, carefully considered the evidence finding compelling arguments for both these approaches.

Structure of Thesis

Chapter 1 – Introduction

This chapter introduces the aims and scope of this doctoral study. The structure of the thesis is outlined, and the theoretical framework is discussed.

Chapter 2 – Paediatric CHCs

Key characteristics of four serious paediatric CHCs are reviewed, including the prognosis, prevalence and daily treatment routines. This provides an orientation to CHCs and the challenges families face following the diagnosis of a serious CHC.

Chapter 3 – Literature Review

This chapter reviews the international literature on siblings and investigates the impacts CHCs have on the different domains of sibling's lives, including their: emotions, relationships, family functioning, and school life. Variables that moderate sibling adjustment are then discussed to consider whether any of these variables could be targeted in a sibling intervention to improve sibling outcomes.

Chapter 4 – Research Aims and Design

Important considerations in the development of an intervention for siblings are discussed beginning with the argument for taking a transdiagnostic approach to sibling interventions. This is followed by a discussion about knowledge translation in the health sector and the importance of developing an intervention that responds to the self-reported needs of the target population.

Chapter 5 – Theoretical Approach

The research theoretical orientation and methodology is presented in this chapter. This includes a discussion on the methodological approach selected for this doctoral study. The methods used to answer the research questions are described and the approach to data analysis is outlined.

Chapter 6 – Systematised Review: Interventions for Siblings of Children with CHCs.

The methodology chosen to answer the research questions (systematised review) is described followed by the details of the search strategies used. An overview of selected sibling interventions is provided in table form and the characteristics and findings of each intervention are presented. Intervention theoretical orientations are then identified and described.

Chapter 7 – Synthesis of Systematised Review Findings

This chapter synthesises the reviewed intervention's outcomes on the variables of interest to enable the identification of the intervention characteristics that are most effective. Key considerations for the development of a psychosocial sibling intervention are then identified and discussed.

Chapter 8 –Implications of Review Findings

Discussion of how the systematised review findings relate to the sibling literature and the self-reported unmet needs of siblings in New Zealand. The chapter then highlights how the implications of this information will inform the development of a psychosocial sibling intervention that meets the self-reported needs of siblings who reside in New Zealand.

Chapter 9 – Development of the Sibling Needs Intervention

Following a discussion of the theoretical principles of the Sibling Needs Intervention this chapter then describes how key findings from the systematised review, the existing literature, and clinical experience, are synthesised to inform how the Sibling Needs Intervention will address the self-reported unmet needs of siblings who reside in New Zealand. The chapter will discuss the development of two of the four Siblings Needs intervention sessions including: Session 2 (Dealing with difficult feelings), and Session 4 (Hope for the future).

Chapter 10 – Summary and Next Steps

This chapter provides a brief summary of this research project and indicates future directions.

CHAPTER 2: LITERATURE REVIEW

This chapter will firstly review the literature looking more broadly at the impacts of childhood chronic health conditions (CHCs) on siblings. It will then review the literature on the impacts of four CHCs that are at the more severe end of the continuum of severity, and therefore, arguably, have the greatest impacts on siblings' lives: Type 1 diabetes mellitus, cystic fibrosis, cancer, and congenital heart disease. The characteristics of each chronic health condition will be outlined (including the prognosis, prevalence and daily treatment routines) to provide an orientation to CHCs and the challenges families face following the diagnosis of a childhood chronic health condition.

The Impacts of Childhood CHCs on Siblings

A review of the literature on siblings of chronically ill children conducted almost forty years ago found siblings are a 'population at risk' (McKeever, 1983). In 1985, a review by Hannah and Midslarsky supported the view that siblings of children with chronic illness are a population at risk of experiencing psychological difficulties. Similarly, a meta-analysis investigating the psychological functioning of siblings of children with chronic illness (from studies published between 1976 and 2000) found a statistically significant and negative overall effect for having a sibling with a chronic illness (Sharpe & Rossiter, 2002). The authors speculated that siblings of children with a chronic illness experience an increase in frustration due to care-giving demands and parental inattention, which they may find difficult to express to their parents due to the precarious state of their unwell sibling. The authors concluded that intervention programs for siblings of children with chronic illness should be developed (Sharpe & Rossiter, 2002).

More recently, Vermaes and colleagues (2012) sought to build upon the existing literature by conducting a systematic review which included thirteen additional studies to Sharpe and Rossiter's (2002) meta-analysis. Findings showed a relatively stable negative effect of chronic illness on siblings, which was almost identical to the original meta-analysis (Sharpe & Rossiter, 2002). The review also found siblings of children with a more intrusive and/or life-threatening chronic illness to be at greater risk of developing psychological problems and that siblings were more at risk of developing internalising problems (such as depression and anxiety) than externalising problems (Vermaes et al., 2012). The authors concluded that future research should involve the development of evidence-based sibling coping programs, especially targeted at high-risk siblings (Vermaes et al., 2012).

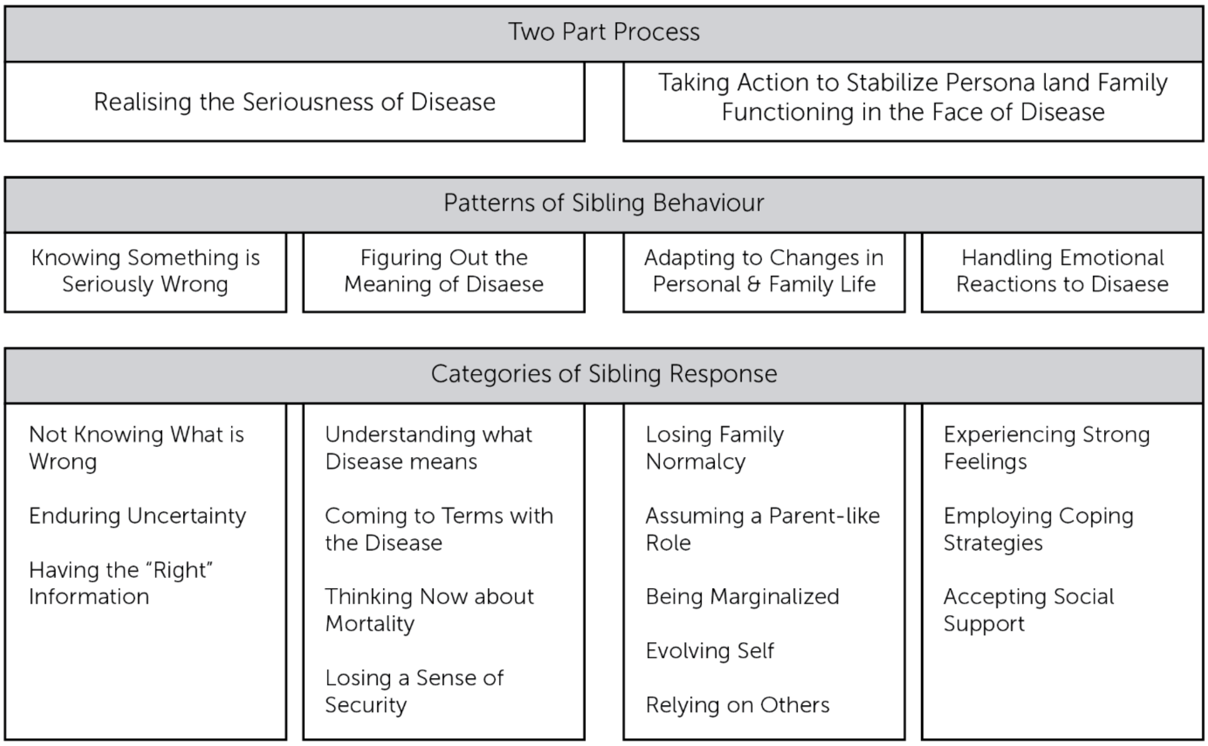
Further large-scale reviews that have examined the psychosocial functioning of siblings of children with CHCs have found post-traumatic stress symptoms (Ingerski et al., 2010); somatic symptoms and internalising problems (Incledon et al., 2015); lower scores reported on quality of life measures (Knecht et al., 2015); an increase in low mood (Hartling et al., 2014); and adjustment problems following a child's diagnosis (Vermaes et al., 2012). A review by Knecht and colleagues (2015) investigated the perspective of siblings of children with chronic illness. Applying a transdiagnostic approach to chronic illness (including siblings of children with cancer), the aim was to identify the unacknowledged issues concerning siblings' experiences. Findings showed: siblings can feel overwhelmed with highly diverse emotions; siblings of children with cancer seem to be concerned about their own state of health; some evidence of lower self-concept; changes in sibling and parent bonds; and evidence of social isolation and withdrawal (Knecht et al., 2015). The authors expressed considerable concern that much of the literature has relied on the etic perspective of adults acting as proxies for siblings, which can lead to a distorted perception of sibling perspectives (Knecht et al., 2015).

A recent meta-synthesis on siblings' perspectives of living with a child with a CHC (excluding cancer), analysed the qualitative literature that focused on psychosocial experiences across chronic illnesses (Deavin et al., 2018). With the objective of producing a synthesis that unified siblings' experiences across conditions, the researchers explored the factors that influenced siblings' emotional wellbeing. Findings highlighted that following the diagnosis of a childhood CHC siblings alter their behaviour to support their own needs and those of their family. This emotional self-sufficiency can lead parents and healthcare professionals to perceive siblings as functioning and coping well, leading to their needs being overlooked. Siblings reported that worrying about their affected brother or sister was pervasive and some recognised this worry negatively impacted their concentration at school and other areas of their life. Other negative emotions reported by siblings were jealousy due to parental inattention, loneliness as a result of peer and familial isolation, and feelings of 'survivor guilt' (Deavin et al., 2018). The authors discussed siblings' concerns regarding the necessity of meeting their own needs in a way that is concordant with their family's needs, and their inability to discuss their feelings due to gaps in communication within their support systems. These experiences potentially lead to the clinical symptoms that are often reported as maladjustment, including mood changes, somatic complaints, attention seeking, and rebellion (Deavin et al., 2018).

Another synthesis of qualitative studies on sibling's experiences used a grounded theory framework called 'Creating a Tenuous Balance' (CTB) which was originally developed by Long and colleagues (2015) to conceptualise the experiences of siblings' of children with cancer. This framework was broadened and named 'Revised Theory of Creating a Tenuous Balance' (see Figure 4) to include siblings' experiences of childhood chronic illness (Havill et al., 2019). CTB included three levels of thematic analysis The first level and the central organising theme is a two-part process of (a) realising the seriousness of the condition and (b) taking action to stabilise family functioning in the face of the disease. The next level includes four patterns of sibling behaviour: (a) knowing something is seriously wrong; (b) figuring out the meaning of the disease; (c) adapting to changes in personal and family life; and (d) handling emotional reactions to the disease. The third level of the CTB model is comprised of fifteen emotional and behavioural responses of siblings that demonstrate the second level responses (Havill et al., 2019).

Figure 4

Revised Theory of Creating a Tenuous Balance



Note. From "Well siblings of children with chronic illness: A synthesis research study," by N. Havill, L. K. Fleming, and K. Knafl, 2019, *Research in Nursing & Health*, 42(5), (https://doi.org/10.1002/nur.21978). Copyright 2019 by Wiley Periodicals, Inc. Reproduced with permission.

The findings from Havill and colleagues' (2019) research demonstrated multiple commonalities in sibling experiences (these findings are discussed further in the following sections). The concept of the tenuous balance captures the experiences of siblings and reflects their challenges in understanding their affected sibling's condition, how they adapt to those changes, strong emotional reactions, and changes in family life (Havill et al., 2019).

Havill and colleagues (2019) echoed multiple calls in the literature for further research to be carried out on siblings' experiences, alongside the development of sibling interventions that recognise siblings needs areas across the domains of providing information, developing coping strategies, and fostering emotion management. This will not only protect this vulnerable group of siblings but also enhance wellbeing and functioning of siblings as a potentially untapped resource for supporting family adaptation (Havill et al., 2019).

Characteristics of Individual Childhood CHCs and their Impacts on Siblings

Type 1 diabetes mellitus, cystic fibrosis, cancer, and congenital heart disease are representative examples of serious paediatric chronic health conditions (CHCs). These conditions are characterised by their chronic nature, potential risk of mortality, and substantial impact on family life. As such, they offer valuable insight into the experiences of siblings of children living with significant health challenges. This section provides a concise overview of these conditions, including their prevalence, prognosis, daily treatment routines, and the impacts they may have on siblings. This contextual background is intended to inform the reader about the broader circumstances that shape sibling experiences in families affected by CHCs.

Cancer

Cancer is an umbrella term for a number of related diseases, but in all types, onset occurs when body cells divide without stopping. These cells spread into surrounding tissue or form tumours (Weinberg, 1996). While different types of cancer vary in their levels of severity, the label of ‘cancer’ is strongly associated with a life-threatening illness, hence the *perceived* level of severity of cancer (regardless of type) is likely to be very high.

Prevalence

Data reported by the New Zealand Children’s Cancer Registry shows the most common cancer registrations for children under the age of 15-years old, between 2010 and 2014, were leukemias (33.3%), tumours of the central nervous system (20.7%), and lymphomas and reticuloendothelial tumours (10.8%; Ballantine et al., 2017).

An analysis of childhood cancer incidence and survival in New Zealand between 2010 and 2019, found 1522 new children (aged between 0-14 years old) were diagnosed with cancer in that period. In 2022 alone there were 216 registrations of paediatric cancer in New Zealand (C. Lewis, personal communication, October 3, 2024).

Prognosis

The survival rate of childhood cancers has increased significantly in the past 30 years, with the most recent New Zealand data showing the five-year survival rate for children aged between 0 – 14 years old was 85.6% (Pugh et al., 2023).

However, this survival rate is associated with aggressive treatment regimens which can cause serious side effects, including fatigue, loss of appetite, mucositis, and gastrointestinal symptoms, that need symptom management (Branstetter et al., 2008).

Daily Treatment Routines

Because each of these diagnostic groups (leukemias, brain cancers, lymphomas, and solid tumours) in addition to the multiple cancers that make up the remaining 35% of childhood cancers, have different causes, treatments, and prognoses, types of treatment and daily regimens vary significantly. However, the most common treatments for cancer are chemotherapy, cortico-steroid therapy, radiation therapy, bone marrow or stem-cell transplants, and surgery (Burgel et al., 2015).

The daily treatment for Acute Lymphoblastic Leukemia (ALL; the most commonly diagnosed childhood cancer in New Zealand) has a significant impact as it is intensive and long-term, typically taking between two to three years to complete (Kato & Manabe, 2018). Treatment begins with an intensive course of chemotherapy aimed at inducing a remission; this is known as the induction phase, and typically lasts for one month (Kato & Manabe, 2018). This initial stage of treatment requires specialist care that is only available at specialised child cancer units; hence, children are admitted to hospital for part, or all, of this treatment. In New Zealand, all children under 15-years old, and some older teenagers, receive chemotherapy by a multidisciplinary team at one of two specialist paediatric cancer units, Starship Hospital in Auckland (North Island of New Zealand), or Christchurch Hospital in Christchurch (South Island of New Zealand; Ballantine et al., 2017).

The second phase of treatment is consolidation therapy which typically lasts for several months (Kato & Manabe, 2018). Chemotherapy treatment alongside courses of cortico-steroid therapy, helps prevent the disease from relapsing or spreading to the central nervous system and is usually the most intense phase. For some high-risk children a stem cell transplant might also be an option at this stage. Consolidation therapy protocols vary depending on the estimated risk of relapse in the future (Kato & Manabe, 2018).

The third phase of treatment is maintenance therapy, which begins if the ALL remains in remission after induction and consolidation and is designed to keep the disease in remission and prevent relapse (Kato & Manabe, 2018). A common protocol of maintenance therapy involves daily chemotherapy (given either orally and/or intravenously) alongside monthly courses of cortico-steroid therapy. When necessary, intrathecal injections of chemotherapy will be given periodically to prevent disease relapse in the central nervous system (Cooper & Brown, 2015).

The side effects of these treatments are common, can be severe, and require intensive daily management particularly during the remission induction and consolidation phases. Hair loss, mucositis, diarrhoea, constipation, nausea and vomiting, loss of appetite, fatigue and seizures are common side effects of chemotherapy drugs. Children respond differently to cortico-steroid treatment, but common side effects include an increased appetite, fluid retention, weight gain, sleep disturbance, mood swings, anxiety, restlessness and nightmares. Increased susceptibility to infections and high blood pressure are also common side effects (Leukemia Foundation, n.d.)

Impacts on Siblings

Of the CHCs, the impact of a childhood cancer diagnosis on the affected child's siblings has been the health condition most studied.

Alderfer is a leader in the field of psychosocial child cancer research who has investigated the psychosocial adjustment of children with cancer and their families for over 25 years. In 2010, Alderfer co-authored a systematic review of 65 qualitative, quantitative, and mixed methods papers on the psychosocial adjustment of siblings of children with cancer (Alderfer et al., 2010). Data were collected from a variety of countries, cultures, socioeconomic groups, and health systems. Findings revealed that while most siblings are well-adjusted, there is a significant subset of siblings who experience poorer quality of life, emotional functioning problems, and post-traumatic stress symptoms when compared to the normative population (Alderfer et al., 2010). The findings of the qualitative analysis showed siblings experience disruptions in normalcy and their sense of security, loss of attention and status within the family, and changes in family roles and relationships (Alderfer et al., 2010).

In 2018, Alderfer co-authored an updated large-scale systematic review which summarised the literature since 2008 and included 102 quantitative, qualitative, and mixed method studies (Long et al., 2018). Findings showed siblings reported no significant difference in emotional and behavioural functioning than the normative population; however, one quarter of siblings met clinical criteria for post-traumatic stress disorder, and two-thirds of siblings endorsed moderate to severe levels of post-traumatic stress symptoms (Long et al., 2018).

Seven categories of major changes were identified in this extensive review (Long et al., 2018). The first category to be reported was ‘emotional changes’ in which the following emotions were reported: shock, fear, uncertainty at the time of the child’s diagnosis; anger and jealousy throughout the treatment period due to parental inattention; anxiety (especially when waiting for an accurate diagnosis); depression, fear, and isolation during the course of the illness; and loss of identity and feelings of uncertainty throughout the cancer experience. Grief and guilt were also reported by siblings as they watched their affected sibling undergo physical changes during treatment and lose the ability to engage in their usual activities (Long et al., 2018).

Changes in relationships were also prevalent in this literature review, with siblings commonly reporting changes in every significant relationship in their lives (peers, friends, parents, and their affected sibling; Long et al., 2018). Changes were identified and analysed in the following areas: family and home life (leading to a disrupted sense of normalcy); school life (including social and behavioural changes and concentration difficulties); and extracurricular activities (having less time to spend on these activities, decreased performance levels, and lack of interest). Finally, ‘psychosocial and physiological impact’ and the ‘need for information’ were also experienced by siblings. The authors concluded that despite the methodological limitations of the reviewed studies, there is a strong need for sibling psychosocial support and for identifying siblings who are at risk of poor psychosocial adjustment (Long et al., 2018).

A recent integrative review on sibling responses to childhood cancer used Meleis' Transition Theory as a framework for understanding the holistic experiences of siblings (Weiner & Woodley, 2018). Meleis' Transition Theory asserts there are four types of life transitions: developmental; situational; organisational; and health/wellness (Meleis, 2010). According to Transition Theory, adolescent siblings whose brother or sister is diagnosed with cancer, experience an intersection of simultaneous transitions - a health/wellness transition as a result of the diagnosis, a situational transition as family life changes and adjusts, and a developmental transition as they navigate the complexities of adolescence (Meleis, 2010).

In their review, Weiner and Woodley (2018) identified seven categories of major changes which broadly encompass the findings of the previous reviews discussed and involve all of the significant areas of a sibling's life, including: an array of emotional changes; relationship changes; family and home life changes; school life changes; extracurricular activity changes; psychosocial and physiological impact; and the need for information and special desires. They also found siblings demonstrate personal growth and resilience and find ways to problem-solve and cope (Weiner & Woodley, 2018).

Type 1 Diabetes Mellitus

Type 1 Diabetes Mellitus (T1DM) is an endocrine disorder characterised by high blood glucose levels due to defects in the body's ability to produce insulin (Katsarou et al., 2017). In a person without T1DM, when carbohydrate foods enter the body glucose levels rise and the pancreas releases insulin which allows glucose to enter body cells where it is used for energy. In a person with T1DM, the beta cells in the pancreas cannot produce insulin because they have been destroyed by the body's immune system (Katsarou et al., 2017)

Hyperglycemia is a complication of T1DM and occurs when the body's cells do not receive the glucose needed for energy and they resort to breaking down other bodily tissue such as muscle and fat stores to provide energy instead. If this occurs too often, it can lead to a build-up of ketones which are a type of acid that is produced when the body burns fat for energy instead of glucose (Edge et al., 2001). This build-up can lead to diabetic ketoacidosis (DKA), a serious and life-threatening complication of diabetes that causes blood-glucose levels to stay high. DKA is associated with various adverse outcomes, including cerebral oedema, which is the most common cause of mortality in children with insulin dependent diabetes (Edge et al., 2001). Hypoglycaemia is another risk factor associated with T1DM, occurring when a person's blood glucose level drops too low. Symptoms occur on a spectrum; while mild symptoms such as confusion and disorientation are common side-effects of insulin therapy, severe hypoglycaemia (defined as an episode requiring external help) affects approximately 30% people with T1DM annually with symptoms including seizures, loss of consciousness; and comas (Leese et al., 2003),

The initial development of T1DM, which involves weeks of progressive insulin deficiency, polyuria (frequent urinating), polydipsia (excessive thirst), and weight loss, is a period of heightened risk of complication. Prior to receiving a diagnosis of T1DM, these symptoms in a person can be overlooked allowing DKA to develop. This occurrence is referred to as new-onset diabetic ketoacidosis (NO-DKA) and is relatively common, present in approximately 29% of newly diagnosed cases in New Zealand (Mencher et al., 2019).

Prevalence

Globally, the prevalence of T1DM is increasing. The latest estimates show over 96,000 new cases of T1DM in children and adolescents under 15 years old are diagnosed per year (Forouhi & Wareham, 2019). This is reflected in New Zealand data which shows an increase from 10.9 per 100,000 young people with T1DM aged 0-14 years in 1990, to 22.5 per 100,000 in the same group in 2012 (Derraik et al., 2012). In 2019 there were 832 hospital admissions where T1DM was the primary reason for admission in New Zealand's paediatric population (S. Carroll, personal communication October 1, 2020).

Prognosis

T1DM is a serious chronic health condition that is accompanied by acute mortality risk factors including hyperglycaemia, hypoglycaemia, and diabetic ketoacidosis, in addition to the risk of premature death due to long-term diabetes-related complications (Wasag et al., 2018). Premature mortality in people living with T1DM (>30 years old) is most commonly related to cardiovascular disease and chronic kidney disease (Groop et al., 2009). The risk of such long-term health complications can be moderated to some extent by careful management from the onset of the condition.

Daily Treatment Routines

A diagnosis of T1DM places considerable stress and burden on all family members as the condition presents both acute and chronic mortality risk. T1DM must be managed carefully to reduce the risk of diabetes-related complications (Clarke, 2011). This includes testing blood sugar levels multiple times daily and replacing the insulin the body needs with injections or using an insulin pump to keep glucose levels as close to the target range as possible. Regular exercise and adherence to a strict diet regimen are also important aspects of ongoing diabetes management (Curtis & Hagerty, 2002). While failure to comply with daily monitoring and treatments can lead to both short and long-term medical complications (as described in the previous section), children and adolescents can feel overwhelmed by the complex and time-consuming tasks required for the management of their condition (Greening et al., 2007).

The degree of daily management required to minimise the risk of acute life-threatening situations as well as long-term diabetes-related medical conditions, is considerable and impacts all family members on a daily basis.

Impacts on Siblings

The literature on siblings of children with diabetes shows a range of potential outcomes. Some studies have found siblings are at risk of developing social, emotional, and behavioural problems (Adams et al., 1991; Ferrari, 1984). Other studies found no significant change in adjustment difficulties (Hollidge, 2001; Lavigne et al., 1982; Sleeman et al., 2010), and one study found siblings of children with T1DM are better adjusted than their peers (Jackson et al., 2008).

Literature shows siblings of children with T1DM have needs in the following areas: information about their siblings treatment, side effects and recovery presented in an age appropriate format (Armstrong, 2020; Herrman, 2010; Wennick & Huus, 2012); worry about being placed in a position of responsibility for their affected siblings medical care without adequate knowledge of how to support them (Armstrong, 2020); help navigating changes in their relationship with their affected sibling (Armstrong, 2020; Hermann, 2010); needing to feel supported and acknowledged by their family and able to spend time with their family and communicate with them about the illness experience (Armstrong, 2020; Wennick & Huus, 2012); to feel supported and understood by friends and able to spend time with other young people with similar experiences (Armstrong, 2020); to have time out from the illness experience to participate in activities and regain a sense of normality (Armstrong, 2020); to be able to express feeling about their siblings condition and the impact on their life and their need for help dealing with feelings such as jealousy, sadness, anxiety, and anger (Armstrong, 2020; Herrman, 2010); and help dealing with the changes in their family (Herrman, 2010).

Siblings of young people with T1DM are often involved in the daily management of their brother or sister's treatments, including dietary management and insulin administration, taking on a parent-like role (Tsamparli & Kounenou, 2004). They can experience feelings of jealousy due to the attention given to the affected child, and resentment for the removal of certain foods from the family diet (Herrman, 2010).

Due to the genetic component of T1DM, people who have a blood relative with T1DM are more likely develop the condition themselves. This means siblings must cope with the stress and uncertainty that they may have inherited a predisposition for the condition (Branstetter et al., 2008; Guthrie et al., 2003; Hamburg & Inoff, 1983; Herrman, 2010; Mazur, 1998).

Siblings also need to tolerate uncertainty related to the affected child's long-term health as people with T1DM have a significantly increased risk of developing another autoimmune condition in addition to cardiovascular problems (Doyle, 2015). Consequently, siblings report feeling fearful and anxious that their affected sibling might die (Armstrong, 2020; Guthrie et al., 2003; Hermann, 2010).

Cystic Fibrosis

Cystic Fibrosis (CF) is an autosomal recessive genetic disorder caused by mutations of the CF transmembrane conductance regulator (CFTR) gene which leads to multi-organ morbidity (Bowen & Hull, 2015). The mutations cause thickened mucus that impairs the body's ability to clear secretions causing a cycle of chronic respiratory infections and inflammation that leads to tissue destruction, pulmonary dysfunction, and premature death (Kuk & Taylor-Cousar, 2015). Cell dysfunction also leads to comorbidities in the pancreas (malabsorption), liver (cirrhosis), sweat glands (heat shock) and infertility in males (Elborn et al., 2016).

Prevalence

CF has a worldwide prevalence of one in 2500 births (Elborn et al., 2016). It is the most common life-limiting genetic condition in New Zealand where over 500 people live with CF; this includes approximately 270 children between the ages of 0 and 17 years (I. Vanderlaan, personal communication, March 27, 2019). If both parents have the defective gene, there is a 25% probability of conceiving a child with CF. CF predominantly affects European populations but can occur in other ethnic populations. In New Zealand, CF is most commonly diagnosed in newborn babies through the heel prick blood test screen, although some children who were born overseas, or have rare CF genes, receive a late diagnosis (Cystic Fibrosis New Zealand, n.d.).

Prognosis

While CF is an incurable condition, the prognosis for children born with the condition is steadily improving due to advances in treatment and specialist care centres. The median life expectancy for people born with CF is now late forties to early fifties; this has increased significantly in the past twenty years and is expected to continue to improve with the development and provision of gene correctors and potentiators which have been approved for certain people with CF (Burgel et al., 2015).

An ever-present threat to people with CF are respiratory infections which can be fatal (Glazner, 2017). A complication of this threat is that respiratory pathogens are easily transmitted between people with CF, in a process called cross-infection. The current recommendations from Cystic Fibrosis New Zealand are that people with CF stay a minimum distance of four metres from each other (Glazner, 2017).

The most common comorbidity associated with CF is cystic fibrosis related diabetes (CFRD) which typically presents in adolescence and early adulthood (Mayer-Davis et al., 2018). Because CFRD is a poor prognostic sign (it is associated with an increase in morbidity and mortality), annual screening from 10-years old for all children with CF who do not have CFRD is recommended in New Zealand (Mayer-Davis et al., 2018)

Daily Treatment Regimen

CF requires intensive daily therapy and medications that help control the symptoms which can be both physically and emotionally demanding (Sawicki & Tiddens, 2012). With many forms of treatment now able to be administered in the family home, it is estimated the daily treatment routine takes between two to four hours per day (Sawicki et al., 2011). Treatment in younger children requires chest physiotherapy and airway clearance to be performed by their parents approximately 20 to 40 minutes twice daily. Because thick secretions in the digestive system can cause malabsorption, children who live with CF also take medication to help the body absorb nutrients and eat energy rich ‘treat’ foods to help maintain their weight (Sawicki & Tiddens, 2012).

Impacts on Siblings

A systematic review of the literature on the impact of cystic fibrosis on unaffected siblings analysed the findings of 13 peer reviewed studies (Chudleigh et al., 2019). Findings centered around impacts on family functioning, psychosocial impacts, and knowledge about cystic fibrosis. Changes in family functioning were reported to impact siblings in the areas of time available to spend as a family, parental differentiation, being expected to participate in the affected child’s care, and being aware of parental worry about the affected child dying (Chudleigh et al., 2019). Psychosocial impacts included feeling different to other children who did not have a sibling with CF and being unable to talk to their parents about their feelings and experiences (Chudleigh et al., 2019). The review also reported the findings that the beliefs siblings have about CF are not always accurate and emphasised the importance of ensuring siblings are well informed (Chudleigh et al., 2019). Findings from the same review showed the psychosocial impact on siblings may change over time leading to the suggestion that strategies to support siblings should be developmentally targeted (Chudleigh et al., 2019).

Congenital Heart Disease

Congenital Heart Disease (CHD) is the result of a defect in the structure of the heart and great vessels of a newborn. There are over forty different types of heart defects which range in severity from a hole in the heart to a complex combination of structural abnormalities (McCusker & Casey, 2016).

Prevalence

CHD is the most common birth defect, affecting almost 9.1 of every 1000 babies born worldwide (van der Linde et al., 2011). CHD is also the most common serious birth abnormality in New Zealand with one percent of babies (twelve babies every week) being born with CHD (Heart Kids, n.d.). Over half of these conditions require either long term medication or surgery. In New Zealand, over 550 major heart surgeries are carried out every year on children with a CHD; over 70% of these surgeries involves stopping the child's heart (Heart Kids, n.d.).

Prognosis

Significant advances in surgical procedures, treatment, and healthcare have resulted in increasing survival rates, with over 90% of these children now reaching adulthood. CHD requires intervention within the first year of life and has a mortality rate of 8%; critical congenital heart disease which requires intervention within four weeks has a mortality rate of 18% (Eckersley et al., 2016). Depending on the complexity of the congenital disease, medical and surgical treatment may commence shortly after birth, and subsequent interventions are common (Connor et al., 2010).

It is now recognised that survivors of complex CHDs are at risk of physical sequelae (Garcia et al., 2016), and for these children, CHD can become a chronic condition requiring heart surgeries, hospitalisations, and medical care throughout their lives (Loup et al., 2009).

As the number of children who survive surgery for CHD increases, there has been an increased incidence of adverse neurological outcomes in these infants and children (Newburger et al., 2003). These include neurodevelopmental deficits such as behavioural difficulties, cognitive deficits and poor academic progress, which can present later in childhood and lead to long-term functional impairments which require daily management (Ballweg et al., 2007; Bellinger et al., 2003).

Daily Treatment Regimen

Infants and children with CHD have an increased risk of respiratory or gastrointestinal infections compared to the general population, hence the prevention and management of infections in this population also require daily consideration (Cabalka, 2004). In particular, the respiratory syncytial virus (RSV) is associated with significantly higher rates of mechanical ventilation and being admitted to an intensive care unit for children with CHD compared to children without CHD (Cabalka, 2004).

Infants and children with CHD can have significant nutrition and feeding challenges due to suck or swallow incoordination, heart failure, or post-operative vocal cord damage (Lantin-Hermoso et al., 2017). Due to inadequate calorie intake, some children with CHD will require supplemental calories which can lead to potential complications including gastroesophageal reflux, aspiration risk, diarrhea, and constipation (Lantin-Hermoso et al., 2017).

It is recommended that children with CHDs participate in daily physical activities and conditioning, as their cardiovascular health is enhanced through the avoidance of a sedentary lifestyle, obesity, and hypertension (Lantin-Hermosos et al., 2017).

Impacts on Siblings

Compared to the general population, research found parents of children with CHD had increased rates of depression, anxiety, and stress (Wei et al., 2015). Studies show parents experience feelings of guilt due to having to prioritise the needs of their affected child over the needs of their siblings (Sood et al., 2018); and, because they don’t want the affected child to be exposed to illness, siblings are expected to refrain from shared activities (Connor et al., 2010). For children with CHD, having a sibling has been found to increase their quality of life (Im et al., 2018).

A synthesis of the research on siblings of children with CHDs pertaining to psychological functioning found siblings of children with more severe (and consequently, life limiting) CHDs had significant problems with both internalising and externalising emotional responses (Vermaes et al., 2012).

A Belgian study on the impact of paediatric CHCs on sibling's self-reported quality of life investigated siblings of children with CHD, cancer, T1DM, and CF (Havermans, 2015). The authors found siblings of children with CHD and cancer reported more behavioural and internalising problems. It should be noted the siblings in the CHD health condition had a brother or sister with *serious* heart defects which may moderate the reports of behavioural and/or internalising problems (Havermans, 2015). Supporting this, a larger study on the parental perception of functional status and impact on the family of children with CHD (n=100) found more complex CHD was associated with lower functional status, which correlated with a greater impact on families (Garcia et al., 2016).

A literature review investigated and synthesised empirical evidence on the impact of having a sibling with CHD (Parker et al., 2020). The synthesis reported that parenting styles and abilities are influenced by having a child with CHD, that siblings are often given more responsibilities leading to restrictions of their social lives, and having a sibling with CHD affects siblings' emotions, behaviours, school functioning, their health, and their quality of life (Parker et al., 2020). The authors concluded there is evidence to date that supports the need for an intervention that mitigates the impact of CHD on siblings and that future research on the experiences of siblings using sibling self-report measures is vital (Parker et al., 2020).

A recent systematic review by Schamong and colleagues (2022) that summarised the knowledge about psychosocial wellbeing and quality of life in siblings of children with CHDs found psychosocial wellbeing was impaired in 14-40% of siblings and quality of life was found to be impaired in up to one-third of siblings. The authors concluded that siblings were most stressed by mental health problems (anxiety, sadness, depression, worries, jealousy and feelings of rejection), behaviour, and school problems and recommended that these could be starting points for developing an intervention (Schamong et al., 2022)

In New Zealand, the only Paediatric Cardiac Unit is in Auckland where 1000 children are treated a year. This results in 70% of families with a paediatric heart defect having to leave their homes, leaving behind their jobs, families, and support networks (*Congenital Heart Conditions (CHD)*, 2023) This disruption and loss of normality is likely to have a negative impact on their siblings, in a similar way that the experiences of siblings of children with cancer who live in New Zealand report the negative impacts of the family disruption when families must travel to one of only two oncology treatment centres which are in Christchurch and Auckland.

Chapter 2 Summary

This review on the impacts of different chronic health conditions (CHCs) on siblings highlights multiple commonalities in sibling experiences across four serious paediatric conditions: type 1 diabetes mellitus, cystic fibrosis, cancer, and congenital heart disease. These conditions are not only chronic (often lifelong) they also place a significant burden on families and carry a substantial risk of early mortality. Importantly, they represent a broader category of rarer CHCs that have received limited research attention, making them valuable proxies for understanding sibling experiences in families affected by a range of serious paediatric illnesses.

Despite the variation in findings in the sibling literature, the potential inaccuracies of proxy reporting, and the need to consider the broader influences on siblings' lives, the literature on siblings is compelling - it is clear there is a subgroup of siblings who experience significant psychosocial adjustment difficulties, including depression, anxiety and post-traumatic stress symptoms, lower quality of life, and disruption to academic and social functioning. Consequently, there is a growing chorus of voices calling for the development of sibling interventions that protect this vulnerable population, both in New Zealand and internationally (Armstrong, 2020; Cohen et al., 1994; Houtzager, Grootenhuis, et al., 2004; Janssens et al., 2010; Long et al., 2018; Martinez et al., 2022; Murray, 2000; Neville et al., 2016; Patterson et al., 2011; Sharpe & Rossiter, 2002).

To broadly integrate the research speaking to siblings of children with CHCs, there is recognition that siblings' lives are profoundly affected by a childhood diagnosis of a CHC across familial, social, emotional, and academic domains. For some people, distress can lead to post-traumatic growth (PTG) which has been defined as the ability to master a distressing experience, recognise benefits from it, and develop beyond the previous level of psychological functioning (Calhoun & Tedeschi, 1998). However, for others distress can lead to post-traumatic stress symptoms (PTSS) if they do not get the support needed to navigate the condition and associated challenges. While many siblings learn to adapt to the changes in their lives over a period of time, and some siblings experience growth during this period, there is a significant subset of siblings for whom the impact of the health condition can lead to adjustment problems including anxiety, depression, and post-traumatic stress symptoms.

CHAPTER 3: THE IMPACTS OF CHILDHOOD CHRONIC HEALTH CONDITIONS ON DOMAINS OF SIBLINGS LIVES

This chapter reviews the impacts chronic health conditions (CHCs) have on five domains in the lives of siblings (family functioning and relationships, roles and routines, emotions, school life and post-traumatic growth) as well as the variables that moderate sibling adjustment.

Family Functioning and Relationships

Children's emotional and social development is influenced by the family environment (Grych & Fincham, 1990). Family life is significantly disrupted following the diagnosis of a child with a chronic health condition due to intensive treatments, hospital visits, and parental stress. Siblings often experience a chaotic and distressing stage and a sense of loss (Yang et al., 2016). Parental support has been found to be essential for siblings at this time, and is strongly related to their emotional, behavioural and academic adjustment (Alderfer & Hodges, 2010; D'Urso et al., 2017).

The increase in time parents spend with the affected child following the diagnosis of a CHC can lead to siblings feeling isolated and rejected by the family system (Long et al., 2015, Long et al., 2018). Siblings can experience parental differential treatment (Wilkins & Woodgate, 2005), and activities are reduced as family occasions are also impacted (Prchal & Landolt, 2012; Weiner & Woodley, 2018). A review by Bellin and Kovacs (2006) found when siblings adopt the role of caretakers, they face a dilemma between feeling burdened, and their need of time for recreation and independence.

A meta-analysis of the qualitative literature on siblings identified the theme 'Changing Family Relationships' and found the relationship between siblings and the affected child to be complex (Deavin et al., 2018). While increased time spent together led to a closer relationship for some siblings, other siblings reported negative changes that were associated with changes in the affected child, such as mood swings. Other changes for siblings following the diagnosis of a childhood CHC included the quality and quantity of parental attention, perceived changes in parental expectations such as helping to care for the affected child, and a reduced level of communication with their parents (Deavin et al., 2018). The meta-analysis found the majority of studies reported siblings feeling jealous and resentful of the time of diagnosis and parents giving special attention to the affected child; however, they also acknowledged the attention was necessary. The authors concluded that reduced communication may lead to the suppression of siblings' needs and that siblings develop reactive strategies to help them cope and accept their circumstances.

The parent-sibling relationship may also change, with regard to decreased discipline, parental preference for the affected child, and attempts to protect siblings from distress (Long et al., 2018). Siblings may spend less time with both parents and more time with parent substitutes (Wilkins & Woodgate, 2005). There is also evidence that one of the changes that alters family functioning is that fathers take on more responsibility caring for siblings due to mothers being the most likely parent to take their affected child to hospital/treatments (Alderfer et al., 2010; Wilkins & Woodgate, 2005). Seeing the challenges the affected child faces, siblings tend to repress their feelings, not wanting to add to their parents' burden (Kobayashi et al., 2015; Prchal & Landolt, 2012; Vermaes et al., 2012).

Roles and Routines

Changes in home-life are frequently mentioned in the literature and siblings' sense of normalcy is disrupted (D'Urso et al., 2017; Nolbris et al., 2010; Weiner & Woodley, 2018). Siblings report having to grow up quickly due to being given an increased number of domestic tasks around the home to help reduce the stress of the family and to support parents in daily household activities (Long et al., 2018; Van Riper, 2003; Williams, 1997). Siblings often take on a caregiving role for the affected child or other siblings; this is particularly true of older female siblings (Alderfer & Hodges, 2010; Knecht et al., 2015; Long et al., 2018; Wilkins & Woodgate, 2005).

Some studies suggest siblings taking on greater responsibilities leads to an increase in family cohesion (Knecht et al., 2015; Long, Marsland, et al., 2015) lower anxiety symptoms, greater use of problem-solving coping, and a greater sense of companionship with the affected sibling (Hilário, 2022). In contrast, other studies report these additional responsibilities strain familial relationships (Neville et al., 2016), can lead to conflict (Prchal & Landolt, 2009), and can contribute to a loss of normal family routine and security (Alderfer & Hodges, 2010; Wilkins & Woodgate, 2005).

It is well documented that siblings experience a decrease in social activities. This is related to experiencing decreased performance and lack of interest, decreased time, logistical challenges such as getting to and from the activity, and reduced parental involvement (Long et al., 2018; Weiner & Woodley, 2018). A reduction in extra-curricular activities for adolescent siblings is a significant loss as they constitute a unique aspect of identity formation, and they have many positive influences on adolescent development and young adult outcomes (Feldman & Matjasko, 2005). Extracurricular activities offer a means to express and explore one's identity. They influence the kinds of values and norms they are exposed to, and help adolescents understand themselves - thus shaping the nature of their developmental pathway (Feldman & Matjasko, 2005).

Mental Health

A review of two meta-analyses on sibling experiences revealed that following a child's diagnosis with a CHC, siblings experience a range of intense emotions including fear, shock, and uncertainty (D'Urso et al., 2017; Yang et al., 2016). Siblings tend to withdraw into themselves, which is characterised by internalising behaviours (Knecht et al., 2015). Because the focus falls on the affected child, siblings typically receive less attention from parents, family members and friends, leading to a sense of isolation (Murray, 1999; Yang et al., 2016), loss (Alderfer et al., 2010; Van Riper, 2003; Wilkins & Woodgate, 2005) and being left out from their own family (Neville et al., 2016). These feelings are exacerbated when information about their sibling's health condition is hidden from them by parents and health professionals who are trying to 'protect' them. This can lead to siblings feeling neglected (Alderfer et al., 2010; Van Riper, 2003), unimportant (Wilkins & Woodgate, 2005), marginalised (Yang et al., 2016), forgotten and rejected (Murray, 1999). These difficult experiences can lead to feelings of jealousy of the affected sibling due to unequal parental attention (Wilkins & Woodgate, 2005) complicated by guilt and shame for feeling jealous (D'Urso et al., 2017; Wilkins & Woodgate, 2005). Siblings also commonly report feeling selfish for having their own needs, then a sense of guilt for being the 'healthy' sibling (Armstrong, 2020).

Instead of feeling able to share these difficult feelings, siblings tend to suppress their emotions due to worry about overburdening their parents. This can lead to estrangement and a change in parent-child intimacy (Yang et al., 2016). Siblings of children with cancer have reported losing their sense of identity and sense of self, and feeling insecure about themselves (Long, Marsland, et al., 2015; Wilkins & Woodgate, 2005) as they defined their world through the experiences of their affected siblings. The literature suggests these intense and overwhelming emotions can lead to depression, anxiety, post-traumatic stress symptoms and affect beliefs around self-worth (Jenholt Nolbris & Ahlström, 2014; Long, Marsland, et al., 2015; Rosenberg et al., 2015; Salavati et al., 2014). (Murray, 1999; Nolbris & Nilsson, 2017; O'Brien et al., 2009; Sharpe & Rossiter, 2002; Yang et al., 2016).

School Life

A child's school life represents an important role in their identity, academic and social development (Yang et al., 2016), due to the amount of time children spend in this setting. Both self-reports by siblings and parental proxy reports found siblings experience academic difficulties (Donnan et al., 2015; Houtzager, Grootenhuis, Hoekstra‐Weebers, et al., 2005; Prchal & Landolt, 2012; Williams et al., 2009), with one study finding 50% of siblings had a decrease in grades (Prchal & Landolt, 2012). The literature suggests the following factors may contribute to siblings academic difficulties: parents finding it difficult to meet the needs of siblings due to pressures on their time and energy (Prchal & Landolt, 2012); lack of parental focus on the sibling (McLoone et al., 2013); and siblings finding it difficult to voice their need for help with schoolwork when their parents are focused on their affected child (Prchal & Landolt, 2012) which may further compound existing difficulties if post-traumatic stress symptoms are present.

Siblings commonly experience an increase in post-traumatic stress symptoms (including strong emotions and intrusive thoughts) which can lead to problems completing homework and concentration difficulties (Gan et al., 2017; Long, Marsland, et al., 2015; Nolbris et al., 2007; Prchal & Landolt, 2012). They have been shown to have less time for homework due to their affected brother or sister being in hospital (Samson et al., 2016). Studies that investigated academic functioning in siblings have found consistent reports of academic problems, including: frequent absenteeism; a decline in academic performance; and school aversion (Gan et al., 2017; Houtzager, Grootenhuis, Caron, et al., 2005; Long et al., 2018).

Absenteeism can increase distress in siblings, as it can lead to disconnection from peers and school (Gan et al., 2017; Woodgate, 2006), and conflict when siblings are forced to choose between attending school or supporting the affected child in hospital (Nolbris et al., 2007). It has been suggested the increased rates of absenteeism may relate to changes in family functioning such as disruptions caused by the affected child's health condition, increased sibling care requirements, increased responsibility around the home, and a lack of transportation (Brennan et al., 2013; Long, Marsland, et al., 2015; McLoone et al., 2013).

The literature on sibling-peer and sibling-teacher relationships is varied. While peer-related problems and social adjustment are reported by some siblings (Houtzager, Grootenhuis, Hoekstra - Weebers, et al., 2005; Sleeman et al., 2010; Sloper, 2000), others report positive peer interactions associated with being a sibling of a child with a CHC (Alderfer & Hodges, 2010) and even increases in popularity due to the perceived change in identity (Long, Marsland, et al., 2015). Difficulties with psychological wellbeing at school may lead to negative impacts on long-term educational achievement (Gan et al., 2017).

Post-traumatic Growth

Reviews have found siblings to be at risk for experiencing psychological difficulties, however there is also research pointing to positive outcomes to growing up with a chronically ill child (Midlarsky et al., 1995; Packman, 1999; Williams, 1997). These positive impacts on siblings are commonly referred to as post-traumatic growth. Post-traumatic growth has been defined as the ability to master a distressing experience, recognise benefits from it, and develop beyond the previous level of psychological functioning (Calhoun & Tedeschi, 1998).

Studies on resilience and post-traumatic growth in siblings have pointed to the development of empathy and compassion (Kiburz, 1994; Pit-Ten Cate, 2000), in addition to patience and sensitivity (Bellin & Kovacs, 2006). Other reviews have identified factors such as personal growth (Van Riper, 2003; Wilkins & Woodgate, 2005), maturity (Murray, 1999; Van Riper, 2003; Williams, 1997), and independence (Alderfer et al., 2010; Wilkins & Woodgate, 2005) as key factors in the experiences of siblings. Wilkins & Woodgate (2005) found that in developing a sense of responsibility, siblings may feel proud about their ability to assist their affected sibling.

These reviews on the sibling literature are striking in their recognition that siblings' lives are profoundly affected by a childhood CHC across familial, social, emotional, and academic domains. Having established a child's diagnosis with a serious CHC has significant impacts on siblings' lives which can lead to adjustment problems, the following section will consider the variables that affect sibling adjustment.

Variables that Moderate Sibling Adjustment

Age and Gender

Adolescence is a period of significant transitions including changes in cognition, physiology and social perspectives (Koenig & Gladstone, 1998). Developmental theory posits an adolescent's social roles and relationships shape the process of self-esteem and identity development (Erikson, 1993) and that during this period individuals have an increased need for autonomy, independence from parents, social acceptance and reliance on peers (Dickey & Deatrick, 2000). In New Zealand, adolescence has been found to be the developmental stage that is the least well supported by the health system, which is not well-equipped to meet the needs of young people with CHCs (Sligo et al., 2019).

Findings from a meta-analysis on the psychological functioning of siblings in families of children with CHCs found older siblings are more vulnerable than younger siblings regarding their self-attributes but not with regards to internalising and externalising problems. This supports the hypothesis that older siblings may be more cognisant of the potential consequences of the CHC and may be expected to take on more caregiving and household duties (Vermaes et al., 2012) and reflects earlier research findings (Houtzager et al., 2005; Labay & Walco, 2004). Recent New Zealand sibling research found the mean percentage of unmet needs was higher in the older age group when siblings over the age of 12-years were compared with the needs of siblings 12-years old and younger (Armstrong, 2020).

While international literature shows varied findings on the moderating influence of gender and psychological functioning (Vermaes et al., 2012), New Zealand sibling research shows a statistically significant difference between the mean percentage of unmet needs between males and females, with females reporting a higher number of unmet needs (Armstrong, 2020).

Time Since Diagnosis

Multiple studies on the impact of serious CHCs on siblings have found a longer time since diagnosis is associated with fewer difficulties (Alderfer et al., 2010; Havermans, 2015; Houtzager, Grootenhuis, et al., 2004; Williams, 1997). Higher distress occurs at the time of diagnosis, then adjustment over time allows for the development of acceptance (especially with good support) (Deavin et al., 2018; Hamama et al., 2008; Sleeman et al., 2010; Weiner & Woodley, 2018).

A study of siblings of children with cancer found approximately 75% of siblings were most affected in the first month after diagnosis; however, 26% of siblings reported clinically relevant emotional problems two years after their sibling's diagnosis (Houtzager et al., 2004). This trend of improvement over time has not been shown for siblings of children with diabetes which remains consistent in terms of impact and seriousness (Jackson et al., 2008).

To summarise, existing literature suggests siblings experience greater levels of distress closer to the time of diagnosis which signals the importance of providing support services in these early stages as siblings adjust to the significant challenges they face. It is likely an early intervention will help ameliorate the risk for those vulnerable siblings who might otherwise suffer long-term negative impacts (Armstrong, 2020).

Family Adaptation

The family is a unit of interacting individuals whose purpose is to create and maintain a common culture that provides for the mental, emotional, physical and social development of each family member (Duvall, 1977).

Following an adverse event (such as the diagnosis of a childhood CHC), when families are able to adjust by changing their interactions with other systems, they are more likely to engage in helpful coping strategies and recover from adversity (Huang et al., 2022). For example, when families are able to use adaptive and prosocial coping strategies, such as drawing upon social resources from healthcare professionals, church, friends, and other people in hospital (Walsh, 1996), it increases family resilience and helps them develop positive relationships (Huang et al., 2022). Family resilience is a dynamic process associated with family coping strategies such as problem solving, family beliefs and family organisation (Walsh, 2003). It has been demonstrated that family functioning mediates the impacts of medical crises on healthy siblings (Gold et al., 2011).

An early review on siblings and paediatric cancer found family and parent variables (in particular cohesion and adaptability) were strongly associated with sibling adjustment (Cohen et al., 1994). Findings reported positive sibling adjustment was associated with an absence of parental depression, effective parent-sibling communication about the illness, good marital adjustment, and high levels of community support and family resources (Cohen et al., 1994).

Sibling Relationships

There is some emerging evidence that the sibling relationship moderates the impact of the diagnosis of a brother or sister’s health condition; however, the sibling relationship in this context has not been comprehensively examined. Early studies found a decrease in intimacy and companionship when one sibling is diagnosed with cancer (Sloper, 2000). Chesler and colleagues (1992) found that siblings experience a loss of status within their family system when compared to the affected child. Surprising results from one study found there is evidence that a warm and caring relationship is associated with greater adjustment problems and decreased social competence for both siblings (Labay & Walco, 2004). This effect is possibly due to closer relationships amplifying the stressors and leading to greater vulnerability to change and periods of separation.

Individual Coping Styles

Siblings of children with chronic health conditions (CHCs) frequently experience heightened stress as they attempt to make sense of complex and evolving health-related information. These challenges are compounded by the frequent changes in both their sibling's condition and the broader family dynamic, making adaptation and coping particularly difficult (Havill et al., 2019). The coping strategies employed by siblings significantly influence their psychological and emotional adjustment to the situation.

Research has shown that siblings who predominantly use avoidant coping strategies such as social withdrawal, distraction, and resignation — have levels of internalising and externalising behaviors, coupled with reduced social support, resulting in poorer adjustment to the CHC (Lummer-Aikey & Goldstein, 2021). In contrast, those who engage in proactive coping strategies — including problem-solving, logical reasoning, physical action in response to stress, and participation in extracurricular activities — demonstrate more effective adaptation to the ongoing challenges associated with their sibling's health condition (Lummer-Aikey & Goldstein, 2021). Additionally, siblings who use internally reactive coping strategies, such as taking mental breaks, challenging their thoughts, and sharing their emotions with trusted individuals, have reported more positive adjustment to the CHC (Houtzager et al., 2004; Long et al., 2015).

Specific Health Conditions

There is evidence that the greater the severity and intrusiveness of the condition, the greater the impact it has on the affected child and their family (Dinleyici et al., 2019). An early meta-analysis that evaluated the functioning of siblings of children with chronic illness found no differences in sibling psychological functioning across a range of illness severity; however, siblings of children with health conditions that required more intensive daily treatments were more negatively affected (Sharpe & Rossiter, 2002). In an updated review of the Sharpe & Rossiter (2002) meta-analysis (which included thirteen new studies), findings showed siblings of children with life-threatening chronic illnesses and/or chronic illnesses that require intrusive daily treatments, had significantly more internalising problems (anxiety, depression), externalising problems (disruptive behaviours), and significantly less positive self-attributes (Vermaes et al., 2012). A systematic review of health-related quality of life (Limbers & Skipper, 2014) found siblings of children with greater disease severity were more negatively impacted. These findings were supported by a more recent study on quality of life evaluations of siblings (Meltem et al., 2020). The authors recommended screening of siblings of children with greater disease severity to monitor siblings for impaired functioning (Limbers & Skipper, 2014).

Literature on Siblings who Reside in Aotearoa New Zealand

As discussed, the experiences of siblings are set within a cultural context and therefore strongly influenced by the country siblings reside in. The experiences of siblings living in New Zealand have not been extensively studied. However, the research that is available indicates that siblings who live in New Zealand experience similar adjustment problems than siblings studied in the international literature.

The earliest known study of siblings in New Zealand was an unpublished master's thesis reporting interviews with thirty-seven siblings of children with cancer (who had been diagnosed within the preceding 18 months). Findings showed 62% of siblings scored above the cut-off score in an epidemiological depression scale (Dobson et al., 2007).

These findings were supported by a later doctoral thesis written on the psychological adjustment of adolescent siblings of cancer survivors, which focused on recognising the needs and perspectives of siblings of children with cancer (Riddick, 2013). While this study had a small (n=31) self-selected sample, findings showed 76% of siblings reported levels of depressive symptoms above the cut-off of on an epidemiological depression scale for children. The qualitative results showed parental differential treatment, lower optimism, and peer alienation were significant predictors of depression (Riddick, 2013). Both Riddick (2013) and Dobson (2007) suggested travel time, and the need to live away from home for extended periods due to the scarcity of paediatric oncologic treatment centers created additional strain for siblings.

A 2019 study on siblings of children with cancer carried out in New Zealand investigated the experiences that positively and negatively impacted on the wellbeing of siblings between the ages of 12 and 18 years (Porteous et al., 2019). Siblings reported it was the multiple concurrent stressors that most negatively influenced their psychosocial adjustment, combined with feeling left out, rejected, or isolated. The majority of siblings reported feelings of guilt and shame for feeling jealous of their sibling as well as parental differential treatment. Experiences that impacted positively on siblings' wellbeing were focusing on positive experiences; feeling involved; knowing they were still a priority for their parents; and connecting with people through their experiences. The authors concluded that there is a strong need for sibling support in New Zealand.

Finally, recent research undertaken by the current author compared the unmet needs of siblings of children with cancer in New Zealand with siblings in Australia (Armstrong, 2020). This research showed strong similarities in the types of unmet needs reported by siblings, but the New Zealand sample was systematically higher. On average, the unmet needs reported in the New Zealand sample were over twenty percent higher than the unmet needs reported in the Australian sample (Armstrong, 2020). The qualitative themes identified in the study reflected many of the themes discussed in the literature review, in particular, the recent large-scale studies (Deavin et al., 2018; Havill et al., 2019; Long et al., 2018; Weiner & Woodley, 2018). For example, similarities in siblings experiences identified in my Master's thesis were supported in a recent meta-synthesis by Deavin et al., (2018) and included: reduction in parental attention making siblings feel jealous and resentful; an increase in parental expectations (to help care for the affected sibling); the parental belief that discussion about the illness is too painful causing siblings to feel expressing their own emotions as threatening or a burden and leading to them becoming isolated and unable to express their needs; the importance of providing siblings with information about the illness; needing the illness to be accepted and 'normalised'; support from family, friends, teachers; and peer support groups which enable siblings to connect with others and share experiences.

Findings in my Master's thesis also reflected the synthesis of almost eighty studies on siblings of children with chronic illness (including cancer) which reported the most common sibling responses were: experiencing fear; assuming a parent-like role and taking an active role in the treatment of the affected child, experiencing other negative emotions; disrupted family relationships; changing family activities and routines; and seeking more information (Havill et al., 2019).

It should also be noted that while the focus of my Master's thesis was on siblings' descriptions of their unmet needs, the findings also revealed siblings showed remarkable maturity through taking on care-giving roles, and compassion in their desire to support their affected sibling and protect their family from any further burden. These findings were also in-line with international literature with some siblings reporting they experienced positive emotions with the support of friends and family (Havill et al., 2019; Weiner and Woodley, 2018).

In light of understanding the impacts of siblings in New Zealand and their similarities with the international literature, there is a strong argument for the development of targeted support services for siblings which are age appropriate, culturally sensitive, and supported by both professional and peer involvement (Armstrong, 2020).

Chapter 3 Summary

This chapter reviewed how the diagnosis of a childhood CHC impacts siblings across major life domains highlighting that this is a major life event that requires siblings to adjust to changes in their emotions, family and peer relationships, home life, and school life. Despite little research in the area, some of the variables that moderate sibling adjustment to these significant life changes were described including age and gender, time since diagnosis, family adaptation, sibling relationships, individual coping styles, and specific health conditions. This was followed by a summary of the impacts of CHCs on siblings who reside in New Zealand which indicated that siblings who live in New Zealand may experience more negative adjustment problems than siblings studied in the international literature.

CHAPTER 4: RESEARCH THEORY AND DESIGN

This chapter discusses important considerations in the development of an intervention for siblings. It begins with the argument for taking a transdiagnostic approach to sibling interventions, before discussing knowledge translation in the health sector and the importance of developing an intervention that responds to the self-reported needs of the target population.

Transdiagnostic versus Diagnosis-specific Approach to Sibling Interventions

While each CHC diagnosis has a distinct biological process which results in diverse treatment plans, there are considerable commonalities in the psychosocial impacts on the affected child and their family members (Wallander & Varni, 1998). In 1975, Pless and Pinkerton supported taking a transdiagnostic approach, arguing the impact of the diagnosis on siblings and parents (along with the ongoing nature of the health condition) led to more experiential commonalities for family members than condition-specific effects. This perspective is underpinned by the understanding that chronically unwell children face common life experiences based on the generic dimensions of their health condition. It has been argued that key factors of different CHCs (such as the nature of onset and course, life threatening potential, intensive and/or painful treatment regimes, familial burden, and social stigma) have greater implications on sibling adjustment than a specific diagnosis (Rolland, 1994; Rosenberg et al., 2015; Stein & Jessop, 1982; Wallander & Varni, 1998). Additionally, the broad range and relative rarity of many paediatric CHCs have also led to support for addressing the needs of the sibling population by taking a holistic, transdiagnostic approach (Armstrong, 2020; Michaud et al., 2004; Rosenberg et al., 2015; Stein & Jessop, 1982; Suris et al., 2004).

A synthesis by Havill and colleagues (2019) investigated the experiences of siblings following the diagnosis of a childhood CHC finding strong similarities between the health conditions and recommending a transdiagnostic approach (see Table 1).

Table 1

Chronic Conditions with Supporting Evidence for Each Pattern of Sibling Behaviour

Patterns of Sibling Behaviour	Categories of Sibling Response	Conditions
Knowing something is seriously wrong	Not knowing what is wrong	Cancer/Diabetes/Hemophilia/Sickle Cell Disease/ Faconi Anemia/ Muscular Dystrophy/End Stage Renal Disease
	Enduring Uncertainty	Diabetes
	Having the right information	Cancer/Diabetes/Sickle Cell Disease/Muscular Dystrophy/Congenital Heart Disease/Multiple
Figuring out the meaning of the disease	Understanding what the disease means	Cancer/Diabetes/Sickle Cell Disease/Epilepsy/ Muscular Dystrophy/Congenital Heart Disease
	Coming to terms with the disease	Cancer/Diabetes/Congenital Heart Disease/ Muscular Dystrophy/Hemophilia
	Thinking now about mortality	Cancer/ Faconi Anemia
Adapting to changes in personal and family life	Losing a sense of security	Cancer/Diabetes/Multiple/Faconi Anemia/ Arthritis/ Congenital Heart Disease
	Losing family normalcy	Cancer/Diabetes/Hemophilia/SpinaBifida/ Multiple/ End Stage Renal Disease/Congenital Heart Disease/Sickle Cell Disease/Epilepsy/ HIV/Muscular Dystrophy
	Assuming parent-like role	Cancer/Diabetes/Sickle Cell Disease/Faconi Anemia/ Multiple/Asthma/Muscular/Dystrophy/ Epilepsy
	Relying on others	Cancer/Diabetes/Spina Bifida/Multiple/ Congenital Heart Disease/Multiple/End Stage Renal Disease
	Being marginalized	Cancer/Diabetes/Cystic Fibrosis/End Stage Renal Disease/Spina Bifida/ Epilepsy/Congenital Heart Disease/Faconi Anemia/Sickle Cell Disease
	Evolving self	Cancer/Diabetes/Spina Bifida/Arthritis/ Sickle Cell/ Disease/Multiple/HIV/ Muscular Dystrophy
Handling emotional reactions to the disease	Experiencing strong feelings	Cancer/Diabetes/Cystic Fibrosis/Spina Bifida/ Multiple/End Stage Renal Disease/ Sickle Cell Disease/Epilepsy/Muscular Dystrophy/Faconi Anemia
	Employing coping strategies	Cancer/Diabetes/Epilepsy/Congenital Heart Disease
	Accepting social support	Cancer/End Stage Renal Disease/Spina Bifida/ Multiple

Note. From "Well Siblings of Children With Chronic Illness: A Synthesis Research Study," by N. Havill, L. K. Fleming, & K. Knafl, 2019, *Research in Nursing & Health, 42*(5), Copyright 2019 by Wiley Periodicals LLC. Reproduced with permission.

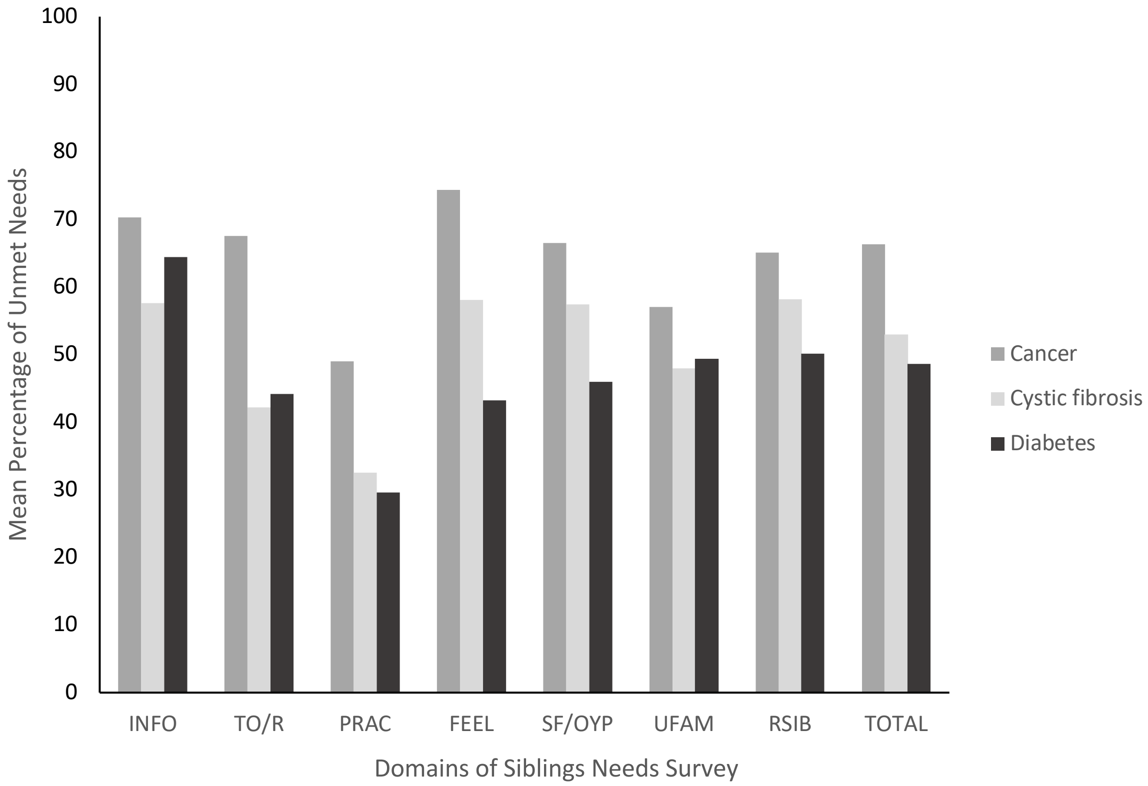
Data from 78 published reports (representing 1,854 families) was analysed to identify which sibling response was associated with each CHC. While cancer was the most frequently studied (followed by diabetes), this synthesis illustrates the strong similarities in sibling experiences across different CHCs. Frequently endorsed sibling responses included experiencing strong feelings including a range of negative feelings as well as some positive feelings such as pride and protection and employing coping strategies such as acceptance and actively mitigating fear. Siblings navigate emotionally charged information about the illness and struggle to adapt and cope with frequent changes in their environment. Siblings had a strong need to know and understand what was happening with their affected sibling and appreciated receiving accurate information from their parents. They made efforts to understand the medical and emotional aspects of the illness, often experienced a great deal of worry and fear when they thought about their affected sibling dying, and reported losing their sense of security. Siblings responded to the disruptions in family normalcy by expanding their role in the family and assuming a level of responsibility and involvement in their sibling's treatment process (Havill et al., 2019).

The authors concluded the likely areas for invention development should be directed to recognising siblings' needs for information, building up their coping strategies, and fostering emotion management (Havill et al., 2019). This study clearly illustrates the similarities in sibling experiences across a broad range of CHCs and supports the argument for taking a transdiagnostic approach.

A recent needs-based study on siblings by the current author compared the unmet needs of siblings of children with CF, cancer, and T1DM in New Zealand (Armstrong, 2020) aligned with the findings of Havill and colleagues (2019). The quantitative results showed strong similarities in the types of unmet needs reported by siblings across domains speaking to the dynamic of the family unit and sibling relationship; access to support from peers as well as practical advice and information; and their ability to take time for recreation away from the family unit.

Figure 5

Mean Percentage of Unmet Needs for Each Health Condition



Note. INFO: The need for information about the CHC; TO/R: The need for time out and recreation; PRAC: The need for practical support; FEEL: The need for help dealing with difficult feelings; SF/OYP: The need for support from friends and other young people; UFAM: The need for understanding from family; RSIB: The need for help navigating the changes in relationship with the affected sibling. From " The Unmet Needs of Siblings of Children with Cancer and Serious Chronic Health Conditions in Aōtearoa/New Zealand," [Master's thesis], by K. Armstrong, 2020, *Massey University of New Zealand*. (http://hdl.handle.net/10179/15677). Reproduced with permission.

While siblings of children with cancer had the highest average percentage of unmet needs in each of the seven domains, there was significant overlap in the types of unmet needs identified across all three health conditions (Figure 5). These findings were reinforced by the qualitative findings, which highlighted that while there were some condition-specific unmet needs (such as siblings with cancer more commonly reporting family disruption), the shared experiences of siblings in all three health conditions showed considerable overlap (Armstrong, 2020).

Some chronic conditions vary greatly in where they fall on the continuum of severity which can lead to significant variation in the impact on the affected child and their family. For example, conditions like asthma and cerebral palsy can range from mild (having minimal impact on the affected child and their families' lives), to severe, which can have a significant impact. Taking everything together, it is likely that one of the reasons the sibling literature on CHCs is difficult to effectively evaluate is the frequency with which studies investigate the impact of specific chronic conditions which range from mild to severe, rather than investigating the impact of health conditions based on their severity.

A condition-specific approach was recommended by the authors of a systematic review on the impact of cystic fibrosis on siblings (Chudleigh et al., 2019). A closer look at the evidence for this recommendation shows the review considered the findings from four studies when analysing condition-specific differences (Derouin & Jessee, 1996; Havermans et al., 2015; Perkins; 1994; and Williams et al., 2009). Two of these studies supported a transdiagnostic approach in the development of sibling support interventions (Perkins, 1994; Williams et al., 2009) and two recommended a condition-specific approach (Derouin & Jessee, 1996; Havermans et al., 2015). Two of these studies are close to three decades old, during which time there have been significant improvements in the management and life expectancy of children born with CF which highlights the importance of accessing up-to-date studies when considering the impacts of CF on siblings (Derouin & Jessee, 1996; Perkins, 1994). Of the two more 'recent' studies, Williams et al. (2009) supported a transdiagnostic approach in the development of sibling support interventions while Havermans et al. (2015) cautioned against this approach having found that CHCs that require intensive daily treatment (T1DM and CF) may provide a greater sense of control leading to higher quality of life scores than CHCs where there is relatively little control that prevents the illness from reoccurring (cancer and congenital heart disease) creating more worry about the risk of recurrence or unexpected problems. Havermans and colleagues (2015) also argued that societal concepts of illness, uncertainty, hidden stressors, and perceived uncontrollability vary significantly between health conditions and are important to take into account.

While there is little doubt there are differences in the impacts of different CHCs on siblings, as discussed there are also multiple similarities. At the core of this argument is the assumption that the impacts of specific CHCs need to be specifically addressed. The counterargument to this, is that by taking a transdiagnostic approach to a sibling intervention that addresses the similarities across CHCs (while simultaneously teaching evidence-based strategies that provide siblings with skills to ensure their own needs are met), the specific impacts of each individual CHC becomes less relevant.

Further supporting the argument of a transdiagnostic approach is that a condition-specific approach to sibling interventions is not feasible from a resource or population perspective. New Zealand has neither the funding, nor the population size to justify the development and implementation of multiple condition-specific sibling interventions. Furthermore, even if funding was sourced, New Zealand's population and geographical spread, alongside the relative rarity of many CHCs, would likely prevent the numbers of siblings needed for a group format which is central to the benefits of a sibling intervention.

Therefore, rather than debating whether sibling interventions should be transdiagnostic or diagnosis-specific, a more appropriate question to ask is: Can a transdiagnostic intervention be developed for siblings of children with CHCs that provides them with the knowledge and skills needed to adjust to the significant changes in their lives?

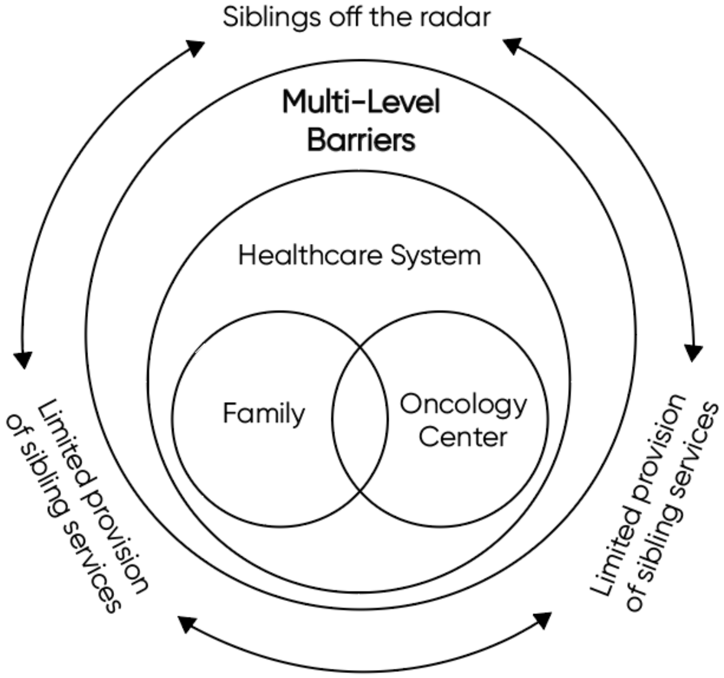
Knowledge Translation

Despite the considerable resources devoted to the study of siblings over the past fifty years, the provision of psychosocial support for siblings has not yet been widely implemented by healthcare systems. It has been shown there is a substantial time-lapse before evidence-based practices (EPBs) and other research findings are translated into routine general practice in the health sector. In fact, the widely reported estimates that EBP's take an average of 17 years to be incorporated into daily practice in healthcare are likely to be optimistic, as only about half of EPB's eventually reach widespread clinical usage (Balas & Boren, 2000). It is now recognised the translation of knowledge into both psychosocial and medical interventions to improve the quality and effectiveness of health services is not spontaneous but requires focused efforts (Bauer et al., 2015).

A recent study on the barriers to implementing services for siblings of children with cancer found barriers to providing sibling services at multiple levels including the healthcare system (Brosnan et al., 2022). The authors developed a diagram (Figure 6) to demonstrate how the interaction of barriers maintains the cycle of poor provision of sibling services (Brosnan et al., 2022).

Figure 6

Negative Cycle Maintaining Poor Sibling Services



Note. From “Psychosocial care providers’ perspectives: Barriers to implementing services for siblings of children with cancer,” by P. Brosnan, K. A. Davis, M. Mazzenga, A. R. Oberoi, C. M. Sharkey, D. Buchbinder, ... & K. A. Long, 2022, *Pediatric Blood & Cancer, 69*(2), e29418. Copyright 2022 by Wiley. Reproduced with permission.

In addition to this widely recognised delay, it is likely the provision of sibling interventions has been further impeded by the variability of findings in the sibling literature and the lack of needs-based research. To this end, the research that has been carried out on siblings in a New Zealand context is particularly valuable in that it directly links the self-reported needs of siblings with intervention development, thus removing a potential barrier in the development of the intervention Armstrong, 2020).

One of the key findings of this needs-based study (alongside other literature) is that siblings should be offered help close to the time of diagnosis to help them adjust to the significant changes they face and aim to ameliorate the risk for the vulnerable subgroup of siblings who may otherwise experience long-term negative impacts (Armstrong, 2020).

Early Prevention

The development and provision of early preventative programs for siblings following a young person's diagnosis with a CHC may reduce the onset of disorders by promoting protective processes and reducing risk factors. Some studies call for further research that helps identify risk factors for siblings, so interventions can be offered to siblings who are identified as vulnerable (Barlow & Ellard, 2005; Lummer-Aikey & Goldstein, 2021); however, there is an argument for a broader approach to sibling support.

Early intervention programs can be divided into three categories: indicated, selective, and universal (Haggerty & Mrazek, 1994). Indicated programs are targeted towards individuals with a diagnosable disorder, selective programs are targeted at individuals who belong to a subgroup of the population whose risk of becoming unwell is above average, and universal preventative measures are targeted at everyone in the eligible population (Haggerty & Mrazek, 1994). Universal programs have a number of advantages, including: avoiding the stigma of being singled out; enabling a greater reach to individuals who may not have been identified as in need; removal of the need to screen; and relatively low dropout rates (Garcia-Escalera et al., 2020).

Considering the benefits of a universal approach to sibling support, alongside the complexity of accurately identifying at-risk siblings, it is important to offer a support program to all siblings, close to the time of the young person's diagnosis with a CHC.

Needs-Based Research

Current best practice recommends that the design and delivery of an intervention should be underpinned by an assessment of the target populations' self-reported needs (Wen & Gustafson, 2004). Needs assessment provides a direct index of an individual's perceived needs and enables services to be directly linked to the target population (Thewes et al., 2004). This type of assessment also allows for the identification of the magnitude of the need for help, allowing resources to be allocated where the need is most urgent (Bonevski et al., 2000). Assessing the needs of a target population provides an opportunity to fully understand the experiences of that group by giving individuals a chance to identify and express the needs they want recognised and addressed by health professionals (Wen & Gustafson, 2004). This enables the development of targeted interventions which are favourable in terms of efficacy, the most efficient use of limited resources, and are a crucial first step in improving the quality and delivery of care.

The psychosocial impact of health conditions on the affected individuals has already led to attempts to assess individuals self-reported needs to improve support services (Hodgkinson et al., 2007). Growing recognition that siblings are also significantly impacted by a young persons' CHC means it is important the self-reported needs of siblings are also investigated and identified so they too can receive targeted support services.

In-line with best practice and understanding the importance of underpinning intervention development with a needs assessment, in collaboration with my primary supervisor, I undertook research to identify the unmet needs of siblings of children with cancer, T1DM and CF in New Zealand (Armstrong, 2020). The unmet needs reported by siblings in this study will be used alongside extant literature to inform the development of a targeted needs-based intervention for siblings (Armstrong, 2020). The needs-based approach will also assist with the timely translation of research findings into the development and provision of a targeted sibling intervention, a process that has historically been found to be slow due to multiple barriers.

Chapter 4 Summary

Despite the variation in findings in the sibling literature, the potential inaccuracies of proxy reporting, and the need to consider the broader influences on siblings' lives, the literature on siblings is compelling. Evidence shows there is a subgroup of siblings who experience significant psychosocial adjustment difficulties, including depression, anxiety and post-traumatic stress symptoms, lower quality of life, and disruption to academic and social functioning. Consequently, there is a growing chorus of voices calling for the development of support services that protect this vulnerable population, both in New Zealand and internationally (Armstrong, 2020; Cohen et al., 1994; Houtzager, Grootenhuis, et al., 2004; Janssens et al., 2010; Long et al., 2018; Murray, 2000; Neville et al., 2016; Patterson et al., 2011; Sharpe & Rossiter, 2002)

Thus, the development and provision of a preventative, evidence-based, comprehensive support service for siblings is critically important. Progress in this area has been slow due to the methodological heterogeneity in the literature on sibling impacts and outcomes causing delays in the translation of sibling research into routine healthcare services, and the more recently recognised need to consider siblings within a socio-ecological framework. However, it is clear the provision of a nationwide psychosocial sibling support service is an imperative component in the supportive care of siblings of children with serious CHCs.

While recognition of the need for sibling support is slowly gaining momentum internationally, with a number of large-scale studies currently underway, the experiences of siblings are set within a cultural context. Therefore, siblings who reside in New Zealand should be provided with a culturally appropriate support service which is underpinned by self-reported needs-based research.

CHAPTER 5: THEORETICAL APPROACH & METHODOLOGY

This chapter describes the theoretical orientation of the study, and the methodological approach selected to answer the research questions.

Theoretical Orientation

A research paradigm is a theoretical framework made up of a set of values and beliefs that guides how knowledge is conceptualised within scientific communities and guides how research is conducted (Morgan, 2007). The pragmatic paradigm developed out of a desire to solve practical problems through scientific inquiry and allows for the use of thoughtful decision-making processes aimed at reaching intended outcomes (Yvonne Feilzer, 2010). It rejects the need to locate a study in either the positivist (postpositivist) paradigm or an interpretivist (constructionist) paradigm and instead seeks to utilise the best approaches to gaining knowledge using every methodology that helps knowledge discovery including the use of both qualitative and quantitative research methods (Kivunja & Kuyini, 2017). In this way pragmatism is based on the premise of using the best methods to investigate real-world problems and allows for a multipronged approach which includes the use of multiple sources of data to answer research questions (Brierley, 2017). A key source of data is human experience which pragmatism argues is a primary means of building knowledge and understanding the world (Kivunja & Kuyini, 2017). The current research is grounded in the pragmatic paradigm weaving together multiple sources of information including human experience, existing literature and cultural context.

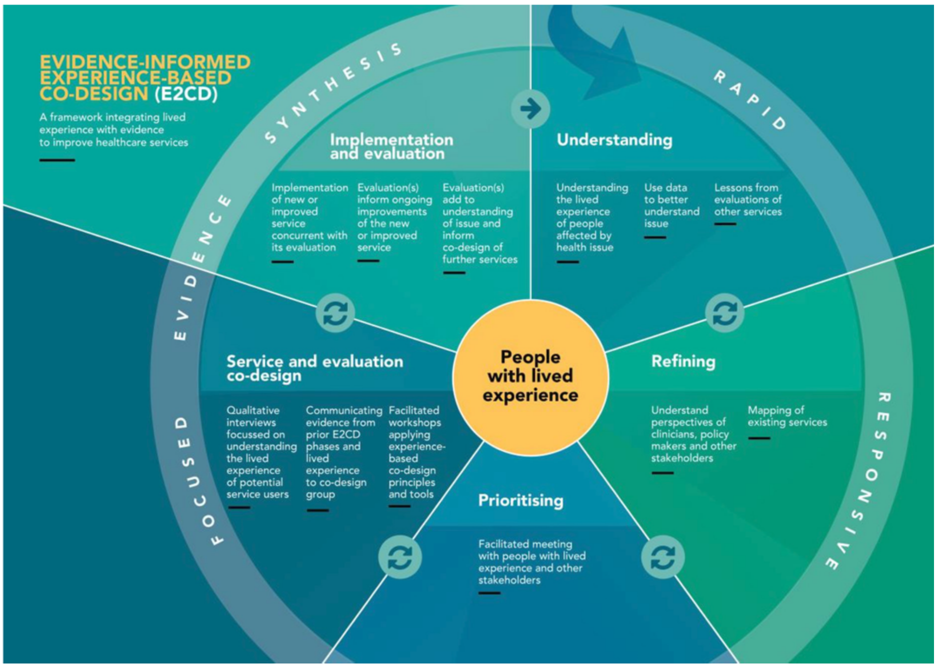
It is increasingly recognised that involving service-users in planning, developing, and implementing services improves the chances of meeting their needs and enhances uptake and sustainability (Rousseau et al., 2019). Experience-based Co-design (EBCD), rooted in action research and design thinking, uses participatory methods that integrate expert knowledge with the lived experiences of the target population (Mulvale et al., 2016; Donetto et al., 2015).

While health services should meet the needs of service users, it is also imperative they deliver evidence-based care. Figure 7 depicts a recently developed framework called Evidence-informed, Experience-based Co-design (E2CD) that integrates research evidence with lived experience that gives people with lived experience a central decision-making role (Morley et al., 2024). Distinguishing key features of E2CD include:

- People with lived experience are kept central to the process and involved in all phases;
- Lived experience, data analysis, and evidence synthesis are integrated throughout the process;
- Researchers are respondent to participant's needs and participants are encouraged to voice questions;
- It includes a priority-setting phase that involves giving people with lived experience an opportunity to decide on co-design priorities;
- Services and their evaluations are co-designed in one process;
- Phases can be revisited as more information emerges (Morley et al., 2024)

Figure 7

Evidence-informed, Experience-based Co-design



Note. Reprinted from "Evidence-Informed, Experience-Based Co-Design: A Novel Framework Integrating Research Evidence and Lived Experience in Priority-Setting and Co-Design of Health Services," by L. Morley et al., 2024, *BMJ open*, *14*(8), e084620. Licensed under CC BY-NC 4.0.

It has been suggested that the E2CD could be particularly useful in health when undertaking research to (re)design health services through the provision of a framework that is likely to result in greater alignment of service development and user's needs (Morley et al., 2024).

In the current study, the development of a psychosocial intervention for siblings of children with serious CHCs is based on the principles of E2CD and grounded in the pragmatic paradigm. The study:

- Has been designed by a sibling with lived experience alongside an experienced clinician;
- Is informed by the lived experiences of service-users (siblings);
- Reviewed previously developed sibling interventions to ensure the existing body of evidence-based research is incorporated into the intervention;
- Incorporates evidence-based therapeutic techniques to meet the self-reported needs of siblings;
- Will incorporate sibling feedback into the intervention design following a feasibility study (outside the scope of the current research project).

Methodology

To address the research questions outlined in the introduction to this thesis (Chapter 1), a two-stage approach was taken, comprising a systematised review and the development of a of Manualised Psychosocial Sibling Intervention.

Stage 1: Systematised Review

The systematised review identified existing sibling interventions in the international literature, reported the efficacy of the intervention on the variables of interest of each study, provided a brief description of the intervention characteristics, and synthesised the findings. Assessment tools were reported for each intervention, in addition to the: targeted health condition/s; study design and aims; sample size and age range of participants, type and format of intervention, whether a comparison group was used, and findings. The methodology used for the systematised review is described fully in Chapter 6.

Stage 2: Development of Psychosocial Intervention for Siblings

In the second stage, a manualised intervention was developed for siblings who reside in New Zealand. The intervention was informed by the systematised review, and my previous needs-based research which identified the unmet needs of siblings of children with cancer and serious health conditions in New Zealand (Armstrong, 2020). In that previous work, I adapted the Sibling Cancer Needs Instrument, a needs-based measure aimed at identifying the unmet needs of siblings of young people with cancer (Patterson et al., 2014), for siblings of children with CHCs who reside in New Zealand (Armstrong, 2020).

The intervention developed for the current research (See Chapter 9 for detailed method) has incorporate evidence-based therapeutic techniques to meet the needs of siblings across the following domains:

1. Relationship with their ill sibling;
2. Understanding from their family;
3. Support from friends and other young people;
4. Dealing with feelings;
5. Time out and recreation;
6. Information about their siblings health condition.

Chapter 5 Summary

This chapter described the theoretical orientation of the study and the methodological approach selected to answer the research questions. The following chapter describes the search criteria of the systematised review, then identifies and describes the interventions that have been developed for siblings of children with CHCs.

CHAPTER 6: SYSTEMATISED REVIEW: INTERVENTIONS FOR SIBLINGS OF CHILDREN WITH CHCS

As described in preceding chapters, paediatric chronic health conditions (CHCs) can cause significant psychosocial distress for the siblings of children who are diagnosed with these conditions. Considering the prevalence of serious childhood CHCs, alongside the specific psychosocial difficulties associated with such health conditions for siblings, interventions that target the siblings of children with serious CHCs are urgently needed. Preventative interventions that are designed to support healthy behavioural and emotional adjustment are of particular interest as they may decrease the risk of psychosocial complications associated with the diagnosis of a CHC.

Recognising the vulnerability of siblings, a number of interventions have already been developed to help improve their outcomes. These have taken various forms, including individual interventions (Prchal et al., 2012; Wallace et al., 2014), group interventions (Dolgin et al., 1997; Houtzager et al., 2001), camps (Sidhu et al., 2006; Williams et al., 2003), and family-based support (Besier et al., 2010; Giallo & Gavidia-Payne, 2008). They have used a wide range of methodological approaches, primary aims, measurement instruments, and populations. Some interventions have taken a transdiagnostic approach and others a condition-specific approach. This variability makes it challenging to compare interventions to determine which approaches are the most effective for improving sibling outcomes. However, two systematic reviews that synthesised the results of existing sibling interventions have been published (Hartling et al., 2014; McKenzie Smith et al., 2018).

The first systematic review of 14 studies published between 1985 and 2008 analysed the findings of interventions developed for siblings of children with a chronic illness or disability (Hartling et al., 2014). This review found a large inconsistency of treatment effects which limited the generalisability of findings and made it difficult to determine which intervention features were critical for the improvement of sibling symptoms. The authors suggested the lack of significant findings could be partially due to the majority of studies taking a universal approach where siblings were included in the intervention despite falling within the ‘normal’ range of mental health prior to the intervention. This highlighted the importance of the sensitivity of measures used to evaluate intervention outcomes particularly when taking a universal ‘health promotion’ approach. The researchers concluded there was the potential for existing interventions to enhance the emotional and behavioural outcomes for siblings but recommended methodological rigour in future research to provide accurate estimates of effect (Hartling et al., 2014).

A more recent review investigating the impact of well-being interventions for siblings of children and young people with a chronic physical or mental health condition also reported variable results (McKenzie Smith et al., 2018). The meta-analysis of 17 studies published between 1990 and 2015 found some evidence of the effectiveness of interventions in the areas of knowledge about the illness, and the pre-test-post-test studies found improvements in both internalising, and externalising behaviours. The authors found the factors that influenced the variability of findings included the following sources of heterogeneity: the variety of techniques used to help improve sibling wellbeing; small samples sizes; poor study designs; and the use of measures with low sensitivity (McKenzie Smith et al., 2018).

Considering the specific psychosocial difficulties associated with such protracted illnesses in the family, and the findings from the reviews above, interventions targeted at siblings of children with serious CHCs are needed. Preventative interventions are of particular interest, as they may decrease the risk of psychosocial complications associated with maladaptive coping and reduce the need for more intensive (indicated) interventions, which focus primarily on psychopathology.

While the reviews provided some evidence for the effectiveness of sibling interventions, the two afore-mentioned reviews adopted broad inclusion criteria which included siblings of children with mental health problems and physical disabilities, in addition to siblings of children with CHCs. The systematised review undertaken for the current research adopts more specific inclusion criteria to focus on siblings of children with CHCs.

Review Methodology

Methodology considers the appropriate methods to accomplish the aims of the research. Grant and Booth (2009) describe systematised reviews as typically including one or more elements of the systematic review process but stopping short of claiming the output is a systematic review. Systematised reviews are typically conducted in postgraduate studies when the resources required for a full systematic review (such as two reviewers) are unable to be drawn upon. Informed by PRISMA (Page et al., 2021) guidelines and the principles of open science, the aspects used in this systematised review similar to that of a systematic review, include:

1. Transparency regarding the purpose and scope of the review;
2. A full search within the chosen databases and reporting of the search terms;
3. Duplicates removed;
4. Records screened;
5. Reports assessed for eligibility; and the inclusion of all identified sibling interventions that met inclusion criteria to minimise selection bias.
6. Studies were then analysed and synthesised.

Search Strategy

Inclusion and Exclusion Criteria

Studies were selected if they evaluated a psychosocial intervention that:

- was developed for siblings of children or young people with cancer or a CHC. Studies with diverse samples (siblings of children with mental health conditions or developmental difficulties) were selected to ensure that studies with any siblings of children with cancer and/or chronic illness were included;
- included participants aged 18-years old or younger;
- included a psychosocial outcome measure;
- used a psychosocial approach (not primarily reliant on medication);
- aimed to prevent or reduce psychosocial problems related to the health condition.

Studies were excluded if the intervention:

- was family-based but did not provide sibling self-report measures and/or siblings were not part of the family-based intervention;

- did not target outcome(s) of interest;
- targeted only siblings of youth with conditions that are not CHCs, such as acute medical illness (e.g., acute pain, broken bone) or neurodevelopmental disorders (e.g., autism spectrum disorder, intellectual disability);
- was developed for bereaved siblings, or siblings of children in palliative care; and
- was not published in English.

Sources

Working with a research librarian, I developed and implemented a search strategy to identify sibling interventions in the following databases: MedLine; Web of Science; SCOPUS; CINAHL; psychINFO; ERIC; and the Cochrane Library with the following:

sibling* OR brother* OR sister* AND “chronic illness*” OR “chronic disease*” OR “cancer*” OR “neoplasm*” OR “oncolog*” OR “tumor*” OR “tumour*” AND “child*” OR “pediatric*” OR “paediatric*” OR “teen*” OR “adoloescen*” OR “youth*” AND intervention* OR therap*.

A total of 4261 studies were identified from the initial searches. After removal of duplicates, 2697 were screened at title and abstract level and 21 studies met criteria.

Included Studies

21 quantitative studies identified as meeting the review inclusion criteria. Study characteristics are summarised below. A more detailed summary of the participants and other study characteristics, as well as source references, is provided in Table 2.

Publication dates: 1990 to 2020. Almost 30% (n = 6) were published between 2018-2022 indicating an increasing awareness and recognition of the need for sibling support.

Country of origin: United States (n = 8), Canada (n = 3), Australia (n = 2), Germany (n = 2) and 1 each from Ireland, Israel, Norway, Netherlands, Switzerland and South Korea.

***Design*:** six of the interventions were randomised control trials and an additional four interventions included control groups. Two of the 11 studies without control groups included two or more measurement timepoints. Of these 21 interventions, 4 were pilot studies.

Interventions targeted: siblings of children with cancer specifically (n = 13), CHCs (n = 3).

Culture: seven of the 21 interventions reported participant ethnicity. Of those seven interventions the range of white participants was between 75.3% to 96.5%. No studies reported outcome data on ethnicity.

Participant samples: typically include some sibling participants between the ages of 12 – 18 years old with the exception of two art therapy intervention studies which included siblings in a younger age group. Over half (n = 14) were family-based; of these, 11 were for siblings and their parents/caregivers, 2 for all family members, and 1 for the affected child and their siblings. Seven of the reviewed studies were developed for siblings only.

Intervention delivery: individual formats (n = 4), group setting comprising between 2-12 sessions (n = 17) with 3 group interventions provided within a camp setting. Interventions were provided by a variety of professionals, including clinical psychologists, clinical psychology and psychiatry trainees, psychologists, plays specialists, clinical social workers, child life specialists, special educators, child psychiatrists, paediatric nurses, art psychologists, interventionists, physicians, psychosocial health professionals, camp counsellors, and art therapists.

A more detailed summary of the participants, as well as the study characteristics are summarised in Table 2.

Table 2 *Intervention Overview*

Author/Name of Intervention	Condition	Design	Participants	Timing	Setting	Siblings (n)	Age	Format	Delivery	Variables of Interest/Findings	Satisfaction
Barrera et al., 2004 (Canada) SibCT	Cancer	PP	FB-S/P	Not specified	Outpatient	47	6-14	Group 8 x sessions	Trained facilitators	SR depression* SR/PR anxiety* PR behaviour problems*	Moderate-high
Barrera et al., 2018b (Canada) SibCT	Cancer	RCT	FB-S/P	>3-months PD + active treatment OR off treatment + follow up care.	Outpatient	75	7-16	Group 8 x sessions	Trained facilitators	SR depression SR/PR QoL	-
Barrera et al., 2018c (Canada) SibCT	Cancer	RCT	FB-S/P	>3-months PD OR off treatment on follow up care.	Outpatient	70	7-16	Group 8 x sessions	Trained facilitators	SR anxiety	-
Besier et al., 2010 (Germany)	Cancer + CHC	PP w/C	FB-AF	Not specified	Inpatient	25	4-16	Group 4-12 sessions	Therapists	SR QoL* PR behaviour problems*	-
Besani et al., 2018 (Ireland)	Cancer	PP	FB-S/P	AT AND >3 months PD	Outpatient	17	7-17	Group 1-day workshop	Clin. Psych Play specialist	SR depression SR anxiety SR self-concept* SR social support*	Moderate
Dolgin et al., 1997 (Israel)	Cancer	PP	Siblings	AT OR <6 months PT	Outpatient	23	7-17	Group 6 x sessions	Clin. Social worker Child life specialist Psych.	SR depression* SR illness-related knowledge* SR adjustment*	High
Giallo & Gavidia -Payne, 2008 (Australia) Sibstars	CHC DD ID	RCT	FB-S/P	Not specified	Inhome/ Online	23	9-16	Individual 6 x sessions	Clinician with postgraduate psych training	PR adjustment SR Coping* PR emotional functioning*	Moderate-high
Haukeland et al., 2020 (Norway) SIBS	CHC	PP	FB-S/P	Not specified	Outpatient	99	8-16	Group 5 x sessions	Clin. Psych Special educator Clin. Psych students	SR adjustment* SR illness-related knowledge* SR emotional problems* PR/SR behavioural problems* SR parent/sibling communication*	High
Heiney et al., 1990 (US)	Cancer	PP w/C	Siblings	Not specified	Outpatient	14	9-15 7 EG 7 CG	Group 7 x sessions	Child psychiatrist Paediatric nurse	SR social adjustment	High
Houtzager, Grootenhuis & Last, 2001 (Netherlands)	Cancer	PP	Siblings	Not specified. TSD: 2 months — 7 years & 5 months	Outpatient	24	7-18	Group 5 x sessions	Psychologists	SR anxiety*	-
Jo et al., 2018 (Korea)	Cancer	PP	Siblings	Complete remission	Outpatient	17	7-10	Individual 12 x sessions	Art psychologist	SR self-esteem* SR anxiety SR depression PR behaviour problems*	-

Author/Name of Intervention	Condition	Design	Participants	Timing	Setting	Siblings (n)	Age	Format	Delivery	Variables of Interest/Findings	Satisfaction
Kazak et al., 2004 (US) Surviving Cancer Competently program	Cancer	RCT	FB-AF	PT>12 months <10 years	Outpatient	99	10-21	Group 1-day intervention	Interventionists Trained therapists	SR PTSD SR anxiety	-
Lobato & Kao, 2002 (US) SibLink	CHC DD LD	PP	FB-S/P	Excl. if affected child at end stage OR <6 months PD	Outpatient	54	8-13	Group 6 x sessions	Doctoral trainees in psychology & psychiatry	PR impact of illness PR behaviour problems* SR illness-related knowledge* SR adjustment*	High
Marusak et al., 2020 (US) Kids Kicking Cancer (KKC)	Cancer CHC	PP	Siblings and ill child	Not specified	Outpatient	23	5-17	Group 1 session	Martial arts therapists	SR emotional symptoms*	High
Niemitz & Goldbeck, 2017 (Germany)	Cancer	Non-randomised control	FB-S/P	Completed acute treatment OR on follow-up treatment.	Inpatient	184	4-18	Group 5 x sessions	Physicians Psychosocial health professionals	SR quality of life SR illness-related knowledge SR emotional symptoms	-
Packman et al., 2004 (US) Camp Oziku	Cancer	PP	Siblings	Not specified	Camp	77	6-17	-	Camp counsellors	SR PTSD* SR anxiety* SR QoL* SR self-esteem*	-
Prchal et al., 2012 (Switzerland)	Cancer	RCT	FB-S/P	<2 months PD	Outpatient	30	6-17	Individual 2 x sessions	Clin. Psychologist	SR illness-related knowledge* SR PTSD SR anxiety SR social support* SR QoL*	
Sidhu, Passmore, & Baker, 2006 (Australia) Camp Onwards	Cancer	PP	Siblings	Active treatment	Camp	31	8-13	Group 4-days	Group facilitators	SR anxiety* SR illness-related knowledge* SR self-concept* SR social adjustment*	-
Wallace et al., 2014 (US)	HSCT	PPw/C	Siblings	HSCT transplant within 3 years	Outpatient	30	6-16	Individual 3 x sessions	Masters level art therapists	SR anxiety SR self-concept SR PTSD*	-
Williams et al., 1997 (US) ISEE	CHC	PP	FB-S/P	Stable health status	Outpatient	22	8-15	Group 11 hours	Paediatric nurse clinician	SR illness-related knowledge*	High
Williams et al., 2003 (US) ISEE	CHC/D	RCT	FB-S/P	Not specified	Camp	79 EG 71 PaT 102 CG	7-15	Group	Paediatric nurse clinician	PR behaviour problems FT* SR illness-related knowledge FT* SR social adjustment FT* PaT* CG* SR depression FT* SR self esteem FT* PaT* SR Negative Attitudes to Illness FT* PaT* CG*	-

Key: CHC-CHCs; DD-Developmental Difficulties; Disabled; ID- Intellectual Difficulties; LD-?; PP-Pretest-Posttest; PPw/C-Pretest-Posttest with Control Group; RCT-Randomised Control Trial; FB-S/P-Family-based Siblings & Parents; FB-AP-Family-based All Family Members; SR-Sibling report; PR-Parent report; *Statistically Significant improvement; HSCT: Hematopoietic Stem Cell Transplant; EG-Experimental Group; CG-Control Group; PaT Partial Treatment; PT-Post-treatment; PD-Post-diagnosis; TSD-Time since diagnosis; AT-Active treatment

Primary Aims

The primary aims of the interventions varied. One study compared the addition of a psychoeducational component to a control group who received Family Oriented Support (FOR) as usual (Niemitz & Goldbeck, 2018). See Table 3 for primary aims of interventions.

Table 3

Primary Aims of Interventions in the Systematised Review

Primary Aims of Interventions	Study Authors
Reducing emotional and behavioural problems of siblings	Barrera et al., 2018; Belsier et al., 2010; Dolgin et al., 1997; Haukeland et al., 2020; Houtzager et al., 2001; Jo et al., 2018; Kazak et al., 2004; Packman et al., 2004; Prchal et al., 2012; Wallace et al., 2014; Williams et al., 2003.
Reducing post-traumatic stress symptoms	Kazak et al., 2004; Packman et al., 2004; Prchal et al., 2012; Wallace et al., 2014.
Improving family functioning	Besani et al., 2018; Giallo & Gavidia-Payne 2008; Wallace et al., 2014.
Improving parent-sibling communication	Haukeland et al., 2020.
Increasing illness-related knowledge	Dolgin et al., 1997, Lobato & Kao, 2002; Sidhu et al., 2006; Williams et al., 1997; Williams et al., 2003.
Increasing adjustment	Giallo & Gavidia-Payne 2008; Heiney et al., 1990; Lobato & Kao, 2002.
Increasing coping	Besani et al., 2018; Giallo & Gavidia-Payne 2008.
Improving quality of life	Belsier et al., 2010; Packman et al., 2004; Prchal et al., 2012;
Improving self-concept	Wallace et al., 2014.
Improving self-esteem	Packman et al., 2004; Williams et al., 2003.
Reducing emotional distress	Marusak et al., 2020; Sidhu et al., 2006.

The following section outlines the structure, key variables, and findings of each intervention. The level of detail provided varies according to the availability and comprehensiveness of information reported in each study.

Sibling Interventions

Family-oriented Group Interventions

Eleven of the studies used family-oriented programs, including all family members (Besier et al., 2010; Kazak et al., 2004) or siblings and their parents (Barrera et al., 2003; Barrera et al., 2018c; Besani et al., 2018; Giallo & Gavidia-Payne, 2008; Haukeland et al., 2020; Lobato & Kao, 2002; Prchal et al., 2012), with one intervention being offered to the affected child and their siblings (Marusak et al., 2020). Based on the principles of family systems theory, these interventions are underpinned by the understanding that parents play a critical role in their child's ability to adapt to living with a chronic illness, both in terms of their child's emotional functioning as well as their child's ability to participate in activities of daily life (Haukeland et al., 2020).

In Germany, family-oriented rehabilitation programs (FOR) are now implemented as the standard of care in four rehabilitation clinics (Besier et al., 2010). The affected child, their parents, and their siblings are offered medical and psychosocial support through a four-week inpatient rehabilitation program aimed at improving the family members wellbeing and quality of life. While the program is tailored to the specific needs of each family, a variety of psychosocial treatments (psychoeducation groups, counselling, art therapy, and relaxation techniques) and physical treatments (medication, physiotherapy and massage) are offered together with educational and leisure programs. Specific interventions for healthy siblings include a weekly psychoeducational group, three sessions of exercise, one relaxation session, and one supportive or psychotherapy session per week. Additionally, specific parent-child sessions which aim to strengthen their often-neglected relationship are also offered up to three times weekly (Besier et al., 2010). The aim is for siblings to learn to talk about their own perceptions and desires and to learn to express difficult emotions such as resentment and anger.

Assessing the efficacy of this program, Besier and colleagues (2010) investigated whether the level of emotional and behavioural problems of children with a chronically ill sibling (cystic fibrosis, congenital heart disease, cancer) decreased during the four-week family-oriented rehabilitation program and whether any beneficial effects were stable over a six-month follow-up period. Parents completed the Strengths and Difficulties Questionnaire (SDQ; Goodman & Goodman, 2009) which is a screening measure of emotional and behavioural problems observed in children, while the siblings completed a self-report quality of life questionnaire (LQ-KID; Goldbeck & Braun, 2003). Findings showed 90% of the siblings who completed the discharge assessment reported a significant reduction in emotional symptoms, conduct problems, hyperactivity/inattention scores, and in the total difficulties score. While in the initial assessment nearly one third of the sample of children with a chronically ill sibling showed at least borderline levels of emotional and behavioural problems, at the time of discharge there were no longer any significant differences between siblings and control group from the German population matched by age, gender and educational background of the parents. The authors concluded family-oriented inpatient rehabilitation is a promising approach to improving the mental health of children with chronically siblings (Besier et al., 2010).

In 2018, Niemitz and Goldbeck performed a controlled study in the four German family-oriented rehabilitation clinics, to investigate the addition of five psychoeducation sessions to the usual inpatient family-oriented rehabilitation program (FOR). The hypothesis that the additional psychoeducational intervention sessions would increase siblings' knowledge about cancer, leading to greater remission of emotional symptoms, and that siblings' quality of life would be improved, was not supported. The authors found significant improvements for both groups from preintervention to postintervention; however, they concluded that overall, the additional psychoeducational sessions did not enhance the outcomes of the siblings in the experimental group (Niemitz & Goldbeck, 2018).

In 2004, Kazak and colleagues conducted a randomised control trial of a one-day, four session, intervention called the *Surviving Cancer Competently Intervention Program* which had two aims: 1. To reduce post-traumatic stress symptoms (using a family therapy orientation) in cancer survivors and their families, and 2. To target anxiety, beliefs about cancer and its treatment, social support, and family communication as areas of change. Post-traumatic stress symptoms are recognised as one of the most important consequences of childhood cancer, as the diagnosis, the disease itself, and treatment and/or treatment complications represent a threat to life which is a central concept of traumatic stress (Kazak et al., 2004).

Session 1: How has cancer affected me and my family? Aimed to promote group cohesion, provide a safe environment and help participants identify cancer-related distressing memories. This session used a cognitive behavioural focus to discuss how post-traumatic-stress memories may continue to be bothersome.

Session 2: Coping Skills. This session focused on coping skills, addressed negative self-talk, and introduced the Adversity/Belief/Consequence model: Adversity is cancer: Beliefs are the thoughts we have about adversities and the basis of self-talk. Consequences are the emotional consequences or feelings about the adversity (the thought-feeling connection is introduced). Reframe beliefs by: Accepting the uncontrollable; Focusing on the controllable; and Using the positive. The majority of time in Session 2 was devoted to siblings identifying their beliefs and consequences, and reframing.

Session 3: Getting on with life. Cancer, Adolescents, and families. This session used the Multiple Family Discussion Model (Steinglass, 1998) to discuss how cancer-related beliefs affect the behaviour of family members. The developmental characteristics of adolescence in the context of illness were also emphasised, such as feeling different from peers, assuming more responsibility, independence, planning for the future (adulthood), and the associated changes in family relationships.

Session 4: Pulling it all together – Family health and our future. This session focused on helping families refine a "take home" message and helped families recognise and respond to distress.

Siblings were not the primary intervention target of this RCT, but detailed findings from mothers, fathers, and cancer survivors were reported and support for the effectiveness of the intervention was found. The exploratory investigation of the impact of the intervention on siblings found no significant differences between the experimental and control groups in either the anxiety or post-traumatic stress symptom measures which included the Impact of Events Scale-Revised (Weiss et al., 1997), Post-Traumatic Stress Disorder Reaction Index (Pynoos et al., 1987), State-Trait Anxiety Inventory (Spielberger, 1983), and Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1985).

The *Siblings Coping Together Program (SibCT)* is an evidence-based intervention developed for the haematology/oncology program at the Hospital for Sick Children in Canada (Barrera et al., 2002) to benefit children with paediatric cancer and each of their family members. The SibCT program addresses siblings' behavioural and emotional difficulties as well as unhelpful views relating to their experience of paediatric cancer (Barrera et al., 2002).

The major conceptual model underpinning SibCT includes behavioural principles and cognitive behaviour theory. Additionally, stress and coping, developmental principles, family systems theory, and group dynamics are constructs and principles that have been integrated into the SibCT framework (Barrera, 2003).

The SibCT program consists of eight weekly sessions, each two hours long. Sessions are conducted in a hospital setting and administered by trained psychosocial healthcare providers under the supervision of a registered psychologist. An overview of the program schedule is outlined below:

Session 1: Introduction/Evaluation aims to create a comfortable and fun setting and establish a baseline evaluation regarding individuals' knowledge about cancer, and their feelings, thoughts and behaviour related to cancer in the family.

Session 2: Medical Education about Cancer directs participants to gain a biological and medical understanding of what cancer is (e.g., different types, medical treatments, variations, side effects).

Session 3: Cancer in the Family Context aims for siblings to gain an understanding of the changes in family daily life events and activities (e.g., role changes) as a result of the paediatric cancer experience. There is also an emphasis on understanding the perspectives of each family member and normalising the changes in the family context.

Session 4: Siblings' Personal Needs supports siblings to identify all types of feelings and troublesome thoughts and ways of expressing them in a socially acceptable manner. There is also a focus on normalising feelings, thoughts, needs, concerns, and building coping strategies for dealing with the feelings and thoughts raised above.

Session 5: Relationships with their affected brother or sister begins with a discussion about normal sibling relationships (both the good and not-so-good things about having a sibling) and emphasises the uniqueness of each sibling and reasons for celebrating that uniqueness.

Session 6: School and Peer Relationships aims for siblings to generate context-specific coping strategies (e.g., how to deal with questions about the ill sibling at school).

Session 7: Focus on the future discusses ways that cancer might affect siblings in both the near future and the distant future and aims to generate hope for a happy future for the sibling regardless of what happens to the brother or sister with cancer.

Session 8: Graduation, Closure, Evaluation has participants review the issues covered and coping skills learned throughout the program, and gives participants the opportunity to celebrate their accomplishment and participate in a graduation ceremony (Barrera, 2003).

The first study that investigated the efficacy of the SibCT intervention used a 'time series' design with two baseline assessments to control for the passage of time, and two post intervention assessments, one immediately after the final intervention session and the other follow-up assessment 6-12 months later (Barrera et al., 2004). Participants included 42 siblings of children with cancer (17 male and 25 female) who had been identified by their parents as having behavioural or emotional difficulties since the affected child began treatment although siblings' perceptions of coping were not assessed (Barrera et al., 2004).

Pre- and post-intervention effects using sibling self-report showed a significant reduction in symptoms of both depression of anxiety at the post intervention assessment. An analysis of the effects of age and gender found adolescent girls had higher depression scores before the intervention than adolescent boys; adolescent girls had higher depression scores after the intervention than younger girls did; and younger boys had the greatest reduction in depression scores from pre to post intervention. The mean group scores of the adolescent girls were at the borderline clinical range before the intervention and returned to normative levels after the intervention. Of the 14 siblings who completed the follow-up measures, the mean scores from post-intervention to follow-up (6-12 months later) remained stable. The authors concluded the study had several methodological improvements over previous studies, such as: controlling for the passage of time; SibCT being a manualised intervention that provided specific conceptual and practical directions; assessments using standardised, objective measures; and the follow-up assessment provided some evidence of the consistency of the intervention's effect (Barrera et al., 2004).

Two recent studies investigated the effectiveness of the SibCT intervention on depression and quality of life (Barrera et al., 2018b) and the other looked at anxiety symptoms of siblings and their caregivers (Barrera et al., 2018c); however, no clear intervention effects were found.

Two further qualitative studies that investigated the SibCT intervention, but did not meet criteria for this systematised review, are important to discuss due to the themes and findings identified by the authors being relevant to this study (Barrera et al., 2018a; Neville et al., 2016). The aim of the 2016 study was to examine siblings' feelings and experiences regarding having a brother or sister with cancer, and their view of the SibCT intervention's impact on them. Twenty-two siblings between 7-18 years old (M=11.7, SD=2.64) took part in the program. Data was collected from homework completed by siblings (in the form of visual materials, text, or both), and logs completed by group observers. The authors used content analysis techniques for text (Cavanagh, 1997) and adaptations of content analysis for visual material (Merriman & Guerin, 2006). Three major categories emerged from the results: siblings' emotional experience related to cancer, their affected brother or sister, and the family; siblings role change and becoming a caregiver, helper and entertainer to the affected child; and changes during the eight-week intervention such as bonding with other siblings, increased trust, participation, and coping strategies (Neville et al., 2016). The text analysis of the third theme documented that as siblings became more comfortable with the group, they gained greater insight into their personal losses and feelings of confusion, frustration, and being left out, in addition to personal gains. Siblings identified benefits to participating in the group intervention (including developing increased problem solving and coping skills), along with the unexpected benefit of positive attention from parents while travelling to and from the group. This study also illustrated how the group became both a trusted environment and a source of support (Neville et al., 2016).

The other qualitative study that investigated the outcomes of SibCT (Barrera et al., 2018a) was structured around arts and crafts. Program targets included learning about cancer, improving emotional control, and learning new coping skills for problem-solving. Using inductive content analysis (Cavanagh, 1997) the following themes across all participants were identified: the importance of having a group just for siblings; improving family relationships; and feeling reassured of the parental role. Themes unique to the SibCT group included: increasing self-confidence; feeling less different; and connecting caregivers and siblings through homework. The authors concluded the importance of qualitative studies for uncovering intervention effects not captured by quantitative measures (Barrera et al., 2018a; Barrera et al., 2018b).

Concerned that parents were not typically being included in sibling group interventions despite evidence that parent and sibling adjustment are interrelated, Lobato and Kao (2002) developed and evaluated a transdiagnostic group intervention called *SibLink* for a sample of 54 parent-sibling dyads of children with developmental difficulties or a chronic illness. The intervention was based on cognitive behavioural principles and included six 90-minute group sessions over a 6–8-week period. Two sessions targeted sibling knowledge and family information exchange; Two sessions focused on identifying and managing siblings' emotions and developing problem solving skills around challenging situations; and One session focused on balancing siblings' individual needs; the final session provided a review and graduation ceremony (Lobato & Kao, 2002).

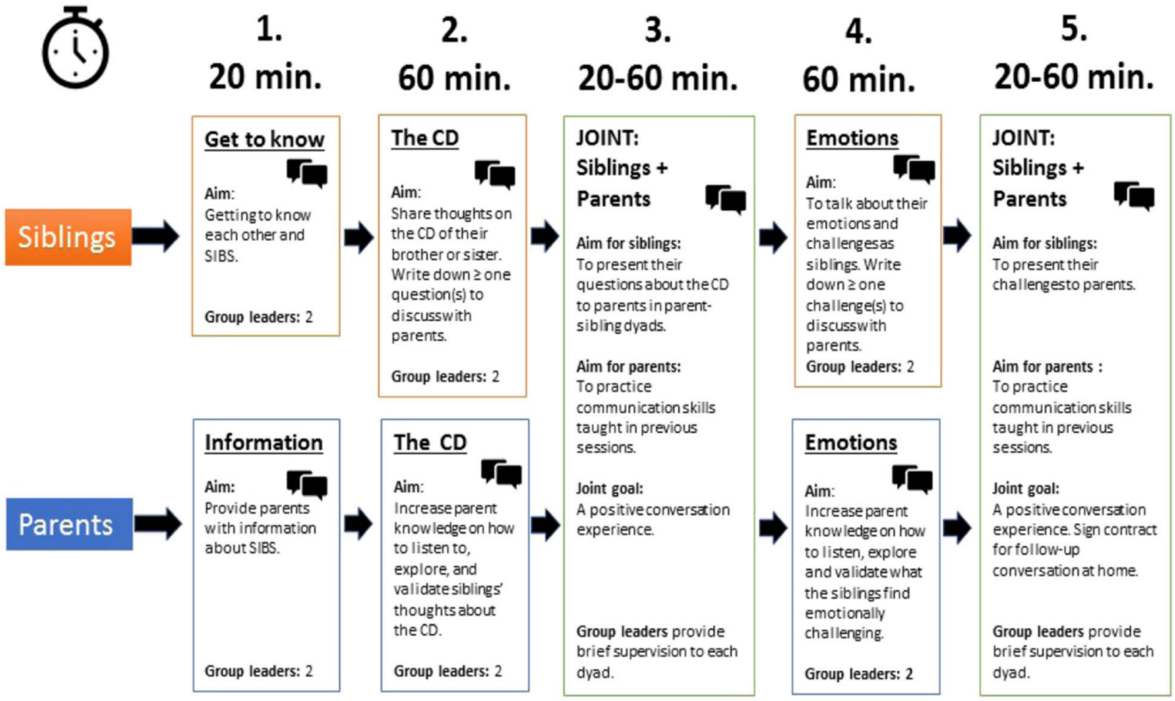
Findings showed siblings' knowledge of the disorder, and connectedness increased, and sibling reports of negative adjustment and parent reports of sibling global behavioural functioning decreased significantly for boys and girls regardless of the health condition. These findings remained stable at the 3-month follow-up. At the time, this study represented a shift from previous sibling group interventions which targeted siblings' needs for information and peer support, to a model that emphasised family as a primary context for sibling understanding and adjustment. When considered from a developmental perspective, the age range of participants (8-13 years) is a period when parents remain the primary attachment figures (Bosmans & Kerns, 2015), so taking a family systems approach was a salient shift.

Acknowledging the importance of family as the vehicle and foundation for support, a recent pilot study developed a family-based intervention for siblings of children with cancer (7-17 years) in Ireland with the aim of improving family functioning, coping, and resilience (Besani et al., 2018). This intervention focused on problem solving therapy with respect to worries and fears, narrative techniques to assist with emotion processing and meaning making, medical education, and psychoeducation within a systemic framework (Besani et al., 2018). Findings showed little change in the depression and anxiety subscales of the Beck Youth Inventory between pre- and post-intervention assessments; however, the improvement on the subscale of self-concept approached significance. Gains were most evident for siblings in terms of increased use of social support and a decrease in self-perceived vulnerability and avoidance strategies. The uptake rate of the intervention was low, and the authors suggested this barrier to treatment could be overcome by offering the intervention as part of the standard care for all families when a child is diagnosed with cancer.

A study that assessed the feasibility of an intervention for siblings of children with chronic diseases called *SIBS* was conducted in Norway (Haukeland et al., 2020). Expressing concerns that existing interventions for siblings are time-consuming (which adds burden to already strained families) and often including no parental involvement when there are documented links between family communication and sibling adjustment, the focus in the development of this intervention was brevity and parent-sibling communication. Delivered as part of a two-night camp, this intervention involved five sessions, three parallel sessions for parents and siblings and two joint sibling-parent sessions (See Figure 8 for a session overview).

Figure 8

The SIBS Intervention



Note. Reproduced from "Evaluation of "SIBS," An Intervention for Siblings and Parents of Children With Chronic Disorders," by Y. B. Haukeland, N. O. Czajkowski, K. W. Fjermestad, et al., 2020, *Journal of Child and Family Studies, 29*, 2201–2217. Licensed under CC BY.

The findings from this first trial of SIBS showed significant improvement in sibling reported parent-sibling communication, knowledge of the chronic illness, emotional and behavioural functioning, and adaptation to the illness. Findings also showed the quality of parent-sibling communication at least partially accounted for the improvement in siblings' mental health symptoms. This led the authors to hypothesise that parent-sibling communication may be central to sibling's mental health and that siblings may benefit from interventions that focus on strengthening parent-sibling communication and empowering parents in their provision of informational and emotional support to siblings (Haukeland et al., 2020).

In response to the lack of empirical data available for interventions that promote psychological adjustment in siblings of children with cancer, Prchal and colleagues (2012) developed a two-session individual intervention for siblings between the ages of 6 and 17 years and ran a randomised control trial pilot study to evaluate its effectiveness. A key point of differentiation used in this intervention was the targeting of a specific time period since diagnosis. The intervention was tailored to the needs specific to the first two months following the cancer diagnosis, a stage which had previously been identified as the most vulnerable for siblings' adjustment (Prchal et al., 2012). Targeting siblings in this early stage of treatment prioritises prevention rather than the treatment of psychopathology.

The RCT was run through two children's hospitals in Switzerland and involved three stages. The two fifty minute sessions included a three-step program: (1) medical information focusing on siblings' understanding of body functioning, the illness, and treatment, (2) coping with stressful situations (this took a cognitive behavioural approach informed by the previously-described coping and stress model developed by Lazarus and Folkman, 1984), and (3) information for parents which was provided in the form of a psychoeducational booklet providing information on how parents can support siblings (Prchal et al., 2012). Findings showed no intervention effects with regard to parent-reported health quality of life, anxiety, or post-traumatic stress symptoms, but a positive impact was found on the medical knowledge of siblings, social support, and psychological wellbeing (Prchal et al., 2012).

Sibling-only Group Interventions

The first study that utilised objective measures to assess the effectiveness of an intervention for siblings (aged 5-9-years old) of children with cancer was carried out by Heiney and colleagues in 1990. The authors used a quasi-experimental non-equivalent control to evaluate the seven-session intervention which focused on diagnosis, treatment, school, coping, family relationships, and the future (Heiney et al., 1990). Findings showed no intervention effects, and the authors suggested the measurement tool may not have tapped into the therapeutic benefits the participants received. They also recommended parents should be educated regarding siblings' concerns.

In 1997 a structured group intervention for siblings of children with cancer was developed by Dolgin and colleagues. The six-week program was adapted for siblings aged 7-11 years and aged 12-17 years and used the following methods: facilitated group discussion; art intervention techniques (Mandala technique; Sourkes, 1991); role playing; and informal social interaction (Dolgin et al., 1997). Results confirmed statistically significant gains in cancer-related knowledge, mood, communication, and intra/interpersonal feelings following the group session.

A five-session support group for siblings (7-18 years old) of paediatric oncology patients aimed to reduce anxiety in this cohort (Houtzager et al., 2001). Identifying that uncontrollability is one of the core characteristics family members must face when a child is diagnosed with cancer and, that anxiety is the most salient emotion evoked by uncontrollability, the support group focused on enhancing feelings of control. A brief overview of each session's goals are as follows:

Session 1: Focused on getting to know eachother;

Session 2: Targeted the processes of change siblings have experienced including changes in attention from significant others and changes in family life and focuses on enhancing problem solving abilities;

Session 3: Focused on recognising and sharing emotions related to the illness (guilt, anger, loneliness, fear, and helplessness);

Session 4: A paediatric oncologist joined the group to answer questions posed by the participants; and

Session 5: Involved siblings visiting the oncology ward to increase their understanding of the illness and strengthen their confidence in the medical professionals caring for their unwell brother or sister.

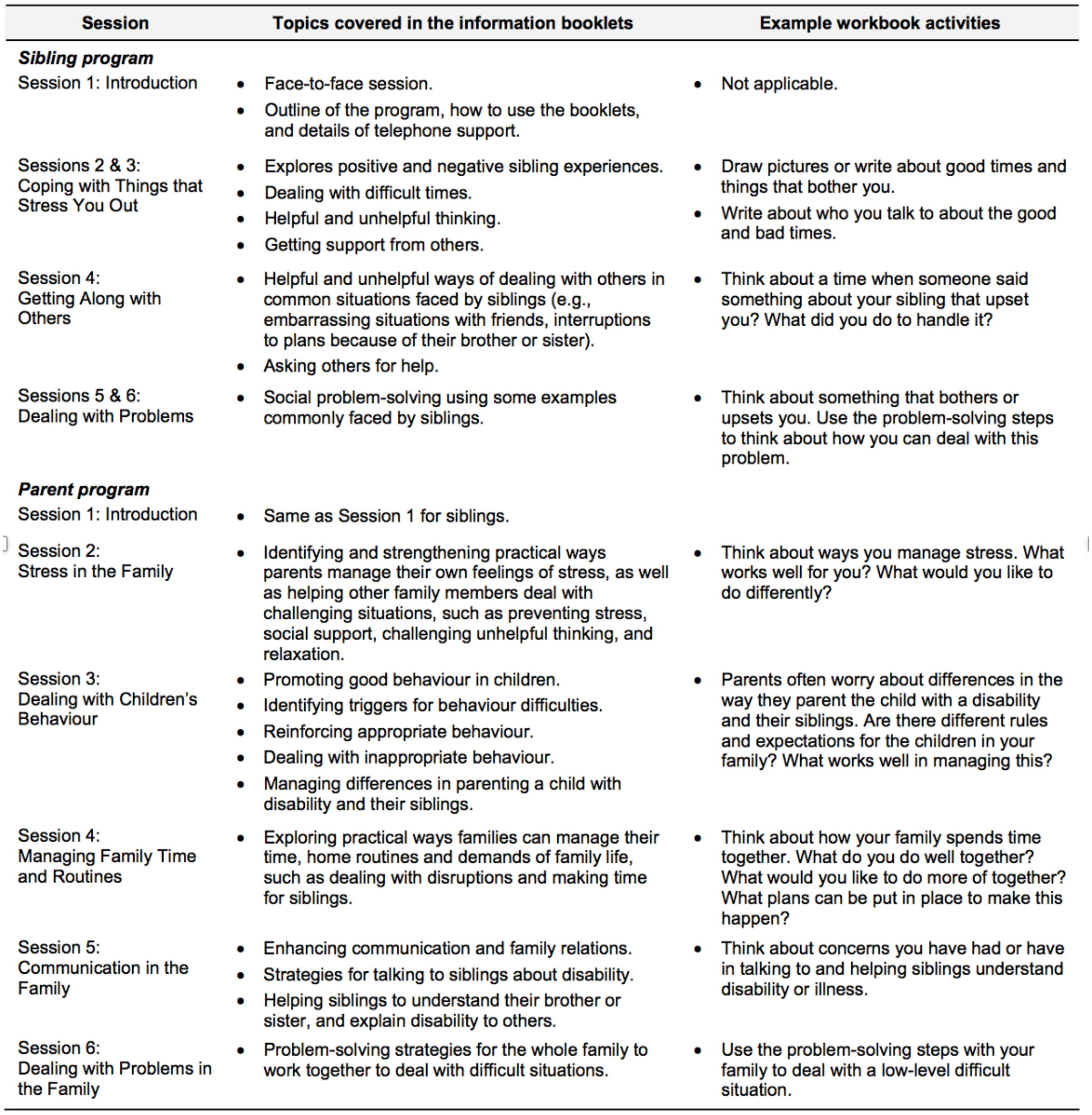
Findings from this study showed the majority of siblings experienced relatively high anxiety scores before group participation when compared to normative data, and the mean anxiety score of group participants was significantly lower after group participation. The authors concluded this study supported earlier research which found that exposure to relevant information was associated with anxiety reduction and that participation in a support group may be beneficial for some siblings (Houtzager et al., 2001).

Sibstars (Giallo & Gavidia-Payne, 2008) was developed in Australia and built on the findings of the Siblink intervention (Lobato & Kao, 2002). Using a randomised controlled design Sibstars is a family-based psychoeducational intervention based on cognitive behavioural principles (Giallo & Gavidia-Payne, 2008). With the aim of improving sibling outcomes, it was delivered to siblings (aged 8-16 years) and parents of children with a disability or chronic illness via telephone and email (Giallo & Gavidia-Payne, 2008). Prior research by the SibLink authors had found high levels of parental stress, poor family communication and problem solving, and limited time spent together as a family were predictive of sibling adjustment problems (Giallo & Gavidia-Payne, 2006). These findings led to the hypothesis that an intervention targeting sibling, parent, and family functioning might be effective and that addressing parent concerns about the impact of illness on the family and supporting them to strengthen family functioning may be just as important as providing direct support to siblings.

The Sibstars program content was informed by research into effective cognitive behavioural programs for children with behavioural and emotional adjustment difficulties in addition to effective family-based approaches for working with families experiencing difficult life circumstances (Giallo & Gavidia-Payne, 2008). The aims of the study were to obtain data regarding the efficacy of Sibstars in strengthening sibling coping, family problem-solving communication, parenting behaviour, family time and routines, family hardiness, and decreasing sibling stress and adjustment problems, alongside assessing satisfaction with the intervention (Giallo & Gavidia-Payne, 2008). The Sibstars program was delivered to families using written information and telephone support (see Table 4).

Table 4

Overview of the Sibstars Program



Session	Topics covered in the information booklets	Example workbook activities
Sibling program		
Session 1: Introduction	- Face-to-face session. - Outline of the program, how to use the booklets, and details of telephone support.	- Not applicable.
Sessions 2 & 3: Coping with Things that Stress You Out	- Explores positive and negative sibling experiences. - Dealing with difficult times. - Helpful and unhelpful thinking. - Getting support from others.	- Draw pictures or write about good times and things that bother you. - Write about who you talk to about the good and bad times.
Session 4: Getting Along with Others	- Helpful and unhelpful ways of dealing with others in common situations faced by siblings (e.g., embarrassing situations with friends, interruptions to plans because of their brother or sister). - Asking others for help.	- Think about a time when someone said something about your sibling that upset you? What did you do to handle it?
Sessions 5 & 6: Dealing with Problems	- Social problem-solving using some examples commonly faced by siblings.	- Think about something that bothers or upsets you. Use the problem-solving steps to think about how you can deal with this problem.
Parent program		
Session 1: Introduction	- Same as Session 1 for siblings.	
Session 2: Stress in the Family	- Identifying and strengthening practical ways parents manage their own feelings of stress, as well as helping other family members deal with challenging situations, such as preventing stress, social support, challenging unhelpful thinking, and relaxation.	- Think about ways you manage stress. What works well for you? What would you like to do differently?
Session 3: Dealing with Children's Behaviour	- Promoting good behaviour in children. - Identifying triggers for behaviour difficulties. - Reinforcing appropriate behaviour. - Dealing with inappropriate behaviour. - Managing differences in parenting a child with disability and their siblings.	- Parents often worry about differences in the way they parent the child with a disability and their siblings. Are there different rules and expectations for the children in your family? What works well in managing this?
Session 4: Managing Family Time and Routines	- Exploring practical ways families can manage their time, home routines and demands of family life, such as dealing with disruptions and making time for siblings.	- Think about how your family spends time together. What do you do well together? What would you like to do more of together? What plans can be put in place to make this happen?
Session 5: Communication in the Family	- Enhancing communication and family relations. - Strategies for talking to siblings about disability. - Helping siblings to understand their brother or sister, and explain disability to others.	- Think about concerns you have had or have in talking to and helping siblings understand disability or illness.
Session 6: Dealing with Problems in the Family	- Problem-solving strategies for the whole family to work together to deal with difficult situations.	- Use the problem-solving steps with your family to deal with a low-level difficult situation.

Note. Reprinted from Evaluation of a Family-Based Intervention for Siblings of Children With a Disability or Chronic Illness," by R. Giallo & S. Gavidia-Payne, 2008, *Australian e-Journal for the Advancement of Mental Health, 7*(2). Reprinted by permission of Informa UK Limited, trading as Taylor & Francis Group, https://www.tandfonline.com.

Results showed the Sibstars intervention was effective in strengthening siblings' emotional functioning but had limited impact on conduct problems, hyperactivity, and peer problems (Giallo & Gavidia-Payne, 2008). In terms of coping strategies (measured by sibling self-report) findings suggested Sibstars was more effective at decreasing ineffective coping strategies rather than increasing proactive coping strategies (Giallo & Gavidia-Payne, 2008).

Recreation Camps

Recreation camps have become an increasingly popular method of psychosocial intervention both for the affected child, and for their parents and siblings. Children with chronic medical conditions who attend camps often report positive psychosocial change including increased hope and positive outlook regarding their future. Family members who attend camps also report positive psychosocial outcomes (Barr et al., 2010).

Two interventions for siblings *Experience Enhancement (ISEE)* studies were included in this review: both the pilot, which confirmed feasibility and acceptability (Williams et al., 1997), and a randomised control trial that was delivered in a camp format (Williams et al., 2003).

Williams et al. (2003) used a residential camp setting to run a RCT with 292 siblings (aged 7-15 years) of children with cancer, diabetes spina bifida, and diabetes. The trial had three parts, with the full intervention (*n*=79) including structured teaching about the brother or sister's illness, psychosocial sessions, a 5-day residential summer camp, and two booster sibling sessions and parent sessions. The partial treatment involved participation in the residential camp without the psychoeducational and psychosocial sessions (*n*=71), and the control group (*n*=102) attended camp after the last data collection.

For siblings in the full ISEE intervention, the first aspect was educational, where information about the four diagnostic conditions was presented with siblings separated into diagnosis-specific groups. The second component was psychosocial and psycho-recreational sessions, in which all siblings were grouped together; these sessions focused on discussing scenarios about common sibling experiences and problems and creating solutions. The psycho-recreational sessions, involving games and activities with peers and parents to foster positive bonding between siblings and their parents. Finally, there was a transdiagnostic parent group session with a focus on developing and enhancing parental focus on sibling needs.

The six outcomes of interest in this study (social support; knowledge about the illness; mood; self-esteem; attitudes; and behaviour problems) were measured at 5-days, and 4-, 9-, and 12-months post-intervention. A dose-response relationship to the intervention was found with the full treatment group showing significant improvements on all six outcomes over most time periods; the partial treatment group (camp only) showing significant improvements on three outcomes (social support, self-esteem, and negative attitudes towards the illness); and the control group (camp only after assessments completed) showed significant improvements on two outcomes (attitudes towards the illness and social support; Williams et al., 2003). Findings also showed these treatment gains were sustained over a 12-month period (Williams et al., 2003). Importantly, this study supported a transdiagnostic approach to chronic illness. With the exception of knowledge about the illness, any differences between illness diagnoses and outcome variables were non-significant (Williams et al., 2003).

In 2004, Packman and colleagues used a pretest-post-test study design to assess *Camp Oziku* which aimed to provide siblings of children with cancer with peer interactions that helped validate their feelings, and increase their confidence and self-esteem (Packman et al., 2004). A group setting was used for siblings to come together for a facilitated discussion of their unique family situations and to share tips on coping strategies. Seventy-seven siblings completed post-test measures revealing significant decreases on all measures. It is notable that baseline testing revealed 38% siblings had post-traumatic stress symptoms prior to the camp; while that dropped significantly to 18% at the post-camp assessment, the authors concluded that this highlights the need for sibling support services more broadly (Packman et al., 2004).

In 2006, Sidhu and colleagues conducted a four-day sibling support camp called *Camp Onwards* as an early intervention strategy for siblings of children with cancer with the aim of reducing distress, improving social competence, and improving knowledge about the impact of cancer and its treatment. A camp format was chosen following a review of the literature which highlighted that weekly interventions often yield poor attendances (Sidhu et al., 2006). The intervention delivered four sessions to siblings divided into three age groups (6-7, 8-9, and 10-13).

Session 1: Develop trust and safety between group members, get to know each other, establish group rules, and outline the purpose of the group.

Session 2: Develop self-awareness and a sense of identity through art activities, exploration of feelings, explore individual stories, provide normalisation and validation of individual experiences.

Session 3: Psychoeducation about the stress response, identify coping strategies, and learn relaxation strategies.

Session 4: Extend group interaction, explore the journey, closure.

To analyse the effectiveness of the intervention, the authors selected the following measures for their sensitivity for picking up subtle emotional and behavioural changes and clinical disorders: The Self

Report of Personality (Reynolds & Kamphaus, 1992), The Self Perception profile for Children (Harter, 1985), and the Sibling Perception Questionnaire (Carpenter & Sahler, 1991). Scoring at baseline showed 40% of siblings fell between the at-risk and clinically significant range in terms of mental health distress. Post-intervention assessments found camp participants reported less anxiety and psychological stress, and an increase in knowledge about cancer (Sidhu et al., 2006). Siblings also perceived themselves to be less isolated, felt more important, and enjoyed greater social acceptance. The authors recommended that timely interventions would prevent more severe problems from developing and would potentially reduce the burden on families (Sidhu et al., 2006).

Art Therapy Interventions

Two art therapy intervention programs were identified in the literature (Jo et al., 2018; Wallace et al., 2014). Art therapy is a tool that encourages emotional expression through art and can be particularly effective in children as it allows those who struggle to accurately verbalise their thoughts and feelings to convey these effectively (Beebe et al., 2010).

The first intervention was developed for siblings of children undergoing hematopoietic stem cell transplantation which is a medical treatment for many childhood cancers and non-malignant diseases (Wallace et al., 2014). The study, which included siblings between the ages of 6-18 years old, aimed to improve the psychosocial wellbeing of siblings across three sessions:

Session 1: concentrated on the expression of feelings to give siblings a voice with which they could express their thoughts and feelings, while the art therapist normalised and validated the siblings' feelings and provided support.

Session 2: focused on exploring changes in family functioning and encouraged siblings to vent in an age-appropriate way the changes and difficulties the family encountered during the HSCT process.

Session 3: took place three months following the completion of HSCT treatment and used an animal metaphor to encourage self-exploration and an awareness of their own strengths.

The study found no differences for self-reported anxiety or self-concept, or parent-reported family functioning or post-traumatic stress symptoms; however, an improvement of statistical significance was found for self-reported post-traumatic stress symptoms (Wallace et al., 2014). This discrepancy between self-report and parent-report is a reminder to interpret any proxy reporting with caution. The authors concluded that art therapy interventions should be considered for increasing siblings' coping strategies and reducing maladaptive reactions (Wallace et al., 2014).

A subsequent 12-session art intervention pilot for younger siblings of children with cancer (7-10 year olds) used a quasi-experimental study design to explore the effects of an art intervention on siblings' self-esteem, anxiety, depression, and problem behaviour (Jo et al., 2018). Individual sessions with a therapist adhered to the following format:

Sessions 1-3: focused on getting to know each other and building rapport.

Sessions 4-8: were the "releasing stage" which was designed to help children experience the freedom of feeling and relieve pent up feelings through expression.

Sessions 9-12: were the "soaring" stage which focused on providing hope for the future and positive awareness.

Findings showed statistically significant improvements in self-esteem and 5 of the 13 items in the Problem Behaviour Syndrome Scale (somatic symptoms, aggressiveness, externalising problems scale, total problem behaviour scale, and emotional instability; Jo et al., 2018).

While these two art interventions used a variety of different measures, they both utilised the Revised Children's Manifest Anxiety Scale to measure anxiety; however no significant effect was found for anxiety in either of these studies (Jo et al., 2018; Wallace et al., 2014).

Martial Arts Intervention

The application of martial arts in health maintenance has been well-documented (Bluth et al., 2016). Both physical and meditative martial art modalities have been shown to increase flexibility, range of motion, mental focus, and decrease anxiety and stress (Baxter & Francis, 2013). Kids Kicking Cancer (KKC; Marusak, 2020) is an international organisation that provides martial arts-based therapy for children with cancer, other CHCs, and their siblings. KKC uses martial arts-based techniques including meditation, breathing, and specific empowering movements to help children cope with pain and distress related to their illness and treatment (Marusak et al., 2020).

Marusak and colleagues (2020) extended this research to a transdiagnostic population by trialing the efficacy of the KKC intervention in reducing pain and emotional distress in children with cancer and other chronic diseases, as well as their siblings. The intervention is intended to imbue the participant with self-control, awareness, and a feeling of empowerment which is achieved through mind-body movements which move the participant from passive acceptance to active engagement towards change (Marusak et al., 2020). Peace is derived from acceptance of one's current situation and can mitigate negative feelings, while purpose introduces elements of conviction and positive value and can help transcend one's situation (Marusak et al., 2020). Participants reported on their pain and emotional distress before and after a standard KKC session and findings showed no changes in siblings pain symptoms; however, of the 26% of siblings who reported pre-session distress, 100% reported a reduction in distress (Marusak et al., 2020). Longer-term effects of the intervention have not been investigated.

Summary of Interventions

In summary, a range of interventions have been developed to support sibling adjustment to a sibling's CHC using diverse intervention formats, delivery methods, and measurement instruments. Key findings from the quantitative studies are that social support is reliably elicited through the use of a sibling group format, while sibling-only groups fail to address adjustment within the context of the family system. This is an important consideration given research shows a strong relationship between sibling, parent, and family functioning (Giallo & Gavidia-Payne, 2006). The reviewed studies also showed that cognitive-behavioural approaches to sibling support are encouraging in the areas of psychoeducation, management of emotions, problem solving, reframing unhelpful cognitions, relaxation techniques, and problem-solving strategies. As highlighted by Barrera and colleagues (2004) measuring the effectiveness of interventions that are preventative and focus on health promotion rather than ameliorating psychopathology can be challenging. Kazak et al. (1994) suggested it is likely that the types of differences seen in siblings of children with cancer are not indicative of psychopathology but related to more subtle aspects of adjustment and coping.

Barrera and colleagues (2018a) argued that quantitative measures do not always capture intervention effects, and that qualitative approaches can offer a rich description which complement quantitative findings. Interventions that use qualitative methods add a richness and depth to sibling experiences. For example, intervention findings such as improved family relationships, feeling reassured of the parental role, and gaining greater insight into feelings of confusion, are valuable improvements but also difficult to capture through the use of quantitative measures. One of the strongest themes to come out of the qualitative studies that used a group format, was the value of belonging to a group for siblings which became a trusted environment and a source of support. In fact, Barrera et al., (2018b) suggested one of the factors leading to no intervention effects in an RCT of the SibCT intervention, is that the control group also took part in a weekly support group (without receiving the SibCT intervention) and the benefits of being part of a support group in general may result in improvements.

Theoretical Orientation of Interventions

The theoretical orientations underpinning the development of interventions were varied. These are discussed in turn below.

Family Systems Theory

Family systems theory views the family as a complex system in which each family member is an important component in the overall functioning of the family unit. It recognises that family systems function within larger systems (e.g., school, hospital, community, society) and that there are subsystems within the family. A major health challenge (such as the presence of a CHC) can destabilise family functioning, affecting all individual members of the family and the family as a whole. There is evidence that subsystems within the family (sibling-parent and sibling-ill child) and the environment (sibling-peer relationships and sibling-teacher relationships) are important to sibling wellbeing, and these have been identified and addressed in the majority of interventions included in this review.

Approximately half of the interventions identified family systems theory as a key part of the theoretical framework (Barrera et al., 2004; Barrera et al., 2018b; Barrera et al., 2018c; Besani et al., 2018; Besier et al., 2010; Giallo & Gavidia-Payne, 2008; Haukeland et al., 2020; Kazak et al., 2004; Williams et al., 2003), and the majority of the remainder included approaches that encompassed aspects of family systems theory in one or more of the sessions (Dolgin et al., 1997; Heiney et al., 1990; Jo et al., 2018; Lobato & Kao, 2002; Niemitz & Goldbeck, 2018; Wallace et al., 2014).

Cognitive Behavioural Theory

Some of the reviewed interventions described using cognitive behavioural theory (CBT) as a key part of the theoretical framework including the three SibCT interventions (Barrera et al., 2004;

Barrera et al., 2018a; Barrera et al., 2018b) and interventions by Kazak and colleagues (SCCIP; 2004) and Prchal and colleagues (2012). The four-session Surviving Cancer Competently Program (SCCIP) by Kazak and colleagues (2004) had a strong CBT focus in the first two sessions. The psychoeducation component focused on how post-traumatic memories can continue to be distressing, and there was an emphasis on developing coping skills for these memories. The ABC Model (Adversity, Beliefs, Consequences) was introduced, self-talk was identified, and reframing was practiced (Kazak et al., 2004).

The manualised SibCT intervention (Barrera et al., 2004; Barrera et al., 2018a; Barrera et al., 2018b) also used a CBT framework which focused on reframing siblings' cognitive distortions (such as "I am not important") and problem-solving skills. Through group exercises and discussions, siblings learnt cognitive skills that may be helpful for coping with the unique stressors of childhood cancer.

Prchal and colleagues (2012) took a CBT approach in the second part of the intervention which involved learning to cope with stressful situations. Siblings were encouraged to think of the three most significant stressors following their brother or sister's cancer diagnosis; these were looked at in detail and helpful coping strategies were discussed. Referring to the coping and stress model (Lazarus & Folkman, 1984), siblings learnt to appraise stressors and develop coping strategies in response to their specific situation.

These studies demonstrate how CBT has been utilised for addressing certain aspects related to sibling distress including the development of problem-solving skills to help siblings successfully navigate their change in circumstances, and reframing some of the cognitive distortions that can result from a family's response to a paediatric chronic health diagnosis.

Developmental Theory

The consideration of developmental maturity level and individual attention skills is necessary to plan activities that are suitable for each sibling's developmental needs. Tailoring interventions to siblings' cognitive, affective, and social levels of functioning is important for intervention effectiveness (Sidhu et al., 2006). In this review, all but one intervention (Kazak et al., 2004) specified the target age group, with two interventions (Haukeland et al., 2020; Sidhu et al., 2006) divided into two or more age groups. It is of note that the majority of studies in this review specified age groups that spanned two developmental periods (middle childhood and adolescence) and the intervention details make it difficult to ascertain whether the groups were divided into developmental stages.

Group Theory

The majority of the interventions included in this review took a group therapy approach which involves two or more individuals meeting face to face in a safe environment with the purpose of achieving mutually agreed upon goals (Gladding, 2003). This has multiple benefits and is a highly effective form of psychotherapy (at least equal to individual psychotherapy in its power to provide benefit) and makes more efficient use of mental health resources (Yalom & Leszcz, 2020). In any group intervention, the dynamics that develop amongst the members play an important role in the effectiveness of the intervention. It provides a forum where people with similar experiences can come together and explore those experiences, providing each other with mutual support. Often the realisation that one's experiences are a shared phenomenon leads to an atmosphere of hope (Langford, 1987).

Chapter 6 Summary

The purpose of this systematised review was to: 1) identify existing sibling interventions available to young people who have a sibling with a serious CHC; 2) identify the findings of the interventions and to what extent the expected outcomes on the variables of interest were achieved; and 3) identify the findings that are important to consider and applicable to the development of an intervention for siblings of children who reside in New Zealand.

Studies in this review included siblings of children with a range of CHCs including: cancer (including but not limited to leukaemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, Ewing's sarcoma, rhabdomy osarcoma, neuroblastoma, brain tumour, acute lymphoblastic leukemia, acute myeloid leukemia, osteogenic sarcoma, hepatoblatoma, and ependymoma), cystic fibrosis, spina bifida, congenital heart disease, and three studies included siblings of children with a broader range of conditions. Findings from the baseline data of studies in this review further clarified that paediatric CHCs can have significant and detrimental impacts on siblings and there is a need for interventions to be developed that ameliorate these adverse effects (Besier et al., 2010; Packman et al., 2004; Sidhu et al., 2005). All but one of the reviewed interventions (Barrera et al., 2004), took a preventative approach to sibling support.

A full synthesis of the findings from the review are presented in the following chapter.

CHAPTER 7: SYNTHESIS OF SYSTEMATISED REVIEW FINDINGS

The reviewed interventions (see Table 6) used a wide range of measures to evaluate targeted outcomes (see Table 7 for intervention measures) and findings varied. While some studies included proxy reporting by parents, due to the broadly recognised discrepancies between self-report and proxy-report, alongside the importance of understanding sibling experiences from an emic perspective, this review focused on the variables of interest that used sibling self-report (other than behavioural problems which used, parent report).

This chapter considers the effectiveness of the reviewed interventions on the key variables of interest and discusses important considerations for the development of a psychosocial sibling interventions.

Table 5

Intervention Measures

Variables	Measure	Studies that used the measure
Post-traumatic stress symptoms	Impact of Events Scale (Weiss & Marmar, 1997)	Kazak et al., 2004
	The University of California at Los Angeles Post-traumatic Stress Disorder Reaction Index (Steinberg et al., 2004)	Kazak et al., 2004; Prchal et al., 2012; Wallace et al., 2014; Packman et al., 2014
Depression	Child Depression Inventory (Kovacs, 1992)	Barrera et al., 2004; Barrera et al., 2018b
	Becks Youth Inventory: Depression subscale (Beck, 2005)	Besani et al., 2018
	Mood Questionnaire (Sahler & Carpenter, 1989)	Dolgin et al., 1997
	DAS Test (Silver, 1993)	Jo et al., 2018
	Sibling Perception Questionnaire, Revised -Mood Scale (Sahler & Carpenter, 1989)	Williams et al., 2003
Anxiety	Multidimensional Anxiety Scale for Children (March, 1997)	Barrera et al., 2018c
	Becks Youth Inventory: Anxiety subscale (Beck, 2005)	Besani et al., 2018
	Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1985)	Jo et al., 2018; Kazak et al., 2005; Wallace et al., 2014; Packman et al., 2004;
	State-Trait Anxiety Scale for Children (Spielberger, 1983)	Barerra et al., 2004; Houtzager et al., 2001
	The Spence Children's Anxiety Scale (Spence, 1998)	Prchal et al., 2012
	Behaviour Assessment System for Children: The Self-Report of Personality (Reynolds & Kamphaus, 1992)	Sidhu et al., 2006
Adjustment/ Social Adjustment	Children's Coping Strategies Checklist (Ayers & Sandler, 1999)	Besani, 2010
	The Sibling Daily Hassles and Uplifts Scale (based on items from the Daily Life Stressors Scale; Kearney et al., 1993)	Giallo & Gavidia-Payne, 2008
	The Self-Report Coping Scale (Causey & Dubow, 1992)	Giallo & Gavidia-Payne, 2008
	Negative Adjustment Scale (Sahler & Carpenter, 1989)	Haukeland et al., 2020
	Social Adjustment Scale – Self Report (Weissman & Bothwell, 1976)	Heiney, 1990
	Social Support Scale (Prchal et al., 2012)	Prchal et al., 2012
	Social Support Scale for Children (Harter, 1985b)	Williams, 2003
Self-perception	Self-Perception Profile for Children (Harter, 1985a)	Sidhu et al., 2006; Williams et al., 2003
	Sibling Perception Questionnaire (Carpenter & Sahler, 1991)	Sidhu et al., 2006; Lobato & Kao, 2002; Niemitz & Goldbeck, 2018; Williams et al., 2003
	Piers-Harris Children's Self Concepts Scale, Second Edition (Piers et al., 2002).	Jo et al., 2018
	Feelings and Attitudes Questionnaire (Sahler & Carpenter, 1999)	Dolgin et al., 1997
	Beck Youth Inventory: subscale self-concept (Beck, 2005)	Besani et al., 2018
	The Self-Esteem Scale (Choi & Chum, 1993)	Jo et al., 2018
	Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Packman et al., 2014
Quality of life	Pediatric Quality of Life Inventory (Varni et al., 1999)	Barrera et al., 2018; Packman, 2004
	LQ-Kid (Goldbeck & Braun, 2003)	Niemitz & Goldbeck, 2018
	KIDSCREEN-27 (Ravens-Sieberer et al., 2005)	Prchal et al., 2012
Behaviour	Youth Self Report (Achenbach, 1991a)	Barrera, 2004
	Child Behaviour Checklist (Achenbach, 1991b)	Lobato & Kao, 2002
	Strengths and Difficulties Questionnaire (Goodman, 2001)	Haukeland, 2020
Illness-related knowledge	Cancer-Related Knowledge (Carpenter, Sahler, & Davis, 1990)	Dolgin et al., 1997
	Knowledge Test (Williams et al., 1997)	Williams, 2003 Williams, 1997
	Sibling Knowledge of Chronic Illness or Developmental Disability (CI/DD; Lobato & Kao, 2002)	Lobato & Kao, 2002 Haukeland, 2020
	Sibling Perception Questionnaire: Fear of Disease Subscale (Carpenter & Sahler, 1991)	Sidhu et al., 2006
Family functioning	Parent-Child Communication Scale (Conduct problems prevention research, 1994)	Haukeland, 2020
Parent report	Strengths and Difficulties Questionnaire - Parent version (Goodman, 1997)	Besier, 2010; Giallo & Gavidia-Payne, 2008; Haukeland, 2020
	Eyberg Child Behaviour Inventory (Eyberg & Robinson, 1983)	Williams, 2003
	Sibling Perception Questionnaire – Parent version (Sahler & Carpenter 1989 — Adapted by Lobato & Kao, 2002)	Lobato & Kao, 2002
	Child Behaviour Checklist (Parents)	Barerra, 2004
	State-trait Anxiety Inventory for children adapted for parents	Barerra, 2004
	The Psychosocial Assessment Tool (PAT2.0; Pai et al., 2008)	Besani, 2018

Effectiveness of Interventions on Variables of Interest

Anxiety

Multiple instruments were used to measure self-reported anxiety as an outcome variable in nine studies (Table 7); however, only the Revised Manifest Anxiety Scale (Reynolds & Richmond, 1978) and the State-Trait Anxiety Inventory for Children (Spielberger, 1983) were used in multiple reports. Of the nine interventions that assessed self-reported anxiety, four showed statistically significant improvements. These included two support groups (Barrera et al., 2004; Houtzager et al., 2001) and two sibling camps (Sidhu et al., 2006; Packman et al., 2004). The results of the study by Barrera and colleagues (2004) were supported by parents' reports of siblings' anxiety with the use of the STAIC adapted for parents. The remaining six studies reported either no intervention effect or a non-significant effect including three RCTs (Barrera et al., 2018c; Kazak et al., 2004; Prchal et al., 2012), two art interventions (Jo et al., 2018; Wallace et al., 2014), and a sibling support group (Besani et al., 2018). While there are no conclusive differences concerning intervention setting or design (between the studies that reported a decrease in anxiety symptoms and those that found no intervention effect), there are two factors that stand out: temporality and format.

All four studies that showed improvements in anxiety symptoms included siblings of children who were either close to the time of diagnosis, were in active treatment, or the time since diagnosis was unspecified. However, perhaps the most salient information gained from the evaluation of anxiety is that all four of the interventions that reported improvements in anxiety symptoms were conducted in a group format, and three of the interventions that reported no improvements in anxiety were administered individually.

These findings suggest there is a relationship between targeting a time period which is close to the time of diagnosis, and a group format, with a decrease in anxiety symptoms.

Depression

Self-reported depression was assessed in six studies (Table 6) including two RCTs. One RCT was an Intervention for Siblings Experience Enhancement camp which reported a statistically significant improvement (Williams et al., 2003), and the other was a sibling group intervention (SibCT) which reported no main effect (Barrera et al., 2018b). Of the four remaining studies, two group interventions reported statistically significant improvements in depression symptoms (Barrera et al., 2004; Dolgin et al., 1997). However, a one-day group intervention (Besani et al., 2018) and an individually administered art intervention (Jo et al., 2018) reported no improvement at post-intervention assessment.

An analysis of the three interventions that reported improvements in depressive symptomology showed the time-period of the intervention was either unspecified or the affected children were in active treatment. The interventions that reported no significant effects either targeted a time-period of complete remission or a less acute period (more than three months post-diagnosis). This suggests interventions targeted closer to the time of diagnosis were more effective at improving depressive symptoms than those that were targeted at a more distal time-period. It should also be noted that of the six interventions that reported on improvements in depression only one study targeted siblings of children with CHCs; that study, a RCT, found improvements in self-reported depression symptoms (Williams et al., 2003).

Social Adjustment

Five studies evaluated self-reported social adjustment including two RCTs — a sibling camp (Williams et al., 2003) and a manualised intervention in an individual format (Prchal et al., 2012), both of which reported significant improvements. Of the remaining three studies, two found significant improvements in sibling social adjustment, including a camp (Sidhu et al., 2006), and a sibling support group (Besani et al., 2018). A small study using a non-equivalent control group with a small sample size (seven siblings) reported no improvement (Heiney et al., 1990).

Of the five studies that reported on social adjustment, four reported significant post-intervention improvements; three of these were delivered in a group format which suggests group interventions can be helpful for improving the variable of social adjustment.

Post-Traumatic Stress Symptoms

Four of the reviewed studies evaluated self-reported post-traumatic stress symptoms using either the Impact of Events Scale (Weiss et al., 1997) or the UCLA Post Trauma Stress Disorder Reaction Index (Steinberg et al., 2004), including two RCTs. Neither the family-oriented group RCT (Kazak et al., 2004), or the individually administered two-session RCT (Prchal et al., 2012) found an intervention effect for decreasing symptoms of post-traumatic stress symptoms. However, both a sibling support camp (Williams et al., 2003) and an art intervention found significant improvements in post-traumatic stress symptoms (Wallace et al., 2014).

Self-esteem/ Self-concept

Five of the six studies that reported on sibling self-esteem/self-concept found significant improvements in this domain. These included an individually conducted art therapy intervention (Jo et al., 2018), three siblings camps (Packman et al., 2004; Sidhu et al., 2006; Williams et al., 2003) and a one-day workshop sibling support group (Besani et al., 2018). An individually administered art therapy intervention (Wallace et al., 2014) found no change at the post intervention assessment. These findings show strong support for the effectiveness of sibling interventions on improving self-concept and self-esteem.

Behavioural Problems

All seven studies that reported on behavioural problems found statistically significant improvements in this variable. All seven studies used parent-report and one study used both self-report and parent-report (Haukeland et al., 2020). These studies included an RCT of a sibling camp intervention (Williams et al., 2003), an RCT of an individual online intervention (Giallo & Gavidia-Payne, 2008), an inpatient family-oriented program (Besier et al., 2010), an art intervention (Jo et al., 2018), two sibling support groups (Barrera et al., 2004; Lobato & Kao, 2002) and a sibling/parent support group that found improvements were reported by fathers but not mothers (Haukeland et al., 2020).

While proxy-report measures should be viewed with caution, these results point toward the effectiveness of sibling interventions for reducing sibling behavioural problems.

Illness-specific Knowledge

Significant improvements in illness-related knowledge were found in seven of the eight studies that reported on this variable. These included three camps (Packman et al., 2004; Sidhu et al., 2006; Williams et al., 2003), an individual two-session intervention (Prchal et al., 2012), a six-session sibling group (Dolgin et al., 1997), a five-session concurrently run sibling/parent group (SIBS; Haukeland et al., 2020) and a six session concurrently run sibling/parent group (SibLink; Lobato & Kao, 2002). During an intervention conducted within a camp format, Williams and colleagues (2003) addressed the need for illness-related knowledge within a transdiagnostic group setting by including diagnosis-specific sibling education sessions for each of the health-conditions, while the subsequent psychosocial sessions took a transdiagnostic approach. While the findings cannot be singularly attributed to the intervention approach, the findings showed statistically significant improvements across multiple variables in this study. Haukeland and colleagues (2020) addressed siblings' need for information in a transdiagnostic intervention using a family systems approach by supporting parent-sibling communication to empower parents to provide informational support to siblings.

Adjustment

Of the six studies that reported on adjustment, three studies used the Sibling Perception Questionnaire (Carpenter & Sahler, 1991) with variable outcomes. A four-day peer support camp by Sidhu and colleagues (2006), and Lobato and Kao's (2002) six-session psychoeducation group found statistically significant improvements in sibling adjustment in the post-intervention evaluations; an RCT (sibling support camp) found significant gains in the mood and attitude subscales only (Williams et al., 2003). A sibling/parent support group (SIBS; Haukeland et al., 2020) also found improvements in sibling adjustment at the post intervention assessment, as did a one-day sibling support group workshop (Besani et al., 2018). The additional psychoeducation sessions provided to siblings in a family-oriented rehabilitation program did not reveal any significant improvements in sibling adjustment when compared to the control group (Niemitz & Goldbeck, 2018).

Quality of Life

Three of the four interventions reviewed that reported on quality of life found improvements in quality of life scores. A two-session individually conducted RCT (Prchal et al., 2012), an inpatient family-oriented intervention (Besier et al., 2010), and a sibling summer camp (Packman et al., 2004) all reported statistically significant improvements. In contrast, an RCT of the SibCT intervention (Barrera et al., 2018b) found no improvements in the quality of life measure at the post-intervention assessment. The authors commented the reason for no intervention effect could be that the study used an attention control group; this is the most conservative form of control group, as the social component of both groups may be the critical ingredient of the intervention.

Important Considerations for the Development of a Psychosocial Sibling Intervention

Timing of Interventions

In terms of temporality, three studies targeted siblings when their affected brother or sister was during, or close to, a period of active treatment or diagnosis. Six studies specified the time since diagnosis (i.e. the affected child had been diagnosed 6 months ago or longer), three studies specified a limit on time since diagnosis, and eight studies did not specify a time period in the inclusion criteria at all.

Of the studies that did specify ‘time since diagnosis’ in the inclusion criteria, the three studies that targeted the acute period when the affected child was either newly diagnosed (Prchal et al., 2012) or in active treatment (Besani et al., 2018; Sidhu et al., 2006), showed significant improvements in nine of the thirteen variables reported on.

The studies that targeted the more distal period (>6 months post diagnosis) and required the affected child not to be in active treatment, showed more variable findings with less than half of the targeted variables finding significant improvements.

Group versus Individual Format

Fewer improvements were reported on the variables targeted in individual format interventions (n = 4) compared to interventions using a group format (n = 17). Approximately 72% of variables in the group settings were found to have significant improvements, compared to 50% for individualised interventions.

Developmental Stages

Many of the reviewed studies also used a broad inclusion criterion for age. This was unexpected given the importance for sibling programs to be developmentally appropriate. The largest sibling age range was 12 years (4–16-year-olds), the smallest age range was 3 years (7-10 year-olds); the mean age range was 8.6 years, with the majority of these interventions spanning two developmental stages (middle childhood and adolescence). It is possible the variability in findings of sibling interventions in the literature is partly attributable to the broad age range of interventions.

Transdiagnostic versus Condition-specific Approach

Eight of the reviewed studies utilised a transdiagnostic approach. An inpatient family-oriented rehabilitation program noted there were no significant differences in siblings' baseline scores in the Strengths and Difficulties Questionnaire (Goodman, 1997) between the three diagnoses of the affected children (cancer, cystic fibrosis, and congenital heart disease), and findings showed significant improvements across all health conditions (Besier et al., 2010). Williams and colleagues (2003) tested whether a transdiagnostic approach was supported and found statistically significant poorer outcome scores for siblings of children with spina bifida but no significant differences between the diagnoses in the outcome variables for siblings of children with cancer, cystic fibrosis, diabetes, or developmental difficulties. These findings support the needs-based research by Armstrong (2020) which found strong similarities in the self-reported needs of siblings of children with cancer, diabetes and cystic fibrosis. Additionally, from a practical perspective, multiple authors (Lobato & Kao, 2002; Williams et al., 2003) described the transdiagnostic approach as being an efficient use of resources which, in itself, is a key consideration of any preventative psychosocial intervention.

Barriers to Treatment

Multiple authors noted that the uptake and retention rates of interventions were lower than expected, and discussed specific barriers to attendance which included transportation and scheduling difficulties (Barrera et al., 2018c; Besani et al., 2018; Jo et al., 2018). Some studies trialed different formats of intervention delivery to help participants overcome these barriers. For example, Sidhu and colleagues (2006) chose a 4-day camp format after stating that the unpredictability of the cancer progression, treatment, and its effects meant that weekly group interventions for siblings often yield poor attendances. To minimise the attrition rates that come with group sessions run over several weeks, Besani et al., (2018) ran an intervention in a one-day workshop format. While all of the participants completed the intervention, the authors still noted significant challenges in terms of recruitment into the program and suggested offering the intervention as an integral part of the standard of care for all families to improve intervention uptake rates. Prchal et al., (2012) hypothesised that the timing of the intervention also impacted on recruitment and attendance, commenting in the limitations section that targeting siblings in the early time period after diagnosis made recruitment more difficult resulting in a small sample size.

Measurement Sensitivity

This systematised review identified concerns around the lack of measurement sensitivity leading to a decrease in the strength of intervention effects (Barrera et al., 2018c; Giallo & Gavidia-Payne, 2008; Kazak et al., 2004). Because siblings in all but one of the reviewed studies are ‘at risk’ (rather than clinically distressed), the symptoms of sibling participants typically fall short of a psychiatric diagnosis resulting in a modest response to treatment. There was variability in the use of measurement instruments, with some studies using psychiatric screening tools, and other studies using measures that were sensitive to both psychosocial emotional change as well as clinical manifestations. These findings reflect those of a previous systematic review which recommended careful consideration of the most appropriate outcome measures for the accurate evaluation of the primary aims (Hartling et al., 2014). Thus, the development of an intervention should be viewed conceptually as a developmental model, rather than a psychiatric one, and use appropriately sensitive measurement instruments.

Participant Satisfaction

Participant satisfaction ratings for the majority of studies that reported this outcome was ‘high’, with a couple of ‘moderate – high’ ratings. Participant ratings are important, as evidence suggests interventions that have been evaluated as acceptable by participants are associated with greater adherence (Tarnowski & Simonian, 1992). They are also more likely to be endorsed by professionals than interventions that have low acceptability (Foster & Mash, 1999).

Chapter 7 Summary

This chapter synthesised the findings of the studies identified in the systematic review and discussed important considerations for the development of a psychosocial sibling intervention. The implications of these findings for siblings within the New Zealand context are discussed in the following chapter.

CHAPTER 8: REVIEW FINDINGS

Implications for the Development of the Sibling Needs Intervention

This chapter discusses how key findings from the systematised review, in combination with existing literature, informs the development of a psychosocial intervention that directly maps onto the self-reported needs of siblings who reside in New Zealand.

The need to consider the context of young people within their family system is a key finding in the development of an intervention that aims to meet the psychosocial needs of siblings. The sibling-parent relationship is notably salient for siblings; with evidence there is a relationship between parental emotional functioning and sibling adjustment (Giallo & Gavidia-Payne, 2006). The parent-sibling relationship is so important that a recent study targeted parent-sibling communication as a way of improving siblings' mental health; this approach had excellent outcomes (Haukeland et al., 2020).

The majority of interventions identified in the systematised review included varying degrees of parental involvement, from providing basic psychoeducation for parents in booklet form, to running concurrent groups for parents. From a developmental perspective, this is unsurprising given most of the reviewed interventions included siblings in early to middle childhood (when a family systems perspective in clearly indicated due to the dependent parent-child relationship). However, adolescence is a stage of life which presents changes in biological, social, psychological, emotional, and cognitive functioning and is characterised by an increased need for parental differentiation, and an increased need for social connection and acceptance (Gowers, 2005).

New Zealand sibling research shows a higher number of unmet needs reported by adolescent siblings (over the age of 12-years old at the time of diagnosis) compared to siblings who were 12-years old and younger in all seven domains, including the need for understanding from parents and families (Armstrong, 2020). Siblings reported they needed to feel they could openly talk with family members about the illness; have their experiences acknowledged by the family; feel as important and valued as their unwell sibling; know their parents haven't forgotten about them; and be able to spend one on one time with parents (Armstrong, 2020).

It is apparent that consideration of the family system, alongside a skills-based independent approach, is important for adolescents who reside in New Zealand.

Implication for the Development of the Sibling Needs Intervention: *Target the developmental stage of adolescence which has the highest number of unmet needs reported by siblings in New Zealand. Focus on providing siblings with strategies to have their own needs met within a family systems framework that supports sibling-parent communication and provide parents/caregivers with information about sibling's experiences and strategies for providing support to siblings.*

A group format approach for sibling interventions is strongly supported by the findings in the systematised review. Group cohesiveness is considered a fundamental therapeutic factor in group therapy where the quality of the relationships between members significantly impacts therapeutic success (Yalom & Leszcz, 2020). Members of cohesive groups are more likely to attend regularly and participate actively allowing the formation of meaningful connections with other members (Yalom & Leszcz, 2020). This sense of acceptance and belonging promotes self-disclosure, risk-taking and interpersonal exploration, all of which are critical for the therapeutic process (Yalom & Leszcz, 2020). The therapeutic benefits of a group intervention were recently identified in a randomised control trial by Barerra and colleagues (2018c) who concluded the most powerful theme across the control group and the experimental group (SibCT) was being part of a sibling group.

A group approach was also supported in a study of New Zealand siblings which found over half of the participants endorsed the need to feel supported/understood by friends, and be able to discuss the illness experience, and spend time, with other young people with similar experiences (Armstrong, 2020). The qualitative findings in this study also supported a group approach. When siblings were asked how their needs would have best been met, siblings made the following comments:

> *"Having a support group or forum to talk to other siblings in";*
>
> *"It would have been cool to have a group of 'the siblings'";*
>
> *"By having sibling rooms at the hospital"*;

> *"I think it would have been valuable for me to have connected with other siblings going through a similar situation to have somebody who fully understood what it was like. I sometimes found it hard to connect to a number of my friends in these times as they had not experienced a hardship to this scale in their lives before"*;
>
> *"A group to go to bimonthly or the likes where siblings got together to chat about our feelings and have a fun activity"*.

A comparison of the interventions in the systematised review that used a group format compared to an individual format, found fewer improvements on the variables evaluated in the individual formats. Group interventions led to statistically significant improvement in the variable of social adjustment/support in all but one group intervention. While other factors cannot be ruled out, this finding does support existing literature that a group format can give siblings the sense that they are not alone, and that meeting others with similar experiences will have a positive impact on the psychological adjustment of siblings.

Implication for the Development of the Sibling Needs Intervention: *Deliver the intervention in a group format to address the need for support and understanding from peers.*

Group cohesiveness is likely to be increased when interventions target specific developmental stages. The majority of interventions in the systematised review spanned the developmental stages of childhood and adolescence. A manualised group intervention for siblings (8-16 years old) suggested in the limitations section that the recruitment of siblings within a narrower age group is worth considering as it was evident the depth to which siblings understood the content varied depending on age (Giallo & Gavidia-Payne (2008). A sibling/parent intervention that limited the age range within each group to three years (so group discussions of emotions, thoughts, and behaviours could be adapted to participants' developmental levels) found improvements for all five targeted variables (Haukeland et al., 2020).

Implication for the Development of the Sibling Needs Intervention: *Focus on one developmental stage (adolescence) to support the development of meaningful connections with peers. When organising groups, aim to minimise the age range to promote in-depth and developmentally appropriate discussions about thoughts, feelings, behaviours and coping skills.*

The majority of the interventions analysed in the review aimed to support sibling's emotional needs and increase coping skills to reduce symptoms of depression, anxiety, and post-traumatic stress symptoms.

The literature shows strong negative feelings including fear, sadness, anxiety, anger, guilt, jealousy, and worry are common following a brother or sister's diagnosis with a CHC. This was echoed in a New Zealand study of self-reported sibling needs, which found that when a child is diagnosed with a CHC, siblings feel strong negative emotions (Armstrong, 2020) and 60% of sibling participants reported needing 'help dealing with difficult feelings' (Armstrong, 2020).

The systematised review found the majority of interventions used cognitive behavioural a range of the following techniques: normalisation and validation of experiences, psychoeducation about emotions, relaxation techniques, mindfulness, identifying and reframing cognitive distortions, problem solving skills, role playing, coping skills, perspective taking, and hope for the future. Some of the interventions also focused on strengthening the sibling-parent relationship through shared activities and communication.

Implication for the Development of the Sibling Needs Intervention: *Use evidence-based strategies to teach skills that help siblings learn to cope with strong negative emotions such as guilt, sadness, anxiety and anger. In addition to this, a family systems approach will provide parents/caregivers with information about how they can provide emotional support to siblings.*

Eight of the studies identified in the systematised review took a transdiagnostic approach to sibling interventions. This provides support for the use of a transdiagnostic approach to sibling interventions on the basis of the multiple similarities in sibling experiences across health conditions. An inpatient family-oriented rehabilitation program noted there were no significant differences in siblings baseline scores in the Strengths and Difficulties Questionnaire (Goodman, 1997) between the three diagnoses of the affected children (cancer, cystic fibrosis, and congenital heart disease), and findings showed significant improvements across all health conditions (Besier et al., 2010). Williams and colleagues (2003) tested whether a transdiagnostic approach was supported and found statistically nonsignificant differences between the diagnoses in the outcome variables for siblings of children with cancer, cystic fibrosis, diabetes, and developmental difficulties. These findings support the New Zealand sibling research which found strong similarities in the self-reported unmet needs of siblings of children with cancer, diabetes and cystic fibrosis (Armstrong, 2020).

From a practical perspective, the transdiagnostic approach has the additional benefit of increasing the pool of potential group participants in a small country like New Zealand where the population is just over five million people and population density is low. The efficient use of resources is a key consideration of any preventative psychosocial intervention.

Implication for the Development of the Sibling Needs Intervention: *Use a transdiagnostic approach.*

Information about the affected child's specific health condition has been shown to be a central need of siblings. Eight of the studies in the review included 'illness-related knowledge' as a primary variable: four diagnosis-specific interventions (cancer; Dolgin et al., 1997; Niemitz & Goldbeck, 2018; Prchal et al., 2012; Sidhu et al., 2006); and four transdiagnostic interventions (Haukeland et al., 2020; Lobato & Kao, 2002; Williams et al., 2003; Williams et al., 1997). A transdiagnostic intervention that found statistically significant improvements in the variable of 'illness-related knowledge' (Haukeland et al., 2020) used parent-sibling communication training, alongside a caregiver education booklet (describing the importance of illness-specific information), to target this variable.

These findings are well documented in the literature which repeatedly identifies the need for siblings to have access to age-appropriate information about the affected child's health condition (Armstrong, 2020; Deavin et al., 2018; Havill et al., 2019; Houtzager et al., 2004; Nolbris, Enskar, & Hellstrom, 2007; Oberoi et al., 2019; Patterson et al., 2011; Prchal & Landolt, 2009; Williams et al, 2002; Woodgate, 2006).

New Zealand sibling research found the four most commonly reported unmet needs endorsed by siblings related to the need for information about the health condition (Armstrong, 2020). Siblings reported they needed: Information about the impact the illness and it's treatment might have on my sibling/whānau member's life in the future (endorsed by 84% of siblings); To be informed about my sibling/whānau member's condition – good or bad (endorsed by 80% of siblings); To get information about the illness and its treatment in a way that I understood (endorsed by 73% of siblings); and, Information about what would happen when my sibling/whānau member came home following treatment (endorsed by 73% of siblings; Armstrong, 2020).

Implication for the Development of the Sibling Needs Intervention: *Address the need for information using a similar approach to Haukeland and colleagues (2020). A parent psychoeducation booklet has been developed which highlights the need for siblings to be provided with age-appropriate information – this is also discussed in the parent/caregiver session. In addition to this, siblings will be taught how to identify their needs alongside communication strategies that will enable them to ensure their needs are met.*

Low uptake and retention rates of interventions were noted by a number of the authors who discussed specific barriers to attendance including transportation and scheduling difficulties (Barrera et al., 2018b; Besani et al., 2018). These common challenges make it clear that potential barriers to participants attending, and completing an intervention need to be carefully considered, particularly regarding scheduling, transportation, parental involvement, and proximity to the time of diagnosis.

In terms of temporality, the majority of studies used a broad inclusion criterion for the length of time since diagnosis and did not target specific time periods. A handful of studies described developing interventions targeting siblings when their affected brother or sister was during, or close to, a period of active treatment or diagnosis (Besani et al., 2018; Dolgin et al., 1997; Prchal et al., 2012; Sidhu et al., 2006). However, the majority of studies focused on time periods that specified the time since diagnosis only (i.e. the affected child had been diagnosed six months ago or longer), and other studies did not specify a time period in the inclusion criteria at all. This was an unexpected finding as the needs and stressors of siblings are specific to different time periods so tailoring interventions to these needs is likely to lead to a more effective intervention. For example, targeting siblings in the early stages of treatment during the initial adjustment to the health condition is aimed at prevention rather the treatment of psychopathology and is considered a useful method of mental health delivery (Haggerty & Mrazek, 1994).

Implication for the Development of the Sibling Needs Intervention: *Target a time period of 0-4 months post diagnosis which has been identified as a key period for supporting sibling adjustment. By targeting this specific timeframe, the intervention will be tailored to the needs and stressors associated with this period.*

In summary, approximately seventy percent of studies found significant improvements in the variables of interest reported in this review, clearly indicating siblings of children with CHCs derived benefits from those interventions in the areas of behavioural problems, social support, self-concept and self-esteem, health-condition related knowledge, particularly when delivered in a group format. Findings remain inconclusive for the variables of anxiety, depression, and post-traumatic stress symptoms. This review also identified several important considerations, including: the tailoring of future interventions to the developmental stage of the sibling participants; the importance of targeting a specific time period post-diagnosis, the value of taking a group approach, and the utilisation of measurement instruments which are appropriately sensitive. Finally, this review helps synthesise the information needed to answer the question raised in Chapter 4 regarding whether a transdiagnostic intervention for siblings of children with CHCs that provides them with the skills needed to adjust to the significant changes in their lives can be developed. Findings from this synthesis illustrate the effectiveness of a transdiagnostic approach to a sibling intervention.

The development of the Sibling Needs Intervention is described in the following chapter (Chapter 9).

CHAPTER 9: DEVELOPMENT OF THE SIBLING NEEDS INTERVENTION

This chapter describes the development of the Sibling Needs Intervention, including the theoretical principles that underpin it, and how key findings from the systematised review informed its development. The intervention is designed to address the self-reported unmet needs of adolescent siblings residing in New Zealand who have a brother or sister with a serious chronic health condition. Beginning with an overview of the design decisions, the chapter then outlines the development and rationale for each of the four sessions, highlighting the integration of relevant theoretical frameworks.

Sibling Needs Intervention Design Process

The Sibling Needs Intervention is a transdiagnostic group-based program developed for young people aged 13–18 years. This age group has been identified in New Zealand literature (Armstrong, 2020) as having the highest number of unmet needs among siblings of children with serious chronic health conditions. The systematised review found that interventions tailored to a single developmental stage — rather than spanning multiple stages — enabled the delivery of developmentally appropriate content, which led to greater improvements in targeted outcomes. The decision to adopt a transdiagnostic format was supported by both international (Williams, 2003) and New Zealand-based research (Armstrong, 2020), which identified consistent and overlapping unmet needs across sibling populations, regardless of the specific diagnosis involved.

The group format is strongly supported by existing literature and the findings of the systematised review. Compared to individual interventions, group-based formats were associated with greater improvements in key psychological and social variables. Research has demonstrated that group participation can reduce feelings of isolation and promote psychological adjustment by helping siblings realise they are not alone in their experiences (Barrera et al., 2018c). Moreover, the group setting directly addresses a commonly reported unmet need: the desire for peer support from others who have had similar experiences.

The intervention is specifically designed for adolescent siblings whose brother or sister has been diagnosed with a serious chronic health condition within the past four months. This timeframe is identified in the literature as a critical period for promoting adjustment and reducing long-term psychosocial difficulties (Haggerty & Mrazek, 1994). However, the intervention is not suitable for siblings whose brother or sister is receiving palliative care or has passed away, as their needs are specific and unique. Although there may be some overlapping psychosocial challenges, this intervention is focused on siblings of children who are currently living with a serious chronic illness, not bereavement-related issues.

In terms of delivery, careful consideration was given to the number, length, and timing of sessions. Several studies included in the systematised review (e.g., Barrera et al., 2018c; Besani et al., 2018; Jo et al., 2018) reported that both uptake and retention rates in sibling-focused interventions were lower than anticipated. In light of this, a weekly, four-session format was chosen, based on the following considerations:

- A minimum of four sessions is recommended to achieve the therapeutic benefits of the 'group effect' (Yalom & Leszcz, 2020);
- Weekly spacing allows participants to practice skills between sessions, a key component of cognitive behavioural therapy (CBT), which facilitates the transfer of skills into daily life;
- A short duration minimises time and logistical burden on families, thereby improving accessibility and engagement.

The intervention has been developed for both in-person and online delivery formats. This dual-mode approach ensures equity and accessibility, particularly for siblings living in remote areas or those facing financial or transport-related barriers to attending in-person sessions.

It is anticipated that young people participating in the Sibling Needs Intervention may be experiencing mild to moderate distress. However, the program is not suitable for individuals experiencing clinical levels of distress, including psychosis or suicidality, who should instead be referred to individual therapy. Similarly, the intervention has not been designed for those with intellectual disabilities. It assumes participants are fluent in English and have the cognitive and emotional capacity to engage with group-based content and discussion.

Participant Safety

While there are no known or anticipated risks or harms directly associated with participation in this program, it is acknowledged that the diagnosis of a serious chronic health condition in a family member represents a significant and stressful life event. As such, reflecting on and discussing these experiences may cause some participants to experience emotional distress.

Participants are encouraged to seek support if they are feeling overwhelmed, distressed, or experiencing thoughts of self-harm or suicide. To assist with this, the participant workbook includes contact information for a range of support services available in New Zealand, including:

- Need to Talk? — Free call or text 1737 to speak with a trained counsellor at any time
- Lifeline — 0800 543 354 or free text 4357 for counselling and support
- Depression Helpline — 0800 111 757 or free text 4202 to speak with a trained counsellor
- Youthline — 0800 376 633, free text 234, or email talk@youthline.co.nz (support for young people, whānau, and friends)

To further support participant safety, it is recommended that each participant provide the name and contact details of a trusted healthcare professional to the group facilitator prior to commencing the program. This precaution allows the facilitator to contact the nominated professional in the event of acute distress or a mental health emergency, ensuring timely and appropriate support can be arranged.

Setting Up the Group

The following information is included in, and drawn from, the Sibling Needs Intervention: Facilitators Manual.

Informed Consent and Screening Telephone Interview

Participation in the Sibling Needs Intervention requires informed consent from both the adolescent sibling and their caregiver. At the time of consent, it is essential that both parties understand the group-based nature of the program, including the importance of maintaining confidentiality regarding what is shared within the group.

Prior to the commencement of the program, the facilitator will conduct individual telephone conversations with both the caregiver and the sibling. These intake screening interviews serve multiple purposes, including the development of rapport, an initial understanding of the participant's experiences, and ensuring the appropriateness of the program for each individual. Specific aims of these interviews include:

- Providing an overview of the progam and answering any questions from caregivers or participants;
- Determining participant availability to schedule sessions at suitable times;
- Gaining insight into the health condition present in the family and its impact;
- Identifying and addressing potential barriers to attendance;
- For participants joining online, assessing their internet connectivity and technology needs;
- Screening for high levels of emotional distress, including conducting a risk assessment for suicidal or self-harming thoughts.

The Sibling Needs Intervention is not appropriate for young people experiencing significant distress or risk. Those presenting with clinical levels of distress should be referred to appropriate services, as outlined in the Participant Safety section in the Facilitator's manual.

Sibling Needs Screening Interview with Caregivers – Key Points

The caregiver interview serves to screen for participant eligibility, address any questions about the program, and organise logistical details. The following elements will be addressed:

1. Introduction. The interviewer should introduce themselves and thank the caregiver for their interest in the program. They should explain that the purpose of the call is to determine whether the young person is eligible and to provide an opportunity to ask questions about the intervention.

2. Mood Screening. Participants will be asked to rate the following emotions — distress, anxiety, depression, and anger — on a scale from 0 to 10, where 0 = none of the emotion and 10 = extreme.

3. Risk Assessment (if any emotion rating is >7/10). If a participant rates any emotion above 7, the interviewer should respond empathetically, normalise fluctuations in mood during challenging life events. A structured risk assessment should be conducted using the Columbia-Suicide Severity Rating Scale.

For low to moderate risk, normalise these thoughts as part of coping with adversity, but stress the importance of ongoing communication about emotional changes during the program.

For high risk, express concern, and discuss help-seeking options. The participant should be encouraged to involve their parent or allow the interviewer to do so. Referral numbers include:

- Free call or text 1737 (anytime support)
- Lifeline: 0800 543 354 or free text 4357
- Suicide Prevention Helpline: 0508 828 865
- Youthline: 0800 376 633 or free text 234
- Samaritans: 0800 726 666

Participants assessed as high risk will not proceed in the program and will be advised to seek one-on-one psychological support.

4. Psychosis Screen. Participants will be asked whether they are receiving treatment for schizophrenia or have experienced hallucinations or other symptoms of psychosis. If current psychotic symptoms are reported, the participant will not be eligible and will be referred to appropriate services.

5. Technology Check (for online participants). Participants attending the online format must have access to a computer with a microphone, webcam, and stable internet connection.

6. Availability. The intervention runs over four consecutive weeks, at the same time and day each week. Participants will be asked to confirm their availability for the scheduled program dates.

7. Next Steps. Explain that pre-program questionnaires will be emailed and must be completed and returned prior to the start of the group.

8. Questions. Provide space for participants and caregivers to ask any further questions or raise concerns.

Group Format and Monitoring

The Sibling Needs Intervention is designed for groups of 3–8 participants, maintaining a facilitator-to-participant ratio of 1:3. A minimum of three participants is recommended to ensure a meaningful group dynamic, even in cases of non-attendance.

To assess the program's effectiveness, participants will complete measures at three time points: prior to the group (baseline), immediately post-group (first follow-up), and two months after group completion (second follow-up). At each time point, participants will also be screened for distress, and if necessary, referred for individual support.

The following instruments will be used to assess psychological wellbeing and unmet needs:

- Kessler Psychological Distress Scale (K-10): Assesses levels of anxiety and depression over the past 30 days.
- Sibling Needs Instrument: An adaptation of the Sibling Cancer Needs Instrument (Patterson et al., 2011), designed to evaluate sibling-specific needs.
- Depression Anxiety Stress Scales – Youth Version (DASS-Y): Assesses negative emotional states in youth aged 7–18 years.

These questionnaires may be emailed to participants prior to the program and are to be returned before the first session.

Intervention Format

Overview of Sessions

The Sibling Needs Intervention consists of four structured sessions, each focusing on specific themes aligned with the emotional and practical needs of adolescent siblings. Below is a summary of each session and its corresponding modules.

Session 1: You Are Not Alone

Module 1A: Welcome, program overview, introductions, and agreement on group guidelines

Module 1B: Discussion about life changes since the sibling's diagnosis to normalise feelings and build connection through shared experience

Module 1C: Introduction to Cognitive Behavioural Therapy (CBT) and the five-part model

Module 1D: Psychoeducation of emotions, their purpose, and different coping styles

Module 1E: Introduction to mindfulness practice

Session 2: Dealing with Difficult Feelings

Module 2A: Recap of Session 1, review of at-home practice, and overview of the current session

Module 2B: Introduction to the Window of Tolerance metaphor

Module 2C: Techniques for distress tolerance and emotion regulation, and daily practices for staying within the Window of Tolerance

Module 2D: Introduction to self-compassion and its benefits

Module 2E: Experiential exercise: mindfulness of emotions

Session 3: Giving and Receiving Support

Module 3A: Recap of Session 2, review of at-home practice, and overview of the current session

Module 3B: Exploring how to offer emotional support to a sibling with a chronic condition

Module 3C: Overview of the most commonly reported unmet needs of siblings in New Zealand and discussion on identifying personal needs

Module 3D: Introduction to interpersonal communication skills for expressing needs

Module 3E: Roleplay activities to practice these skills in situations relevant to each participant

Session 4 (Siblings): Hope for the Future

Module 4A: Recap of Session 3, review of at-home practice, and overview of the final session

Module 4B: Exploration of values and their importance in guiding behaviour

Module 4C: Completion of the Bullseye exercise to identify values across key life areas and development of SMART goals aligned with personal values

Module 4D: Joint session with caregivers/whānau where participants share key learnings from the program

Module 4E: Program celebration and completion of post-intervention measures

Session 4 (Parents/Caregivers): Hope for the Future

Module 4A: Welcome, program overview, introductions, and group guidelines

Module 4B: Discussion of life changes since the diagnosis to normalise feelings and foster connection

Module 4C: Summary of research on the needs of siblings

Module 4D: Joint session with siblings to hear their reflections and celebrate progress

Module 4E: Program celebration and completion of post-intervention measures

Session Duration and Cultural Practices

The Sibling Needs Intervention is delivered over four 120-minute sessions. The time of day and day of the week will be collaboratively decided upon by the facilitator and participants prior to program commencement, to reduce logistical barriers and maximise attendance.

Each session opens and closes with a karakia (Māori prayer) or whakataukī (Māori proverb) that reflects the theme of the session. The first 10–15 minutes of sessions 2, 3, and 4 are reserved for check-ins and discussion of home practice exercises, creating a buffer for late arrivals. A 15-minute break is included in each session to support whakawhanaungatanga (relationship-building) and sharing of kai (food).

Parents and caregivers are invited to attend Session 4, which is delivered in two parts: a 60-minute separate session for parents and caregivers, followed by a joint session with siblings. Parents are welcome to bring other whānau (extended family group) members. If they are unable to attend, siblings are still encouraged to participate.

Program Materials

Program materials include:

- *Facilitator Manual: A comprehensive guide to delivering the intervention;*

- *Participant Workbook: Provided to each participant at the start of the program;*
- *Caregiver Booklet: Mailed to caregivers prior to the program; this booklet includes information on how a sibling's experience may be affected by the diagnosis and guidance on how caregivers can offer effective support.*

Offering a Positive Sibling Pathway

This research represents a practical response to the findings of my Master's thesis (Armstrong, 2020), which demonstrated that when the needs of siblings are left unmet, it can lead to significant psychosocial and adjustment difficulties (see Figure 9). The study identified a pattern of experiences commonly reported by siblings following the diagnosis of a brother or sister with a chronic health condition (CHC).

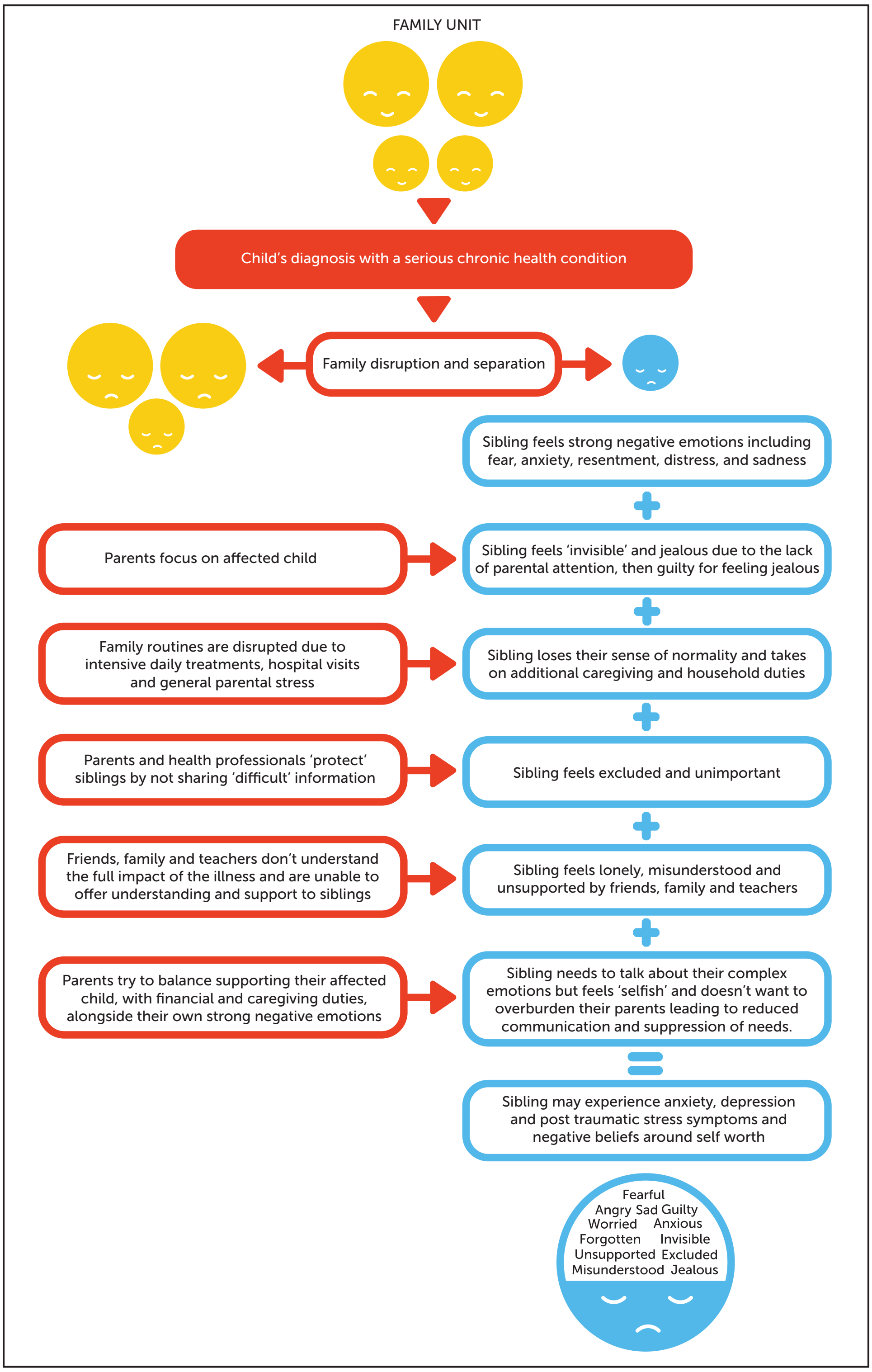
Reduced parental attention — often a result of the heightened focus on the affected child — can leave siblings feeling invisible, forgotten, and jealous. This jealousy is frequently followed by guilt for feeling jealous of the sibling receiving care. When information about the CHC is withheld by parents or health professionals (typically in an attempt to protect the sibling), it can further contribute to feelings of exclusion and insignificance. Siblings may also experience a profound sense of being misunderstood or unsupported by others, particularly when family and friends are unaware of the impact the health condition has on them personally.

In response to these challenges, siblings often suppress their emotions. Many report not wanting to burden their parents further, feeling selfish for having needs of their own, or guilty for being the "healthy" child. The literature indicates that when these complex emotional needs are not addressed, siblings may go on to experience anxiety, depression, post-traumatic stress symptoms, and negative beliefs related to self-worth (Armstrong, 2020).

The Sibling Needs Intervention has been developed to mitigate the risk of this trajectory. By equipping siblings with emotional regulation strategies, communication tools, and peer connection opportunities, the intervention offers a more positive and empowering pathway. It aims not only to address current unmet needs but also to build resilience, promote wellbeing, and foster a greater sense of self-worth and agency in adolescent siblings navigating the challenges of living with a brother or sister diagnosed with a serious chronic health condition. The intervention also seeks to improve communication and understanding between family members, particularly caregivers and siblings.

Figure 9

Potential Sibling Pathway



Note. From " The Unmet Needs of Siblings of Children with Cancer and Serious Chronic Health Conditions in Aōtearoa/New Zealand," [Master's thesis], by K. Armstrong, 2020, *Massey University of New Zealand*. (http://hdl.handle.net/10179/15677). Reproduced with permission.

Underpinning Principles and Techniques

New Zealand's bicultural context was formally established through the signing of the Treaty of Waitangi between Māori and the British Crown (Network Waitangi, 2016). Bicultural practice in Aotearoa New Zealand is grounded in the principles of the Treaty, which serves as a foundational document for social justice. In alignment with this, the current research is underpinned by bicultural principles that acknowledge and value both Māori and non-Māori worldviews.

To ensure cultural relevance, my Master's thesis (Armstrong, 2020) examined potential differences in the self-reported unmet needs of Māori and non-Māori siblings. The findings indicated no significant differences in the overall percentage of unmet needs between the two groups, with the only statistically significant difference observed in the domain of 'Support from friends and other young people' — a domain in which non-Māori siblings reported a higher percentage of unmet needs. These findings supported the development of a shared intervention model, capable of addressing the needs of both Māori and non-Māori siblings.

Guided by bicultural principles, the Sibling Needs Intervention incorporates tikanga Māori (Māori cultural values and practices) in the following ways:

Whakawhanaungatanga – fostering a sense of connection and building relationships among group members;

Manaakitanga – demonstrating hospitality, generosity, kindness, and mutual respect within the group context;

Te taha wairua – acknowledging spirituality through the inclusion of appropriate Māori *karakia* (prayers) and *whakataukī* (proverbs) to open and close each session (Bennett, Flett, & Babbage, 2016).

Cognitive Behavioural Therapy and Third-Wave Approaches

Cognitive Behavioural Therapy (CBT) is a well-established, evidence-based intervention for emotional and behavioural disorders, with strong support for its effectiveness in children and adolescents across a range of presentations in group settings (Kim et al., 2018; Weersing et al., 2017). As a second-wave therapeutic approach, CBT is based on the principle that thoughts, feelings, and behaviours are interconnected. It aims to reduce psychological symptoms through techniques such as cognitive restructuring and behavioural modification (Epp & Dobson, 2010).

Third-wave CBT approaches — including Acceptance and Commitment Therapy (ACT) and Dialectical Behaviour Therapy (DBT) — extend traditional CBT by incorporating mindfulness, emotional regulation, values clarification, and strategies to enhance psychological flexibility (Hayes & Hofmann, 2017; Hayes & Hofmann, 2021). These approaches reflect a shift from solely symptom reduction to also fostering positive psychological states, resilience, and wellbeing. Research supports the integration of second- and third-wave CBT techniques in a coherent, theoretically sound manner, especially within transdiagnostic frameworks (Kennedy & Pearson, 2020; Dalrymple et al., 2010). Both second- and third-wave CBT strategies have been successfully implemented with young people in schools, community settings, and online formats (Burckhardt et al., 2017; Mazza et al., 2016; Shaw et al., 2024).

CBT was the most frequently reported therapeutic approach identified in the interventions reviewed in the systematised review. The majority of these interventions employed a combination of cognitive, behavioural, relational, and group-based strategies aimed at strengthening siblings' coping skills and enhancing interpersonal functioning.

Informed by these findings, the Sibling Needs Intervention is grounded in transdiagnostic CBT principles, as outlined in the Unified Protocol for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents (Ehrenreich-May et al., 2017). It also incorporates evidence-based techniques from third-wave therapies, such as mindfulness and awareness-based practices, to enhance emotional regulation and psychological flexibility.

This integrated therapeutic framework enables the Sibling Needs Intervention to respond flexibly and effectively to the self-reported unmet needs of siblings identified in New Zealand-based research. These needs include:

- support for managing difficult feelings (FEEL);
- access to appropriate and accurate information about the chronic health condition (INFO);
- increased understanding and support from family members (UFAM);

- peer support and connection with others who have similar experiences (SF/OYP);
- guidance in navigating the sibling relationship with the affected child (RSIB);
- access to time out and recreational opportunities (TO/R).

For a detailed summary of these need domains, refer to Table 6 (Armstrong, 2020).

Table 6

Description of Unmet Needs

Unmet needs:	Abbreviation	Description of unmet needs:
Information about my sibling's health condition	INFO	For information about their sibling's treatment, side effects and recovery, presented in an easily understood, age appropriate format
"Time out" and recreation	TO/R	To "have a break"/"time out" from the pressure of the illness experience and participate in activities including sports or social events to regain a sense of normality
Dealing with feelings	FEEL	To be able to express feelings about their sibling's illness, it's impact on their life and their needs for help dealing with feelings including sadness, anxiety and anger
Support from my friends and other young people	SF/OYP	To feel supported/understood by friends, able to discuss the illness experience and spend time with other young people with similar experiences
Understanding from my family	UFAM	To feel supported/acknowledged by family, able to spend time with family and able to communicate with them about the illness experience
Relationship with my ill sibling	RSIB	For help with issues involving their relationship with their ill sibling and navigating changes in that relationship

Note. From " The Unmet Needs of Siblings of Children with Cancer and Serious Chronic Health Conditions in Aōtearoa/New Zealand," [Master's thesis], by K. Armstrong, 2020, *Massey University of New Zealand*. (http://hdl.handle.net/10179/15677). Reproduced with permission.

The Sibling Needs Intervention, based on findings from the systematised review, provides siblings with a practical toolkit to help them respond adaptively to difficult thoughts, feelings, and situations as they arise. This intervention aims to increase siblings' coping strategies and build resilience by addressing their diverse emotional needs through evidence-based techniques integrated across four sessions.

Session 1 focuses on psychoeducation about emotions, including their purpose and different coping styles. Session 2 teaches specific strategies for managing difficult emotions. Session 3 helps siblings identify their needs and learn how to effectively ask for support. Session 4 runs two parallel sessions: a caregiver session that educates parents and caregivers on how to provide support to siblings, and a sibling session centered on identifying personal values to foster a sense of hope and direction for the future.

Together, these four sessions target multiple unmet sibling needs using evidence-based techniques that emphasise skill development applicable to common sibling experiences, ensuring the intervention is flexible and broadly accessible. Furthermore, they aim to enhance siblings' self-efficacy and sense of agency, which is especially important during adolescence (Schoon & Cook, 2021; Zimmerman & Cleary, 2006).

A detailed summary of each session and the evidence-based second- and third-wave CBT techniques employed is provided in Table 7.

Table 7

Sibling Needs Intervention Session Plan

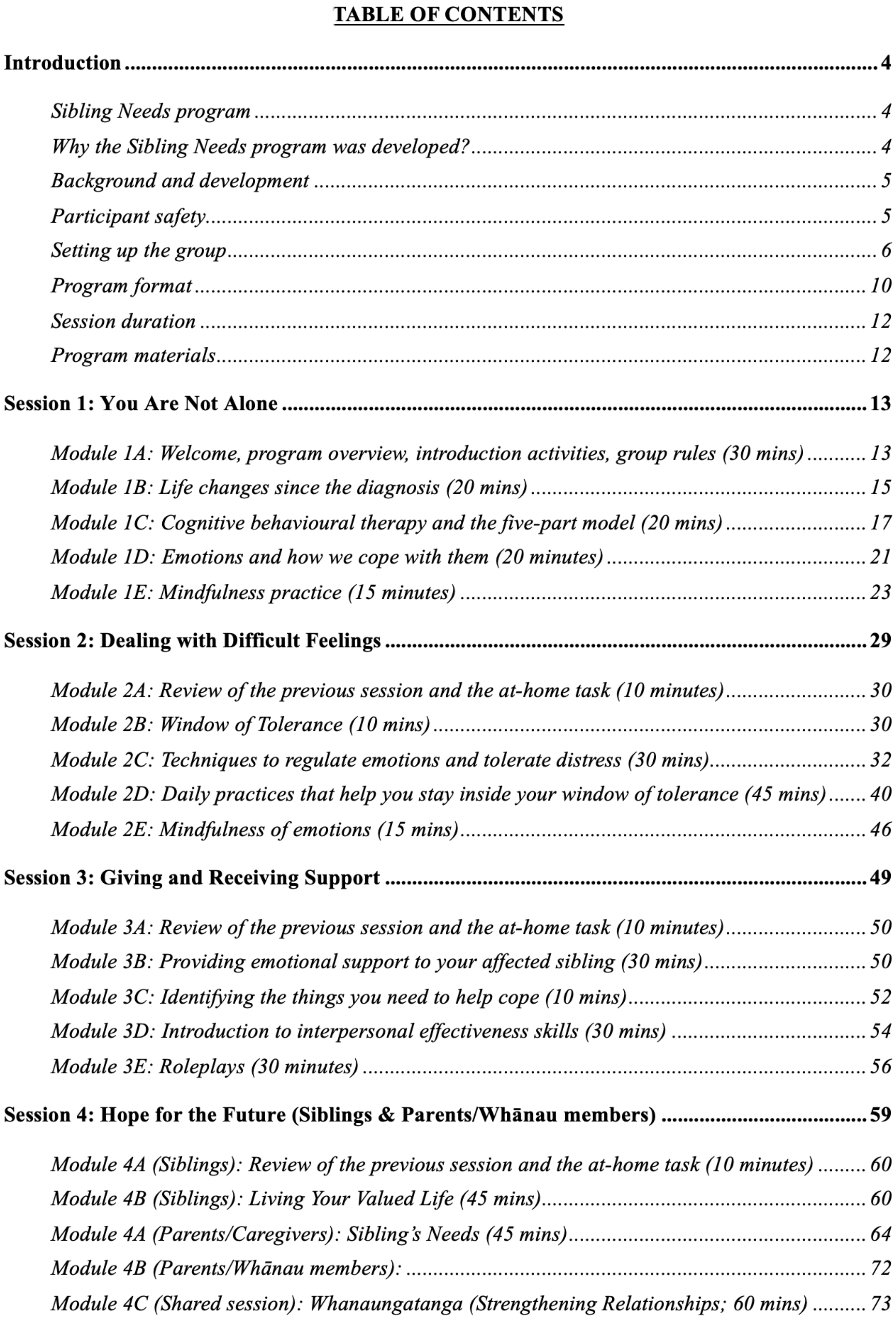
Sibling Needs Intervention Sessions	**Targeted unmet needs**	**Evidence-based techniques**
Session 1: You are not alone	SF/OYP	Introduction to peers with shared experiences.
		Identifying, validating and normalizing thoughts and feelings.
	FEEL	Psychoeducation of the 5-part model and the links between thoughts, feelings, and behaviour.
		Psychoeducation about emotions.
		Developing coping strategies and helpful ways to manage emotions.
		Introduction to the benefits of mindful practice.
Session 2: Dealing with difficult feelings	FEEL	Introduction to the Window of Tolerance metaphor
		Psychoeducation about the flight or fight response
		Techniques to regulate strong emotions.
		Techniques to tolerate distress
		Practicing self-compassion
		Mindfulness of Emotions
	SF/OYP	Development of supportive peer relationships
	RSIB	Techniques to provide support to the affected child

Session 3: Giving and receiving support		Strategies to strengthen the sibling — affected child relationship
	INFO TO/R FEEL UFAM	Learn how to identify needs and develop interpersonal communication skills to have needs met.
		Practice interpersonal communication skills through role plays.
	SF/OYP	Development of supportive peer relationships
Session 4: Hope for the future	UFAM	Parents/whanau members provided with information about sibling's experiences and techniques for how to support siblings.
	FEEL	Values work creating a sense of hope for the future
	SF/OYP	Development of supportive peer relationships

The contents page of the full intervention is provided in Figure 8 as an overview of the session structure.

Figure 8

Contents Page (reproduced from the Sibling Needs Intervention: Facilitator Manual)



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Development of Session 1: You Are Not Alone

Rationale and development

This session focuses on meeting the self-reported unmet needs of siblings who live in New Zealand in the two following domains: Support from friends and other young people (SF/OYP); and Dealing with feelings (FEEL; Armstrong, 2020). The SF/OYP domain encompasses both the need to feel supported from one's own friendship group, and from other young people who share a similar experience of having a sibling with a CHC. The FEEL domain focuses on the need for young people to be able to express how they are feeling about their sibling's cancer, and also the need for help in dealing with these feelings. The aims of this session include:

- Welcome, overview of the program, introduction activities, agreement on group rules;
- Discussion about life changes since the diagnosis to normalise feelings by sharing similar experiences;
- Introduction to Cognitive Behavioural Therapy and the five-part model;
- Psychoeducation on why we have emotions and the different kinds of coping styles;
- Introduction to mindfulness practice.

Introduction to Peers with Shared Experiences

As previously outlined, a prominent theme in the sibling literature from New Zealand – echoed in international research – is the need to connect with others who have similar lived experiences (Armstrong, 2020). Siblings consistently report the need to spend time with peers who understand the challenges associated with growing up alongside a child with a chronic health condition (CHC). They emphasise the importance of feeling supported, understood, and able to share their CHC-related experiences with others who can empathise with their unique circumstances (Armstrong, 2020).

In recognition of this need for relational connection, and in alignment with bicultural principles and the integration of tikanga Māori (Māori customs and protocols), the first session of the intervention opens with the following karakia (a traditional Māori prayer or blessing). This practice not only acknowledges cultural context but also serves to create a respectful, inclusive space for participants to engage in the therapeutic process.

E te whānau hui
Whāia te mātaurangi kia mārama
Kia whai take ngā mahi katoa
Tū māia, tū kaha
Aroha utu, aroha mai
Tātou I a tatou katoa
For this gathering
Seek knowledge for understanding
Have purpose in all that you do
Stand tall, be strong
Let us show respect for each other.

The initial phase of Session 1 is designed to promote interpersonal connection and establish a safe, inclusive group environment. The facilitator leads some icebreaker activities and participant introductions, aimed at fostering rapport and encouraging the development of peer relationships. This process is underpinned by the principle of whakawhanaungatanga – a cornerstone of Māori values and worldviews which emphasises the importance of building meaningful connections and relationships.

Following these introductory activities, the facilitator provides an overview of the program structure to familiarise participants with the content and format of the four-session intervention. To promote psychological safety and shared responsibility, a collaborative group agreement is developed, outlining behavioural expectations and group norms. These include:

- Respectful communication (e.g., one person speaking at a time, no bullying, allowing everyone the opportunity to contribute if they wish);
- Commitment to confidentiality;
- Demonstrating compassion, tolerance, and kindness toward others;
- Ensuring mobile devices are on silent during sessions;

- Agreement not to make personal recordings;
- Notifying the facilitator if unable to attend a session;
- Commitment to punctuality.

These guidelines are co-constructed with participants to encourage ownership and accountability, thereby reinforcing the values of mutual respect and psychological safety that underpin the intervention.

Listening, Validating, and Normalising Experiences

The facilitator will initiate a guided group discussion focused on the positive and negative life changes participants have experienced since their sibling's diagnosis of a CHC. To support this discussion, the Potential Sibling Response diagram will be presented as a visual summary of research findings detailing siblings' reported needs at the time of diagnosis. This aims to stimulate group reflection on the similarities and differences within participants' personal experiences.

Through this sharing process, the discussion aims to identify, normalise, and validate a diverse range of emotional reactions — an approach frequently used in the interventions included in the systematised review (see Table X; Barrera et al., 2004, 2018a, 2018b; Dolgin et al., 1997; Haukeland et al., 2020; Houtzager et al., 2001; Kazak et al., 2004; Lobato & Kao, 2002; Sidhu et al., 2006; Wallace et al., 2014; Williams et al., 2003). This process facilitates emotional processing and supports the ongoing development of interpersonal connections among group members. It also reinforces a key aim of the intervention: to reduce feelings of isolation and being different through shared understanding and relational support.

Introduction to Cognitive Behavioural Theory

Early in Session 1, cognitive behavioural therapy (CBT; Fenn & Byrne, 2013) and the five-part model is introduced. CBT provides a structured framework for understanding the interconnectedness of thoughts, emotions, physiological responses, behaviours, and situational contexts (Wenzel, 2017). This model facilitates the development of insight into internal experiences and supports individuals in identifying patterns that may contribute to psychological distress. The five-part model will be illustrated using an example relevant to the context of CHCs, enabling participants to engage with the material in a personally meaningful way. Through a facilitator-led group discussion, participants will be guided to apply the model to their own experiences.

Emotions and Coping Styles

Psychoeducation is provided on the nature and function of emotions, emphasising how the avoidance of emotions through unhelpful coping styles can contribute to the maintenance of psychological distress. Psychoeducation about emotions is an evidence-based approach commonly used to support emotional awareness and regulation in both second- and third-wave cognitive behavioural therapies (Iwakabe et al., 2023). It was also identified as a frequently used technique in the systematised review. Key components of emotion-focused psychoeducation include understanding why emotions occur, how to identify them, recognising the urges they generate, and exploring both helpful and unhelpful coping responses to difficult emotions (see Table 8).

Table 8

Techniques identified in the Systematised Review

Techniques	Studies & Intervention Type
Psychoeducation about emotions	Barrera et al., 2004: Siblings Coping Together (CBT) Barrera et al., 2018a: Siblings Coping Together (CBT) Barrera et al., 2018b: Siblings Coping Together (CBT) Besier et al., 2010: Family-oriented Rehabilitation Program Giallo & Gavidia -Payne, 2008: Sibstars (CBT) Haukeland et al., 2020: SIBS Houtzager, Grootenhuis & Last, 2001: Sibling Support Group Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Packman et al., 2004: SIBS (Camp Ozuku) Sidhu, Passmore and Baker, 2006: Camp Onwards (CBT)
Identifying, validating & normalising emotions	Barrera et al., 2004: Siblings Coping Together (CBT) Barrera et al., 2018a: Siblings Coping Together (CBT) Barrera et al., 2018b: Siblings Coping Together (CBT) Dolgin et al., 1997: Sibling Group Haukeland et al., 2020: SIBS Houtzager, Grootenhuis & Last, 2001: Sibling Support Group Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Lobato & Kao, 2002 Packman et al., 2004: SIBS (Camp Ozuku) Sidhu, Passmore and Baker, 2006: Camp Onwards (CBT) Wallace et al., 2014 (Art therapy) Williams et al., 2003 (Camp)

In the later part of Session 1, the concept of coping styles is introduced, with participants encouraged to reflect on the strategies they typically use to manage intense emotional experiences. Particular attention is given to distinguishing between helpful and unhelpful coping responses. Enhancing awareness of one's coping styles is a foundational element in both cognitive behavioural therapy (CBT) and dialectical behaviour therapy (DBT), where it is used to support emotion regulation and behavioural change (Care, 2024). This psychoeducational component establishes a conceptual base that will be built upon in Session 2, where coping styles are explored in greater depth.

Following discussion, normalisation, and validation of participants' emotional experiences, and having established a shared understanding of the nature and function of emotions and individual coping styles, Session 1 concludes with an experiential mindfulness exercise. This practice is designed to promote present-moment awareness and emotional grounding, providing participants with an initial introduction to mindfulness as a tool for self-regulation.

Mindfulness Practice

Mindfulness has been defined as "paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally" (Kabat-Zinn, 2001, p. 4). While mindfulness was not commonly identified as a technique in the systematised review, its demonstrated efficacy in supporting the development of emotion regulation — particularly in adolescents — supports its inclusion within this program (Davis & Hayes, 2011; Tan & Martin, 2012). Furthermore, mindfulness-based approaches are widely implemented in health care settings to address a range of psychological and emotional needs (Minor et al., 2006). On this basis, mindfulness has been selected as a relevant skill to support siblings in the domain of Dealing with feelings.

Psychoeducation is provided to introduce the concept and utility of mindfulness practice, with a particular emphasis on its role in enhancing emotional awareness and self-regulation. This is followed by a brief experiential exercise focused on mindful breathing. Participants are then invited to engage in mindfulness practice during the week as part of their at-home task. Encouraging the application of therapeutic strategies between sessions is a core component of cognitive behavioural therapy (CBT), supporting the generalisation of skills to everyday contexts (Dozois, 2010).

The session is closed with the following karakia:

Whakataka te hau ki te uru
Whakataka te hau ki te tonga
Kia mākinakina ki uta
Kia mātaratara ki tai
E hī ake ana te atakura
He tio, he huka, he hau hū
Tīhei mauri ora!
Cease the winds from the west
Cease the winds from the south
Let the breeze blow over the land
Let the breeze blow over the ocean
Let the red-tipped dawn come with a sharpened air.
A touch of frost, a promise of a glorious day.

Development of Session 2: Dealing with Difficult Feelings

Rationale and development

Session 2 focuses on meeting the self-reported unmet needs of siblings who live in New Zealand in the same two domains as Session 1 (Dealing with difficult feelings and Support from friends and other young people) as outlined in Table 9.

Table 9

Sibling Needs Intervention Session 2

Sibling Needs Intervention Sessions	Targeted unmet needs	Evidence-based techniques
Dealing with difficult feelings	FEEL	Introduction to the Window of Tolerance metaphor
		Psychoeducation about the flight or fight response
		Techniques to regulate strong emotions

		DBT TIPP Skills
		PLEASE Skills
		Techniques to tolerate distress
		Distraction Skills
		Self-soothing Skills
		Progressive Muscle Relaxation Skills
		Practicing self-compassion
		Mindfulness of Emotions
	SF/OYP	Development of supportive peer relationships

The literature consistently shows that siblings of children diagnosed with CHCs experience a range of negative emotions, including fear, sadness, anxiety, anger, guilt, jealousy, and worry. Supporting this, research conducted in New Zealand found that 60% of sibling participants reported a need for assistance in managing these difficult feelings (Armstrong, 2020).

Given the considerable evidence highlighting the challenges siblings face in coping with strong emotions – particularly in the period immediately following diagnosis – it is unsurprising that emotion management emerged as a core component in the majority of interventions identified in the systematised review. Table 10 provides a detailed summary of the studies targeting emotional regulation within sibling interventions, specifying, where available, the particular CBT techniques employed.

Table 10

Techniques to Support Siblings Coping with Difficult Emotions

Techniques	**Studies & Intervention Type**
Identifying helpful and unhelpful thinking styles	Giallo & Gavidia -Payne, 2008: SibStars (CBT)
	Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT)
Developing coping strategies and helpful ways to manage emotions	Barrera et al., 2004: Siblings Coping Together (CBT)
	Barrera et al., 2018a: Siblings Coping Together (CBT)
	Barrera et al., 2018b: Siblings Coping Together (CBT)
	Giallo & Gavidia -Payne, 2008: Sibstars (CBT)
	Haukeland et al., 2020: SIBS
	Heiney, 1990: Sibling Group
	Houtzager, Grootenhuis & Last, 2001: Sibling Support Group
	Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT)
	Marusak et al., 2020 (Martial Arts Intervention)
	Packman et al., 2004: SIBS (Camp Ozuku)
	Prchal et al., 2012 (CBT)
	Sidhu, Passmore and Baker, 2006: Camp Onwards (CBT)
	Wallace et al., 2014 (Art therapy)

Cognitive reframing	Barrera et al., 2004: Siblings Coping Together (CBT)
	Barrera et al., 2018a: Siblings Coping Together (CBT)
	Barrera et al., 2018b: Siblings Coping Together (CBT)
	Besani et al., 2018: Sibling/Parent Group
	Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT)
Relaxation techniques	Besani et al., 2018: Sibling/Parent Group
	Besier et al., 2010: Family-oriented Rehabilitation Program
	Marusak et al., 2020 (Martial Arts Intervention)
	Sidhu, Passmore and Baker, 2006: Camp Onwards (CBT)
Using art to express emotions	Besier et al., 2010: Family-oriented Rehabilitation Program
	Dolgin et al., 1997: Sibling Group
	Giallo & Gavidia -Payne, 2008: Sibstars (CBT)
	Jo et al., 2018: Art Therapy Intervention Program
	Sidhu, Passmore and Baker, 2006: Camp Onwards (CBT)
	Wallace et al., 2014 (Art therapy)
Problem solving strategies	Giallo & Gavidia -Payne, 2008: Sibstars (CBT)
	Lobato & Kao, 2002
Martial Arts	Marusak et al., 2020 (Martial Arts Intervention)

The aims of Session 2 are to:

- Introduce the Window of Tolerance and explore factors that influence the size of the window;
- Develop techniques that enable emotion regulation and distress tolerance;
- Learn daily practices aimed at maintaining regulation within the Window of Tolerance;
- Introduce the benefits of practicing self-compassion;
- Engage participants in an experiential exercise focused on mindfulness of emotions.

The session opens with the following karakia:

Hā ki roto

Hā ki waho

Kia tau te mauri e kokiri nei

I ngā piki me ngā heke

Ko te rangimarie tāku e rapu nei

Tihei mauri ora!

Breathe in
Breathe out
Settle the mauri that stirs inside of me,
through the ups and downs
It is peace that I seek.

Evidence-based Skills

This session integrates evidence-based skills designed to support siblings in tolerating distressing emotions, regulating their emotional responses, and reducing engagement in maladaptive coping behaviours. Cognitive Behavioural Therapy (CBT), Dialectical Behaviour Therapy (DBT), and Acceptance and Commitment Therapy (ACT) are therapeutic frameworks that address underlying transdiagnostic mechanisms perpetuating emotional distress. Common strategies shared across these approaches include psychoeducation about emotions, identification and labelling of emotional states to reduce their intensity, mindfulness practices, acceptance-based techniques, and exposure exercises.

Notably, DBT has developed a manualised protocol tailored for adolescents, incorporating core mindfulness, emotion regulation, and distress tolerance skills. These interventions have demonstrated efficacy within adolescent group settings (Hastings et al., 2022) and are detailed in a published skills manual for this population (Mazza et al., 2016). Drawing upon these established frameworks, a combination of skills has been selected specifically to address the unique needs of siblings.

Introduction to the Window of Tolerance Metaphor

The Window of Tolerance is a valuable metaphor that helps adolescents understand how emotional regulation can shift in response to stress. Originally developed by Dr. Dan Siegel (2001), this concept refers to the optimal zone of arousal in which individuals are best able to function when their nervous systems are balanced. Within this window, people can typically manage daily stressors and respond to emotional experiences with flexibility, resilience, and control (Siegel, 2001).

However, when individuals encounter significant stress, they may move outside of this optimal zone, entering states of hyperarousal (e.g., anxiety, panic, agitation – often linked to the “fight or flight” response) or hypoarousal (e.g., emotional numbness, withdrawal, dissociation). Participants will explore how stress can push them outside their window and how these shifts impact emotional regulation. It is also explained that chronic or repeated stress can narrow the Window of Tolerance, making it harder to stay regulated even in the face of everyday challenges (Siegel, 2001).

The facilitator will introduce the Window of Tolerance as a foundation for further psychoeducation on the physiological stress response, including the roles of the sympathetic and parasympathetic nervous systems. A group discussion will follow to explore factors that can either widen or constrict an individual’s Window of Tolerance, encouraging participants to reflect on their own experiences and regulation strategies.

Emotion Regulation and Distress Tolerance Skills

Building on the emotion regulation foundations established in Session 1 – which included psychoeducation on the function of emotions, and skills in identifying and naming emotional states — Session 2 introduces specific strategies that adolescents can use to rapidly down-regulate intense emotional responses. A central component of this session is the teaching of Dialectical Behaviour Therapy (DBT) TIPP skills: Temperature, Intense Exercise, Paced Breathing, and Progressive Muscle Relaxation (Mazza et al., 2016). These skills have been shown to be effective in helping adolescents manage acute emotional dysregulation (Whitener et al., 2025).

In addition to TIPP skills, participants are introduced to a range of distress tolerance strategies. Progressive Muscle Relaxation (PMR) is taught and practiced as a technique for reducing physiological arousal and increasing awareness of bodily tension. Self-soothing using the five senses is also presented as a core DBT skill that promotes self-care during periods of emotional distress. Participants are invited to engage in an experiential self-soothing exercise using a variety of materials (e.g., scented items, textured objects, calming visuals) provided by the facilitator. As part of their homework, participants are encouraged to create a personalised and easily accessible self-soothing kit to support the use of this skill outside of the session.

Distraction strategies are also introduced to provide participants with alternative, healthy ways of managing overwhelming emotions. The DBT PLEASE skills – targeting physical self-care through attention to Physical illness, Eating, Avoiding mood-altering substances, Sleep, and Exercise are also covered. These strategies promote emotional stability by encouraging adolescents to maintain behaviours that support physiological well-being and mood regulation.

Self-Compassion

Self-compassion has been identified as a protective factor for adolescents, with evidence suggesting it may buffer the negative impact of social stressors (Bluth et al., 2016). It is increasingly recognised as a key construct in interventions targeting adolescent distress and psychological well-being (Marsh et al., 2017). In Session 2, self-compassion is introduced as a skill that can support participants in responding to distress with greater kindness and understanding toward themselves.

To facilitate this, the cognitive behavioural therapy (CBT) five-part model is used in a facilitator-led group exercise. Initially, the model is populated with examples of self-critical thoughts, and the corresponding emotional, behavioural, and physiological responses are explored. This is followed by a contrasting exercise in which the same model is completed using self-compassionate thoughts. The aim is to help participants observe the impact that different cognitive appraisals have on their emotional and behavioural responses.

Throughout this exercise, participants are reminded of the thought–feeling connection central to CBT, and are encouraged to become more aware of self-critical thinking pattern. By developing this awareness, the intervention aims to support more compassionate self-talk as a mechanism for improving emotional regulation and resilience.

Mindfulness Practice

As discussed in the development of Session 1, mindfulness has been incorporated as a core technique across all four sessions of the intervention to support the development of emotional regulation and distress tolerance skills. The practice of intentionally bringing attention to the present moment has been shown to reduce cognitive processes such as rumination and catastrophising, both of which contribute to emotional distress (Sears, 2015). As such, mindfulness is a valuable and accessible tool within the "sibling toolkit."

In Session 1, participants were introduced to the concept of mindfulness and guided through a basic mindful breathing exercise. They were encouraged to continue practising this technique between sessions as part of their homework, promoting the integration of mindfulness into daily life. In Session 2, the focus shifts to internal mindfulness, with an experiential activity called Riding the Wave of Emotions. This exercise is designed to help participants observe their emotional experiences without judgement or the need for immediate reaction, fostering greater emotional awareness and acceptance. Through regular practice, mindfulness skills aim to support siblings in navigating difficult emotional experiences with greater clarity, self-regulation, and resilience.

Session 2 closes with the following karakia;

Kia tau kia tātou katoa
Te āio, te aroha me te marutau
Tihei Mauri Ora
May peace, love, and safety
Be upon us all.

Development of Session 3: Giving and Receiving Support

Rationale and development

Session 3 teaches evidence-based techniques to address the self-reported unmet needs of siblings who live in New Zealand in the five following domains: My relationship with my affected sibling (RSIB) – this domain addresses the need for help with issues involving their relationship with their sibling with a CHC and navigating any challenges in that relationship that may arise as a result of the CHC experience; Information about my sibling's CHC (INFO) – this domain entails young people having age appropriate access to information about their sibling's CHC to be presented to them in a way that they can understand; "Time out" and recreation (TO/R) – this domain deals with the need for young people to be involved in sport and social activities. It also encapsulates the need for occasional escapism and “time out” from the pressures of having a sibling with a CHC; Dealing with feelings (FEEL) – this domain focuses on the need for young people to be able to express how they are feeling about their sibling’s CHC and the need for help in dealing with these feelings; to be more involved in their sibling’s CHC experience and not feel excluded from it; to have attention from immediate or extended family members; and to have open and honest communication with them; and Support from my friends and other young people (SF/OYP) – this domain encompasses both the need to feel supported from one’s own friendship group, and from other young people who share a similar experience of having a sibling with a CHC (see Table 11).

Table 11

Sibling Needs Intervention Session 3

Sibling Needs Intervention Sessions	Targeted unmet needs	Evidence-based techniques
Giving and receiving support	RSIB	Techniques to provide support to the affected child
		Strategies to strengthen the sibling — affected child relationship
	INFO TO/R FEEL UFAM	Learn how to identify needs and develop interpersonal communication skills to have needs met.
		Practice interpersonal communication skills through role plays.
	SF/OYP	Development of supportive peer relationships

The aims of Session 3 are to:

- Develop an understanding of how to provide both practical and emotional support to a sibling affected by a CHC;
- Explore and reflect on the most commonly reported unmet needs of siblings, as identified in research;
- Support participants in identifying and articulating their own needs within the context of their sibling’s CHC experience;
- Introduce and practice interpersonal communication skills that enable participants to ask for support effectively.
- Practice these skills through facilitated roleplays tailored to the specific circumstances and of individual group members.

Session 3 opens with the following karakia:

Kia hora te marino
Kia whakapapa pounamu te moana
Hei huarahi mō tātou i te rangi nei
Haumi ē, hui ē, tāiki ē!
May peace be widespread
May the seas be as flat as pounamu
To provide a path for us today
Join, group, and affirm.

Over half of the siblings in Aotearoa New Zealand reported needing guidance on how to provide both emotional and practical support to their unwell sibling (Armstrong, 2020). In response to this identified unmet need, Session 3 begins with a structured module designed to build these skills. The session introduces strategies for offering emotional support, including active listening, acknowledgment, and validation of the affected sibling's emotional experiences. These interpersonal strategies aim to develop skills that support sibling relationships that have been impacted by chronic illness.

To assist participants in recognising and identifying their own needs, the facilitator uses the CBT five-part model to make the connection between strong emotions and unmet needs (Greenberger & Padesky, 2016). A group discussion follows, encouraging participants to reflect on their needs in different areas of their lives such as, the need for: information about the CHC; time out and recreation; understanding from their family; and support dealing with difficult feelings. This prompts a facilitator-led problem-solving exercise focusing on how the identified needs might be met either through skills they have acquired during the intervention, or with the support of trusted adults or peers. This approach promotes agency, insight, and problem-solving skills in a developmentally appropriate manner.

The need for information about the CHC is addressed in the second module of Session 3. The need for information about the illness was among the top four most commonly endorsed unmet needs by siblings who reside in New Zealand (Armstrong, 2020), including:

- Information about the impact the illness and its treatment might have on my sibling/whānau member's life in the future (endorsed by 84% of respondents);
- Information about my sibling/whānau member's condition — good or bad (endorsed by 80% of respondents);
- Information about the illness and its treatment in a way that I understood (endorsed by 73% of respondents);
- Information about what would happen when my sibling/whānau member came home following treatment (endorsed by 73% of respondents).

Qualitative data from the same study reinforced these findings, with siblings expressing a preference for open communication about their sibling's condition. Many reported feeling excluded from difficult conversations by adults and described wanting information they could understand (Armstrong, 2020). These findings align with a wide body of literature highlighting the importance of access to age-appropriate and developmentally suitable information for siblings (Deavin et al., 2018; Havill et al., 2019; Houtzager et al., 2004; Nolbris, Enskär, & Hellström, 2007; Oberoi et al., 2019; Patterson et al., 2011; Prchal & Landolt, 2009; Williams et al., 2002; Woodgate, 2006).

The systematised review identified illness-related knowledge as a key variable in eight of the reviewed interventions, including four transdiagnostic interventions (Lobato & Kao, 2002; Haukeland et al., 2020; Williams et al., 1997; Williams et al., 2004). Methods for delivering this information included the provision of illness-specific education by health professionals (Williams et al., 2004) and strategies to facilitate family communication (Haukeland et al., 2020).

Building on this evidence, the Sibling Needs Intervention integrates the provision of age-appropriate information, grounded in both developmental theory and family systems theory. From a developmental perspective, adolescence is marked by a growing capacity for abstract thinking, identity exploration, and a drive for autonomy (Erikson, 1968; Steinberg, 2014). Providing young people with opportunities to learn about illness in a way that supports their agency — including helping them articulate and advocate for their needs — is developmentally appropriate and empowering.

Family systems theory (Bowen, 1978) reinforces the importance of open communication and emotional responsiveness within families. It posits that individual wellbeing is inherently linked to the functioning of the wider family unit. Accordingly, the intervention prioritises strengthening communication pathways and supporting emotional attunement within families, particularly around the topic of the CHC.

While increasing access to information is a central goal, the intervention also recognises that not all siblings benefit from receiving illness-specific information. For some, this may heighten anxiety or emotional burden. In response, the intervention adopts a needs-based, flexible approach – helping participants identify their personal information needs and develop the confidence to communicate these. This aligns with the developmental emphasis on autonomy and agency, supporting adolescents to navigate their family and healthcare environments with greater confidence and clarity.

Accordingly, Session 3 incorporates teaching from Dialectical Behaviour Therapy (DBT) interpersonal effectiveness skills (Mazza et al., 2016). These skills equip participants with the tools to effectively and appropriately communicate their needs – whether emotional, informational, or practical – to parents, teachers, healthcare professionals, or peers. The session culminates in participant-led roleplays, in which individuals practice applying these communication skills in scenarios relevant to their own lives. These exercises serve to consolidate learning and promote the real-world application of the interpersonal strategies taught.

Session 3 closes with the following karakia:

Kia whakairia te tapu
Kia wātea ai te ara
Kia turuki whakataha ai
Kia turuki whakataha ai
Haumi e. Hui e. Tāiki e!
Restrictions are moved aside
So the pathways is clear
To return to everyday activities

Development of Session 4: Hope for the Future

Rationale and development

The fourth and final session of the Sibling Needs Intervention addresses the self-reported unmet needs of siblings who live in New Zealand in the domains of Dealing with feelings, Understanding from family, and Support from friends and other young people (see Table 12).

Table 12

Sibling Needs Intervention Session 4

Sibling Needs Intervention Sessions	Targeted unmet needs	Evidence-based techniques
Session 4: Hope for the future	UFAM	Parents/whanau members provided with information about sibling's experiences and techniques for how to support siblings.
	FEEL	Values work creating a sense of hope for the future
	SF/OYP	Development of supportive peer relationships

The session was designed to introduce values-based goal setting for the sibling participants, bring together the learnings from previous sessions, and enhance family communication. The aims of Session 4 are to:

- Introduce the concept of values and explore the importance of identifying what matters most in guiding behaviour and decision-making, particularly during challenging times;
- Support participants in identifying their personal values across key life domains (e.g., family, friendships, school, leisure);
- Assist participants in formulating SMART (Specific, Measurable, Achievable, Relevant, and Time-bound) goals that are aligned with their values, with the intention of fostering meaningful engagement and promoting psychological flexibility;
- Provide parents and caregivers with psychoeducation on the experiences of siblings of children with chronic health conditions (CHCs), and equip them with strategies to support their child's emotional and practical needs;

- Introduce parents and caregivers to the key components of the Sibling Needs Intervention, where participants review skills they have learned during the intervention, share insights, and identify personal takeaways that may guide future coping and interpersonal strategies;
- Celebrate completion of the program.

As discussed in the literature review (Chapter 3), CHCs affect not only the diagnosed child but the entire family system, disrupting established relational patterns and roles. Despite this, many sibling interventions to date have excluded parental involvement, or when included, have offered minimal description or engagement with the parent component. This lack of integration is notable given the well-established influence of the sibling–parent relationship on sibling adjustment. Empirical evidence suggests that the quality of the sibling–parent relationship is strongly associated with sibling coping and psychological wellbeing (Fredriksen et al., 2023). Furthermore, parental attitudes, behaviours, and communication styles have been shown to play a significant role in relieving siblings' emotional distress (Incledon et al., 2015; Lobato & Kao, 2002).

In light of this, the inclusion of parents or caregivers in sibling interventions warrants careful consideration. Within the systematised review conducted for this study, approximately half of the identified interventions were informed by a family systems framework using a variety of techniques (Table 13). This theoretical orientation recognises that siblings' experiences are deeply embedded within broader family dynamics, and that effective support requires interventions that address not only the individual needs of siblings but also the relational and systemic contexts in which they exist.

Table 13

Interventions Developed within a Family Systems Framework

Techniques	Studies & Intervention Type
Family Systems Approach	Besier et al., 2010: Family-oriented Rehabilitation Program Besani et al., 2018: Sibling/Parent Group Giallo & Gavidia -Payne, 2008: SibStars (CBT) Haukeland et al., 2020: SIBS Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Lobato & Kao, 2002: SibLink Niemitz & Goldbeck, 2017 Prchal et al., 2012 (CBT) Williams et al., 1997 Williams et al., 2003 (Camp)

Provide parents with information about sibling experiences	Besier et al., 2010: Family-oriented Rehabilitation Program Dolgin et al., 1997: Sibling Group Lobato & Kao, 2002 Haukeland et al., 2020: SIBS Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Lobato & Kao, 2002: SibLink Niemitz & Goldbeck, 2017 Prchal et al., 2012 (CBT) Williams et al., 1997 Williams et al., 2003 (Camp)
Normalise worries by sharing experiences in a therapeutic setting	Besani et al., 2018: Sibling/Parent Group Besier et al., 2010: Family-oriented Rehabilitation Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT)
Parent-Sibling Communication	Besier et al., 2010: Family-oriented Rehabilitation Giallo & Gavidia -Payne, 2008: SibStars (CBT; 6 x parent sessions: 1 x shared) Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT)
Strengthening parenting behaviour	Giallo & Gavidia -Payne, 2008: SibStars (CBT; 6 x parent sessions: 1 x shared)
Increasing parental coping skills	Giallo & Gavidia -Payne, 2008: SibStars (CBT; 6 x parent sessions: 1 x shared) Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Besier et al., 2010: Family-oriented Rehabilitation
Dealing with children's behaviour	Giallo & Gavidia -Payne, 2008: SibStars (CBT; 6 x parent sessions: 1 x shared)
Increase parent knowledge on how to listen, explore, and validate siblings' thoughts and emotions about the CHC.	Haukeland et al., 2020: SIBS (5 x parent sessions: 3 shared)
Combination of individual and shared parent and sibling sessions	Besier et al., 2010: Family-oriented Rehabilitation Program Besani et al., 2018: Sibling/Parent Group Giallo & Gavidia -Payne, 2008: SibStars (CBT) Haukeland et al., 2020: SIBS Kazak et al., 2004: Surviving Cancer Competently Intervention Program (CBT) Lobato & Kao, 2002: SibLink Prchal et al., 2012 (CBT)

New Zealand sibling research found that the need to feel acknowledged and supported by family, being able to spend time with family, and being able to communicate with them about the illness experience was an important need that was often unmet (Armstrong, 2020). The qualitative findings of the same study showed the depth of need for family support:

> "I found that my parents' focus shifted when my brother was diagnosed, and for a few years I felt almost completely second-priority. If I could have had some way of knowing they still cared about me as much as him, my mental health during that time might have improved." (Armstrong, 2020).

Another participant succinctly captured this theme, stating:

> "The best that could've been done in my situation would be more understanding from family." (Armstrong, 2020)

These insights reflect the profound emotional impact that limited parental attention and support can have on siblings during a time of heightened family stress. However, while the inclusion of parents in sibling interventions is theoretically and empirically supported, it is essential to weigh this against the practical realities faced by families of children with CHCs. In the early stages following diagnosis, families often experience significant emotional, logistical, and financial strain, which may limit their availability to participate in structured interventions. Accordingly, any parental involvement must be designed to be accessible, minimally burdensome, and responsive to the realities of family life during times of medical crisis.

With the goal of minimising time pressures on parents a single group session for parents and caregivers, which runs concurrently with the sibling group session has been incorporated into Session 4. Following these parallel sessions, there is a 15-minute break and sharing of kai (food) before a shared 60-minute session is conducted, during which siblings present the tools they have learnt during the program to their parents and caregivers. This structure facilitates mutual understanding and collaboration between siblings and their caregivers.

Parent/Caregiver Module

This module begins with a welcome to parents (and any additional whānau members who are present) and opens with the following karakia:

E huri tō aroaro ki te rā
Tukuna tō ataarangi ki
Muri I a koe
Turn your head towards the sun
and the shadows will fall behind you.

This is followed with an icebreaker exercise to encourage rapport-building among parents and caregivers, followed by facilitator-led psychoeducation. Parents are provided with a booklet summarising the content, including a list of recommended support services.

The session addresses the wide-ranging emotional impact that a CHC diagnosis has on the family system. Parents are reminded that while the focus often shifts understandably to the affected child, siblings often experience complex emotional responses — such as jealousy, guilt, sadness, and anxiety — that are frequently suppressed due to fears of burdening already-stressed parents (Armstrong, 2020). These themes are explored using a visual diagram illustrating common sibling responses post-diagnosis, and the facilitator guides parents through a discussion reflecting on their own family dynamics.

Key areas of sibling need identified in previous New Zealand research (Armstrong, 2020) are presented, including:

- The need for age-appropriate information about their sibling's condition and treatment;
- The need for emotional and practical guidance on how to support their unwell sibling;
- The need for support dealing with difficult feelings;
- The importance of individual time with parents and being seen as equally valued family members;
- The need for connection and support with others in similar circumstances;
- The need for recreation and normalcy in supporting psychological adjustment.
- Parents are invited to reflect on how their typically-developing children have responded to the CHC diagnosis and to consider how they can provide support that is both emotionally validating and practically helpful.

Facilitators then offer practical strategies, including:

- Maintaining open communication and creating safe opportunities for siblings to talk;
- Providing developmentally appropriate information;
- Spending one-on-one time with siblings;
- Encouraging participation in everyday routines and extracurricular activities;
- Accepting help from schools, relatives, and community resources;
- Supporting sibling relationships through empathy and facilitated conversations.

Parental involvement in the session also reflects findings from Haukeland et al. (2020), who demonstrated that strengthening sibling–parent communication leads to better emotional outcomes and family cohesion.

Sibling Module

The individual sibling module of Session 4 is a 60-minute session designed to help siblings identify their personal values and develop practical, values-aligned goals. This session responded to evidence from the sibling literature and qualitative findings from recent New Zealand research (Armstrong, 2020), which highlighted how siblings of children with CHCs often experience changes to their identity and sense of self-worth. It also draws on principles from Acceptance and Commitment Therapy (ACT), an evidence-based framework that encourages individuals to live in accordance with their values, even in the face of difficult internal experiences such as fear, anxiety, or guilt.

Incorporating values work into Session 4 for siblings aligns with evidence supporting its efficacy in adolescent interventions. Values work has been found to be effective for interventions with adolescents (Gauntlett-Gilbert et al., 2013) and has been incorporated into a psychosocial intervention for the offspring of parents with cancer (Allison et al., 2023). Values work can be particularly helpful during the developmental stage of adolescence when individuals are developing their identities, particularly whilst also dealing with other life stressors and developmental demands (Petersen et al., 2022) and has been found to decrease emotional/behavioural problems in adolescents in a universal school-based setting (Takahashi et al., 2020). Values work provides individuals with the opportunity to act in a way that leads them towards greater life satisfaction and improves quality of life (Naseri et al., 2024).

The session begins with an introduction to the concept of values as the deeply held beliefs that guide how we want to behave and who we want to be in the world. Participants explore how values differ from goals – while goals are concrete achievements that can be checked off, values provide ongoing direction and purpose. Living a values-driven life is described as bringing vitality, meaning, and a sense of fulfilment. The concept of values was further reinforced using the “Passengers on a Bus” metaphor, which helps young people understand that unhelpful or difficult thoughts (represented as disruptive passengers) often accompany us on our journey toward valued living. Rather than attempting to eliminate or argue with these thoughts, participants were encouraged to stay in the "driver's seat" and continue to move in the direction that matters to them which is a cognitive defusion metaphor commonly used in ACT (Harris, 2009).

To support this process, siblings engaged in a values-identification activity using a worksheet called the Bullseye exercise (Lundgren, 2004). This tool asked participants to reflect on four key domains of life: relationships (both with family and friends), education/work, personal growth and health, and leisure. For each domain, they selected two to four values that felt important to them and considered how closely their current behaviour aligned with those values. They marked their alignment visually on the Bullseye diagram in their workbook, with the centre representing strong alignment and the outer ring representing disconnection from that value.

This activity aims to promote greater self-awareness, particularly around areas of life where siblings may feel disconnected or undervalued. For example, in previous research, siblings described feeling invisible within their families following a brother or sister's diagnosis with a CHC. By encouraging participants to reflect on what mattered to them in different life areas, the intervention aims to re-centre their experiences and empower them with clarity around their own identity and priorities.

The session concludes with the development of SMART goals — goals that are Specific, Measurable, Achievable, Realistic, and Time-based. Each participant was asked to choose one area of their life where they would like to live more in line with their values, and to identify a small, actionable step they could take over the coming week to move in that direction. For example, a participant who valued kindness in their family relationships might set a goal to perform a thoughtful act for a family member. Another who valued connection in their friendships might aim to organise a fun activity with a peer.

By translating values into achievable goals, the session helps participants link insight to action, reinforcing the idea that small steps can support meaningful change. This approach also helps siblings build confidence and agency, which is particularly important for adolescents who may feel powerless within the broader context of a sibling's illness.

In summary, Module 4B supports siblings to reconnect with their identity, clarify what matters most to them, and begin to take steps toward living in a way that reflects those values.

Combined Caregiver and Sibling Session

The final module of the Sibling Needs Intervention is a shared 60-minute session for siblings and their parents, focused on strengthening relationships through connection, reflection, and communication. The session emphasises the importance of family relationships and a sense of belonging. This theme resonated with the intervention's broader goal of supporting sibling wellbeing within the family context and was particularly relevant given the findings from New Zealand research (Armstrong, 2020), which showed that siblings of children with CHCs often felt invisible and disconnected from family life.

The session opens with a karakia (Māori prayer), setting a respectful tone for the collective experience. This is followed by an icebreaker activity, designed to foster light-hearted interaction between siblings and caregivers. The purpose of this activity is to ease participants into the shared space, support connection across generations, and reinforce the idea that playfulness and laughter remain important, even during challenging family journeys.

The central focus of the session is to showcase and celebrate the work completed by the siblings across the four prior sessions of the intervention. Each group member is invited to present highlights and learning from the module they found most meaningful. This peer-led format helps siblings consolidate their knowledge, offering parents insight into their child's emotional world.

The session concludes with encouragement to maintain the connections built during the program as research shows that siblings of children with CHCs have a need for support from peers who understood their situation (Armstrong, 2020). As such, the intervention intentionally nurtures peer relationships and participants are reminded that these friendships could provide ongoing support and understanding in the future.

Finally, siblings are asked to complete the Sibling Needs Instrument and other outcome measures. This provides an opportunity for self-reflection and evaluation of the program's impact, and also contributes to ongoing research into the needs of siblings in families affected by chronic illness.

In summary, Session 4 serves as a culmination of learning, an opportunity to reinforce family bonds, and a platform for celebrating the strengths and resilience of the participants. By creating a space that is inclusive, respectful, and strengths-based, the session helps re-centre the experiences of siblings within the broader family narrative.

Chapter 9 Summary

The current chapter described how the literature on siblings and findings from the systematised review were synthesised to inform the development of a psychosocial intervention that provides siblings with a toolkit of strategies that will enable them to ensure their needs are met. However, it is well recognised that developing effective preventative interventions is only the first stage toward improving health outcomes and that transferring programs into real world settings is a long-term process which includes dissemination, adoption, implementation and sustainability (Durlak & DuPre, 2008).

CHAPTER 10: SUMMARY AND NEXT STEPS

Recent advances in paediatric healthcare have markedly improved the management of many childhood chronic health conditions (CHCs), transforming what were once terminal or life-threatening diagnoses into manageable, long-term conditions resulting in children living longer with CHCs. These positive developments also bring ongoing psychosocial challenges for families, particularly for siblings, who face increased risks of depression, anxiety, post-traumatic stress symptoms, lower quality of life, and disruptions to social and academic functioning.

In New Zealand and internationally, research has highlighted unmet needs among siblings – particularly in relation to emotional support, information about the CHC, peer connection, the relationship with the affected sibling, and understanding from family. Given the strong association between unmet needs and psychological distress, these findings underscore the importance of a timely, needs-based intervention.

This study developed a manualised psychosocial intervention that maps onto the self-reported unmet needs of siblings of children with chronic health conditions (CHCs). A literature review and a systematised review were undertaken to examine the impact of CHCs on siblings and evaluate the effectiveness of existing interventions. The systematised review identified international interventions targeting siblings of children with CHCs. Insights from these interventions—alongside service-user feedback and evidence-based therapeutic approaches—informed the development of a targeted, needs-based intervention for use in the New Zealand context.

Consultation with key stakeholders and service-users early in the research process provided multiple perspectives helping to clearly define and understand the needs of siblings. The engagement of service-users in my master's thesis produced specific needs-based information in the form of a direct index of the self-reported unmet needs of siblings (Armstrong, 2020) highlighting the urgent need for a targeted support service to protect the wellbeing of siblings in Aotearoa New Zealand.

This research presents several important limitations. One key limitation relates to the underrepresentation of cultural and gender diversity in both the existing literature and the studies included in the systematised review. Of the interventions reviewed, only seven reported participant ethnicity, with the majority of participants reported as ‘white’ or ‘caucasian’. This lack of representation limits the generalisability of findings to non-white populations, particularly indigenous groups such as Māori. Although research undertaken during my Master’s thesis suggested that Māori siblings reported fewer unmet needs in the domain of ‘Understanding from family’ than non-Māori siblings, this study was not conducted within a Kaupapa Māori framework and therefore lacks cultural grounding. This is a particularly important consideration in health as the influence of institutional racism within the health system suggests that Māori sibling experiences may involve complex dynamics that were not captured in this research.

In addition to limited ethnic diversity, gender diversity was not reflected in the included studies. All interventions that reported gender did so using binary categories of male and female, omitting the experiences of gender-diverse siblings entirely. This lack of inclusion further limits the applicability of current findings and highlights a significant gap in the literature that warrants future attention.

From a methodological standpoint, while a full systematic review and meta-analysis was initially considered, the decision was made to conduct a systematised review and synthesis. This approach was selected to balance academic rigour with the practical objective of developing an evidence-informed psychosocial intervention. The systematised review was constrained by significant heterogeneity in targeted outcomes, intervention approaches, and the sensitivity of measurement tools employed. This variability made it difficult to compare intervention effectiveness. Additionally, many studies relied heavily on parental proxy reports—rather than sibling self-reports—which may not accurately reflect the sibling’s own experience. Research has repeatedly shown discrepancies between parental perceptions and sibling self-reports, with parents (particularly mothers) tending to overestimate how well siblings are coping (Kobayashi et al., 2015; Sharpe & Rossiter, 2002; Upton, Lawford & Eiser, 2008). The limited use of control groups, empirical methodologies, and differences in the sensitivity of outcome measures across the reviewed interventions further restricts the strength of conclusions that can be drawn from the review.

Finally, the systematised review focused exclusively on quantitative studies in order to evaluate measurable outcomes of intervention effectiveness. While this approach provided clarity on statistical outcomes, it excluded the rich, subjective insights that qualitative research can offer regarding siblings' lived experiences. Incorporating qualitative data in future reviews and intervention development may enhance our understanding of sibling needs.

Next Steps

This research project will continue to actively engage service-users in the planning, development, and implementation of the intervention as it has been shown that this approach results in a greater likelihood the final product will meet the need of users improving both uptake and sustainability.

The next stage of this research project will be obtaining stakeholder and consumer feedback on the current iteration of the Siblings Needs Intervention, which will be integrated into the current version of the program. This will be followed by a feasibility study to assess the practicality and likelihood of successful implementation of this program in addition to estimating the fidelity of implementation and the retention of participants in the intervention. Drawing from the Experience-based Co-design methodology, feedback from siblings who participate in the feasibility study will be incorporated into subsequent iterations of the intervention to inform evidence-based care. Feasibility studies may serve to identify potential refinements to the intervention, address uncertainties around the feasibility of intervention trial methods, or test preliminary effects of the intervention (Pearson et al., 2020).

This feasibility study will be conducted at the Massey University Health Conditions and Cancer Psychology Service by the primary supervisor and the evaluation will be conducted by myself to ensure research objectivity and separation from program delivery. An evaluation of program feasibility and acceptability will be assessed by data collected from both participants and facilitators. Facilitators will record participant's attendance at session; session start and end times; self-perceived session delivery competence; and whether activities were delivered as intended (session content fidelity). Facilitators will be asked to provide general session feedback, and the details of any adaptations. Program acceptability will be measured using satisfaction questionnaires and post-program interviews with the facilitators as well as rating their agreement that participants were engaged on a 7-point Likert scale (1=strongly disagree to 7= strongly agree) at the end of every session. Participants will be asked to rate their agreement that the session was helpful, relevant, meaningful and interesting on a 7-point Likert scale (1=strongly disagree to 7= strongly agree) at the end of each session. Participants will also be asked to rate program satisfaction, indicate whether they would recommend the program to other siblings, and answer open-ended questions on the most and least liked elements of the program as well as areas for improvement.

Participants in this study will be asked to complete pre- and post- measures of both the Sibling Needs Instrument and the Kessler Psychological Distress Scale (K10; Kessler et al., 2002), both of these measures are sensitive for picking up subtle emotional and behavioural changes. The Sibling Needs Instrument was adapted from the Sibling Cancer Needs Instrument (SCNI; Patterson et al, 2011). It was developed to measure the unmet needs of young people who have a sibling with cancer to assist with the development of targeted support services as well as evaluating the impact of interventions targeted at siblings (Patterson, Millar, & Visser, 2011). The SCNI has 45 items across the following seven domains: Information; ‘Time out’ and recreation; Support (friends and peers); Practical assistance; Feelings; Relationship with sibling; and Understanding from family. The questionnaire measures the number, and type, of unmet needs that siblings experience at the time of their brother or sister’s cancer diagnosis. Under the heading of each of the seven domains is the statement “I currently need” followed by each question in that domain for which participants select one of the following options on a Likert-type scale, 1 (no need), 2 (low need), 3 (moderate need), or 4 (strong need). For data analysis, the results are then dichotomised. ‘No need’ and ‘low need’ are categorised as ‘met’ needs, and ‘moderate need’ and ‘high need’ are categorised as ‘unmet’ needs. The SCNI has strong psychometric properties.

The SCNI was adapted for siblings of children with chronic health conditions who reside in New Zealand in 2019. In this adapted version (named the Sibling Needs Instrument), language was altered to reflect biculturalism in New Zealand and the word ‘cancer’ was replaced with ‘health condition' (Armstrong, 2020). The Sibling Needs Instrument was found to have strong psychometric properties; face and content validity, construct validity, and excellent internal consistency ($\alpha = .97$; Armstrong, 2020)).

The Kessler 10 (K10; Kessler et al., 2002) is a widely used 10-item measure of psychological distress (in the anxiety-depression spectrum) with very high internal consistency ($\alpha = .93$). It has been used in community surveys of children and adolescents and has norms for young people aged 10 years and older (Andrews & Slade, 2001). Participants reflect on how they felt over the past 30 days using a 5-point likert-type scale (1=never to 5=all the time). Scores range between 10 and 50 with higher scores reflecting greater distress, and are reported in four bands; low (10-15), moderate (16-21), high (22-30), and very high (31-50; Kessler et al., 2002).

Descriptive statistics will be obtained for both measures and the relationship between distress and unmet needs will be explored. A statistical analysis of the pre- and post- test measures will test the hypothesis that the intervention reduces the number of unmet needs reported by siblings. In a follow up survey, participants will be given an open-ended question about what they would change and a thematic analysis will be conducted to analyse the data.

In terms of long-term sustainability, the ideal scenario would see this targeted intervention offered as a standard component of care for siblings soon after a child's diagnosis. This would result in services being provided in line with national recommendations. In 2011, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Faculty of Child and Adolescent Psychiatry published an issues paper titled 'Siblings of Children with Disabilities Need Support', which outlined major systemic gaps in services for siblings across Australia and New Zealand. As part of its advocacy, RANZCP committed to ensuring siblings' needs are recognised in policy, supporting professionals to identify and address these needs, increasing sibling-specific services, promoting research, and establishing a national clearinghouse for sibling-related resources.

In terms of a national implementation (following from the feasibility study and consumer feedback), New Zealand's 'Parent to parent' is a national charitable organisation which offers support to the families of children with disabilities or health impairments. With eleven regional offices nationwide, they run free programs to support siblings of children with any disability in the form of a ‘SibShop’, SibCamp’ and ‘SibDays for young people aged between 8 – 18 years. ‘Parent to parent’ is the largest organisation in New Zealand that offers support services to siblings and has a contract with the Ministry of Health for providing information services but the majority of their funding comes through grants and donations (‘Parent to Parent’, personal communication, August 23, 2019). The Chief Executive of Parent-to-Parent has expressed a willingness to engage in discussions regarding this research, which may represent an initial step toward the potential implementation of the program on a national scale.

REFLECTION

My motivation for choosing the topic of sibling support stemmed from personal experience: I am a sibling of a child who had cancer. Looking back on my own journey, and that of my two sisters, it is evident that the cancer diagnosis had a profound impact on all of us. At the time, my own difficulties were the most visible, and as a result, I was the only sibling to receive psychological support. But no one noticed the struggles of my older sister – sent to stay with friends, excluded from important conversations – as our parents grappled with the overwhelming emotional and logistical demands of Debbie's illness. Despite their deep love and best intentions, even the most dedicated of parents can struggle to meet the diverse and competing needs of all their children in the face of such adversity.

Throughout this research, what has resonated most deeply with me is how other siblings have responded. I've been approached by both friends and strangers who have shared their own experiences, often with tears, gratitude, and a sense of relief that this topic is finally being acknowledged. These moments have been profoundly moving. They reaffirm the truth that such experiences leave lasting imprints, shaping the lives and identities of siblings in ways that often go unspoken and unrecognised.

My own transformative experience of therapy with the late Dr. John Williams, Clinical Psychologist, played a pivotal role in guiding me toward a career in clinical psychology. It was through his care and insight that I came to understand the value of emotional support during times of crisis. His influence inspired my commitment to supporting families navigating serious health challenges.

Now working in a children's hospital following the completion of my clinical psychology internship has allowed me to bring together my personal experiences and insights, and academic research, to support families as they adapt to the realities of childhood illness. Yet in the fast-paced environment of inpatient care—where time and resources are stretched—it remains clear that siblings often go unnoticed. In many cases, the most I can do is offer parents information about how they might support their other children – something they are always grateful for, but which never feels quite enough.

I look forward to the day when siblings are routinely screened as part of standard care, and where a three-tiered model of support—universal, targeted, and clinical—is available to them, as outlined in the Blueprint for Sibling Psychosocial Services (Davis et al., 2024). I continue to look to Australia for leadership in this space, where initiatives such as the recently launched website siblingsaustralia.org.au are already making strides in raising awareness and offering practical support for siblings, families, and health professionals alike.

Until that day comes, I remain deeply grateful for the work I do. I am committed to advancing this area of research and practice because siblings have been overlooked for far too long. Many learned to stay silent as children in a world that suddenly became frightening and unpredictable. Now, it is time for them to step out of the shadows. Siblings deserve to be heard, recognised and truly valued—for who they are, and for all that they carry.

REFERENCES

Achenbach, T. M. (1991a). Manual for the youth self-report and 1991 profile. University of Vermont Department of Psychiatry.

Achenbach, T. M., & Edelbrock, C. (1991b). Child behavior checklist. Burlington (vt), 7, 371-392.

Adams, R., Peveler, R. C., Stein, A., & Dunger, D. B. (1991). Siblings of Children with Diabetes: Involvement, Understanding and Adaptation. *Diabetic Medicine*, *8*(9), 855-859. https://doi.org/10.1111/j.1464-5491.1991.tb02124.x

Akeret, R. U. (2000). *Photolanguage: How photos reveal the fascinating stories of our lives and relationships*. WW Norton & Company.

Alderfer, M. A., & Hodges, J. A. (2010). Supporting siblings of children with cancer: A need for family–school partnerships. *School mental health*, *2*(2), 72-81.

Alderfer, M. A., Long, K., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology*, *19*(8), 789-805. https://doi.org/https://doi.org/10.1002/pon.1638

Alderfer, M. A., & Noll, R. B. (2006). Identifying and addressing the needs of siblings of children with cancer: (commentary on Sidhu et al., page 580). *Pediatric Blood & Cancer*, *47*(5), 537-538. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=16317731&site=eds-live&scope=site

Allison, K. R., Patterson, P., McDonald, F. E., Bibby, K., Ciarrochi, J., Tracey, D., Hayes, L. L., Wright, A., Konings, S., & Davis, E. (2023). Truce: Feasibility and acceptability of an Acceptance and Commitment Therapy-based intervention for adolescents and young adults impacted by parental cancer. *Journal of Contextual Behavioral Science*, *28*, 91-101. https://doi.org/http://dx.doi.org/10.1016/j.jcbs.2023.03.014

Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler psychological distress scale (K10). *Australian and New Zealand journal of public health*, *25*(6), 494-497.

Armstrong, K. (2020). *The Unmet Needs of Siblings of Children with Cancer and Serious Chronic Health Conditions in Aōtearoa/New Zealand* [Master's thesis]. Massey University of New Zealand. http://hdl.handle.net/10179/15677

Ayers, T. S., & Sandler, I. N. (1999). Manual for the children's coping strategies checklist & the how I coped under pressure scale. Internet: http://asuprc. Asu. Edu.

Balas, E. A., & Boren, S. A. (2000). Managing clinical knowledge for health care improvement. *Yearbook of Medical Infomatics*, *9*(1), 65-70. https://doi.org/https://doi.org/10.1055/s-0038-1637943

Ballantine, K. R., Watson, H., Macfarlane, S., Winstanley, M., Corbett, R. P., Spearing, R., Stevanovic, V., Yi, M., & Sullivan, M. J. (2017). Small numbers, big challenges: adolescent and young adult cancer incidence and survival in New Zealand. *Journal of Adolescent and Young Adult Oncology*, *6*(2), 277-285.

Ballweg, J. A., Wernovsky, G., & Gaynor, J. W. (2007). Neurodevelopmental outcomes following congenital heart surgery. *Pediatric Cardiology*, *28*(2), 126-133.

Barlow, J. H., & Ellard, D. R. (2006). The psychosocial wellbeing of children with chronic disease, their parents and siblings. An overview of the research evidence base. *Child: care, health and development,* 32(1), 19-31.

Barr, R. D., Silva, A., Wong, M., Frid, W., Posgate, S., & Browne, G. (2010). A comparative assessment of attendance and nonattendance at Camp Trillium by children with cancer and their families; including their utilization of health and social services. *Journal of pediatric hematology/oncology*, *32*(5), 358-365.

Barrera, M., Atenafu, E., Nathan, P., Schulte, F., & Hancock, K. (2018b). Depression and Quality of Life in Siblings of Children With Cancer After Group Intervention Participation: A Randomized Control Trial. *Journal of Pediatric Psychology*, *43*(10), 1093-1103. https://doi.org/10.1093/jpepsy/jsy040

Barrera, M., Chung, J., & Fleming, C. (2003). Group intervention for siblings of pediatric cancer patients. In (Vol. 12, pp. S175-S176).

Barrera, M., Chung, J., & Fleming, C. (2004). A Group Intervention for Siblings of Pediatric Cancer Patients. *Journal of Psychosocial Oncology*, *22*(2), 21-39. https://doi.org/10.1300/J077v22n02_02

Barrera, M., Chung, J., Greenberg, M., & Fleming, C. (2002). Preliminary investigation of a group intervention for siblings of pediatric cancer patients. *Children's Health Care*, *31*(2), 131-142. https://doi.org/10.1207/s15326888chc3102_4

Barrera, M., Hancock, K., Saleh, A., Atenafu, E., Schulte, F., & Nathan, P. (2018c). A randomized controlled trial of a group intervention for siblings of children with cancer: Changes in symptoms of anxiety in siblings and caregivers [Article]. *Psycho-Oncology*, *27*(6), 1629-1634. https://doi.org/10.1002/pon.4707

Barrera, M., Neville, A., Purdon, L., & Hancock, K. (2018a). "It's Just for Us!" Perceived Benefits of Participation in a Group Intervention for Siblings of Children With Cancer [Article]. *Journal of Pediatric Psychology*, *43*(9), 995-1003. https://doi.org/10.1093/jpepsy/jsy026

Barrera, M. F. M. C. (2003). *Therapist's Training Manual for the Siblings Coping Together Program: Group Psychotherapeutic Treatment for Siblings of Children with Cancer* [Training Manual]. The Hospital for Sick Children.

Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. *BMC Psychology*, *3*(1), 2-12. https://doi.org/https://doi.org/10.1186/S40359-015-0089-9

Baxter, A., & Francis, A. J. (2013). Positive impact of Tai Chi Chuan participation on biopsychosocial quality of life compared to exercise and sedentary controls: a cross-sectional survey. *Journal of Complementary and Integrative Medicine*, *10*(1), 165-174.

Beck, J. S. (2005). Beck youth inventories for children and adolescents: Manual. (No Title).

Beebe, A., Gelfand, E. W., & Bender, B. (2010). A randomized trial to test the effectiveness of art therapy for children with asthma. *Journal of Allergy and Clinical Immunology*, *126*(2), 263-266. E261.

Bellin, M., & Kovacs, P. (2006). Fostering Resilience in Siblings of Youths with a Chronic Health Condition: A Review of the Literature [Article]. *Health & Social Work*, *31*(3), 209-216. https://doi.org/http://dx.doi.org/10.1093/hsw/31.3.209

Bellin, M. H., Bentley, K. J., & Sawin, K. J. (2009). Factors associated with the psychological and behavioral adjustment of siblings of youths with spina bifida. *Families, Systems, & Health*, *27*(1), 1. https://doi.org/https://doi.org/10.1037/a0014859

Bellinger, D. C., Wypij, D., Rappaport, L. A., Jonas, R. A., Wernovsky, G., & Newburger, J. W. (2003). Neurodevelopmental status at eight years in children with dextro-transposition of the great arteries: the Boston Circulatory Arrest Trial. *The Journal of thoracic and cardiovascular surgery*, *126*(5), 1385-1396.

Bennett, S. T., Flett, R. A., & Babbage, D. R. (2016). Considerations for culturally responsive cognitive-behavioural therapy for Māori with depression. *Journal of Pacific Rim Psychology* 10 (2016): e8.

Bertalanffy, L. (1968). *General system theory: Foundations, development, applications / Ludwig von Bertalanffy*. George Braziller.

Besani, C., McCusker, C., Higgins, A., & McCarthy, A. (2018). A family-based intervention to promote adjustment in siblings of children with cancer: A pilot study. *Psycho-Oncology*, *27*(8), 2052-2055. https://doi.org/10.1002/pon.4756

Besier, T., Hoelling, H., Schlack, R., West, C., & Goldbeck, L. (2010). Impact of a family-oriented rehabilitation programme on behavioural and emotional problems in healthy siblings of chronically ill children. In (Vol. 36, pp. 686-695).

Bluth, K., Roberson, P. N., Gaylord, S. A., Faurot, K. R., Grewen, K. M., Arzon, S., & Girdler, S. S. (2016). Does self-compassion protect adolescents from stress?. *Journal of child and family studies*, *25*, 1098-1109.

Bluth, M. H., Thomas, R., Cohen, C., Bluth, A. C., & Goldberg, E. (2016). Martial arts intervention decreases pain scores in children with malignancy. *Pediatric health, medicine and therapeutics*, *7*, 79.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., Boyes, A., & Group, S. C. R. (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer*, *88*(1), 217-

225. https://doi.org/https://doi.org/10.1002/(SICI)1097-0142(20000101)88:1<217::AID-CNCR29>

Bosmans, G., & Kerns, K. A. (2015). Attachment in middle childhood: Progress and prospects. *New directions for child and adolescent development*, *2015*(148), 1-14.

Bowen, S.-J., & Hull, J. (2015). The basic science of cystic fibrosis. *Paediatrics and Child Health*, *25*(4), 159-164. https://doi.org/http://dx.doi.org/10.1016/j.paed.2014.12.008

Branstetter, J., Domian, E., Graff, C., Piamjariyakul, U., & Williams, P. (2008). Communication in families of children with chronic illness or disability. *Issues in Comprehensive Pediatric Nursing*, *31*(4), 171-184.

Brennan, C., Hugh-Jones, S., & Aldridge, J. (2013). Paediatric life-limiting conditions: Coping and adjustment in siblings. *Journal of health psychology*, *18*(6), 813-824.

Brierley, J. A. (2017). The role of a pragmatist paradigm when adopting mixed methods in behavioural accounting research. *International Journal of Behavioural Accounting and Finance*, *6*(2), 140-154.

Bronfenbrenner, K., & Hickey, R. (2004). Changing to organize. *Rebuilding labor: Organizing and organizers in the new union movement*, 17.

Brosnan, P., Davis, K. A., Mazzenga, M., Oberoi, A. R., Sharkey, C. M., Buchbinder, D., Alderfer, M. A., & Long, K. A. (2022). Psychosocial care providers' perspectives: Barriers to implementing services for siblings of children with cancer. *Pediatric Blood & Cancer*, *69*(2), e29418.

Burckhardt, R., Manicavasagar, V., Batterham, P. J., Hadzi-Pavlovic, D., & Shand, F. (2017). Acceptance and commitment therapy universal prevention program for adolescents: a feasibility study. *Child and Adolescent Psychiatry and Mental Health*, *11*(1), 1-10.

Burgel, P.-R., Bellis, G., Olesen, H. V., Viviani, L., Zolin, A., Blasi, F., & Elborn, J. S. (2015). Future trends in cystic fibrosis demography in 34 European countries. *European Respiratory Journal*, *46*(1), 133-141.

Cabalka, A. K. (2004). Physiologic risk factors for respiratory viral infections and immunoprophylaxis for respiratory syncytial virus in young children with congenital heart disease. *The Pediatric infectious disease journal*, *23*(1), S41-S45.

Calhoun, L. G., & Tedeschi, R. G. (1998). Beyond recovery from trauma: Implications for clinical practice and research. *Journal of social Issues*, *54*(2), 357-371.

Carpenter, P., & Sahler, O. (1991). Sibling perception and adaptation to childhood cancer. Conceptual and methodological considerations. *Advances in child health psychology*, *30*, 193-205.

Carpenter, P. J., Sahler, O. J. Z., & Davis, M. S. (1990). Use of a camp setting to provide medical information to siblings of pediatric cancer patients. Journal of Cancer Education, 5(1), 21-26.

Carvalho, S., Martins, C., Almeida, H., & Silva, F. (2017). The evolution of cognitive behavioural therapy–The third generation and its effectiveness. *European Psychiatry*, *41*(S1), s773-s774.

Causey, D. L., & Dubow, E. F. (1992). Development of a self-report coping measure for elementary school children. Journal of Clinical Child and Adolescent Psychology, 21(1), 47-59.

Cavanagh, S. (1997). Content analysis: concepts, methods and applications. *Nurse researcher*, *4*(3), 5-16.

Choi, B. G. (1993). A study on the development of the Self–esteem Inventory (1). Family and Environment Research, 31, 41.

Chudleigh, J., Browne, R., & Radbourne, C. (2019). Impact of cystic fibrosis on unaffected siblings: a systematic review. *The Journal of pediatrics*, *210*, 112-117. E119.

Clarke, W. L. (2011). Behavioral challenges in the management of childhood diabetes. In: SAGE Publications.

Cohen, D., Friedrich, W., Jaworski, T., Copeland, D., & Pendergrass, T. (1994). Pediatric cancer: Predicting sibling adjustment. *Journal of Clinical Psychology*, *50*(3), 303-319. https://doi.org/https://doi.org/10.1002/1097-4679(199405)50:3<303::AID-JCLP2270500302>3.0.CO;2-#

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual review of clinical psychology*, *8*, 455-480. https://doi.org/https://doi.org/10.1146/annurev-clinpsy-032511-143108

Conduct Problems Prevention Research Group (CPPRG). (1994). http://fasttrackproject.org/techrept/p/pcp/index.php.

Connor, J. A., Kline, N. E., Mott, S., Harris, S. K., & Jenkins, K. J. (2010). The meaning of cost for families of children with congenital heart disease. *Journal of pediatric health care*, *24*(5), 318-325. https://doi.org/http://dx.doi.org/10.1016/j.pedhc.2009.09.002

Consolini, M. (2020). *Children with Chronic Health Conditions*. https://www.msdmanuals.com/en-nz/professional/pediatrics/caring-for-sick-children-and-their-families/children-with-chronic-health-conditions?query=Chronic%20Health%20Problems%20in%20Children#v1084639

Cooper, S. L., & Brown, P. A. (2015). Treatment of pediatric acute lymphoblastic leukemia. *Pediatric Clinics*, *62*(1), 61-73.

Curtis, J. A., & Hagerty, D. (2002). Managing diabetes in childhood and adolescence. *Canadian family physician*, *48*(3), 499-502.

Cystic Fibrosis New Zealand. (n.d.). *How is CF diagnosed?* Cystic Fibrosis New Zealand. https://www.cfnz.org.nz/about/how-is-cf-diagnosed/

D'Urso, A., Mastroyannopoulou, K., & Kirby, A. (2017). Experiences of posttraumatic growth in siblings of children with cancer. In (Vol. 22, pp. 301-317).

Dalrymple, K. L., Fiorentino, L., Politi, M. C., & Posner, D. (2010). Incorporating principles from acceptance and commitment therapy into cognitive-behavioral therapy for insomnia: A case example. *Journal of Contemporary Psychotherapy*, *40*, 209-217.

Davis, D. M., & Hayes, J. A. (2011). What are the benefits of mindfulness? A practice review of psychotherapy-related research. *Psychotherapy*, *48*(2), 198.

Deavin, A., Greasley, P., & Dixon, C. (2018). Children's perspectives on living with a sibling with a chronic illness. *Pediatrics*, *142*(2). https://doi.org/https://doi.org/10.1542/peds.2017-4151

Denny, S., de Silva, M., Fleming, T., Clark, T., Merry, S., Ameratunga, S., Milfont, T., Farrant, B., & Fortune, S. A. (2014). The prevalence of chronic health conditions impacting on daily functioning and the association with emotional well-being among a national sample of high school students. *Journal of Adolescent Health*, *54*(4), 410-415.

Derraik, J. G. B., Reed, P. W., Jefferies, C., Cutfield, S. W., Hofman, P. L., & Cutfield, W. S. (2012). Increasing Incidence and Age at Diagnosis among Children with Type 1 Diabetes Mellitus over a 20-Year Period in Auckland (New Zealand). *PLOS ONE*, *7*(2), e32640. https://doi.org/10.1371/journal.pone.0032640

Dickey, S. B., & Deatrick, J. (2000). Autonomy and decision making for health promotion in adolescence. *Pediatric Nursing*, *26*(5), 461.

DiNapoli, P. P., & Murphy, D. (2002). The marginalization of chronically ill adolescents. *The Nursing Clinics of North America*, *37*(3), 565-572. https://doi.org/https://doi.org/10.1016/S0029-6465(02)00012-9

Dinleyici, M., Çarman, K. B., Özdemir, C., Harmancı, K., Eren, M., Kirel, B., Şimşek, E., Yarar, C., Duyan Çamurdan, A., & Şahin Dağlı, F. (2019). Quality-of-life Evaluation of Healthy Siblings of Children with Chronic Illness. *Balkan Medical Journal*, *37*(1), 34-42. https://doi.org/10.4274/balkanmedj.galenos.2019.2019.7.142

Dobson, R., Owens, R., & Cameron, L. (2007). Childhood cancer: An investigation into the experience for siblings. *Pediatric Blood & Cancer*, *49*, 543-544. https://doi.org/https://siop-online.org/journal/

Dolgin, M. J., Somer, E., Zaidel, N., & Zaizov, R. (1997). A structured group intervention for siblings of children with cancer. *Journal of child and adolescent group therapy*, *7*(1), 3-18.

Donetto, S., Pierri, P., Tsianakas, V., & Robert, G. (2015). Experience-based co-design and healthcare improvement: realizing participatory design in the public sector. *The Design Journal*, *18*(2), 227-248. https://doi.org/http://dx.doi.org/10.2752/175630615X14212498964312

Donnan, B. M., Webster, T., Wakefield, C. E., Dalla-Pozza, L., Alvaro, F., Lavoipierre, J., & Marshall, G. M. (2015). What About School? Educational Challenges for Children and Adolescents With Cancer. *Australian Educational & Developmental Psychologist*, *32*(1).

Doyle, E. A. (2015). Autoimmune conditions associated with type 1 diabetes. *Pediatric Nursing*, *41*(2), 89.

Dozois, D. J. (2010). Understanding and enhancing the effects of homework in cognitive-behavioral therapy.

Durlak, J., & DuPre, E. (2008). Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American journal of community psychology*, *41*, 327-350. https://doi.org/http://dx.doi.org/10.1007/s10464-008-9165-0

Duvall, E. M. (1977). *Marriage and family development (5th ed.)*. Lippincott.

Eckersley, L., Sadler, L., Parry, E., Finucane, K., & Gentles, T. L. (2016). Timing of diagnosis affects mortality in critical congenital heart disease. *Archives of Disease in Childhood*, *101*(6), 516-520.

Edge, J., Hawkins, M., Winter, D., & Dunger, D. (2001). The risk and outcome of cerebral oedema developing during diabetic ketoacidosis. *Archives of Disease in Childhood*, *85*(1), 16-22. https://doi.org/http://dx.doi.org/10.1136/adc.85.1.16

Ehrenreich-May, J., Kennedy, S. M., Sherman, J. A., Bilek, E. L., Buzzella, B. A., Bennett, S. M., & Barlow, D. H. (2017). *Unified protocols for transdiagnostic treatment of emotional disorders in children and adolescents: Therapist guide*. Oxford University Press.

Elborn, J. S., Bell, S. C., Madge, S. L., Burgel, P.-R., Castellani, C., Conway, S., De Rijcke, K., Dembski, B., Drevinek, P., & Heijerman, H. G. (2016). Report of the European Respiratory Society/European Cystic Fibrosis Society task force on the care of adults with cystic fibrosis. *European Respiratory Journal*, *47*(2), 420-428. https://doi.org/http://dx.doi.org/10.1183/13993003.00592-2015

Epp, A. M., & Dobson, K. S. (2010). The evidence base for cognitive-behavioral therapy. *Handbook of cognitive-behavioral therapies*, 39-73.

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. Journal of marital and family therapy, 9(2), 171-180.

Erikson, E. H. (1993). *Childhood and society*. WW Norton & Company.

Eyberg, S. M., & Robinson, E. A. (1983). Conduct problem behavior: Standardization of a behavioral rating. Journal of Clinical Child & Adolescent Psychology, 12(3), 347-354.

Farmer, J. E., Marien, W. E., Clark, M. J., Sherman, A., & Selva, T. J. (2004). Primary care supports for children with chronic health conditions: Identifying and predicting unmet family needs. *Journal of Pediatric Psychology*, *29*(5), 355-367. https://doi.org/ttps://doi.org/10.1093/jpepsy/jsh039

Feldman, A. F., & Matjasko, J. L. (2005). The role of school-based extracurricular activities in adolescent development: A comprehensive review and future directions. *Review of educational research*, *75*(2), 159-210.

Fenn, K., & Byrne, M. (2013). The key principles of cognitive behavioural therapy. *InnovAiT*, *6*(9), 579-585.

Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings: I. Chronically ill boys. . *Journal of Child Psychology and Psychiatry 3*(25), 459–476.

Forouhi, N. G., & Wareham, N. J. (2019). Epidemiology of diabetes. *Medicine*, *47*(1), 22-27. https://doi.org/https://doi.org/10.1016/j.mpmed.2018.10.004

Foster, S. L., & Mash, E. J. (1999). Assessing social validity in clinical treatment research: Issues and procedures. *Journal of Consulting and Clinical Psychology*, *67*(3), 308.

Fredriksen, T., Marie Vatne, T., Bjartveit Haukeland, Y., Tudor, M., & Fjermestad, K. W. (2023). Siblings of children with chronic disorders: Family and relational factors as predictors of mental health. *Journal of Child Health Care*, *27*(1), 145-159.

Futcher, J. (1988). Chronic illness and family dynamics. *Pediatric Nursing*, *14*(5), 381-385. http://www.pediatricnursing.net/

Gan, L. L., Lum, A., Wakefield, C. E., Nandakumar, B., & Fardell, J. E. (2017). School Experiences of Siblings of Children with Chronic Illness: A Systematic Literature Review [Review Article]. *Journal of Pediatric Nursing*, *33*, 23-32. https://doi.org/10.1016/j.pedn.2016.11.007

Gannoni, A. F., & Shute, R. H. (2010). Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry*(1), 39-53. https://doi.org/https://doi.org/10.1177/1359104509338432

Garcia, R. U., Aggarwal, S., & Natarajan, G. (2016). Parental perception of functional status and impact on the family of children with congenital heart surgery. *Early human development*, *96*, 45-51.

Gauntlett-Gilbert, J., Connell, H., Clinch, J., & McCracken, L. M. (2013). Acceptance and values-based treatment of adolescents with chronic pain: Outcomes and their relationship to acceptance. *Journal of Pediatric Psychology*, *38*(1), 72-81.

Gerhardt, C. A., Lehmann, V., Long, K., & Alderfer, M. A. (2015). Supporting Siblings as a Standard of Care in Pediatric Oncology. *Pediatric Blood and Cancer*, *62*, 678-732. https://doi.org/https://doi.org/10.1002/pbc.25821

Giallo, R., & Gavidia-Payne, S. (2008). Evaluation of a Family-based Intervention for Siblings of Children with a Disability or Chronic Illness [Journal Article]. *Australian e-Journal for the Advancement of Mental Health, The*(2), 84. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsihc&AN=edsihc.398541603855660&site=eds-live&scope=site

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of intellectual disability research*, *50*(12), 937-948. https://doi.org/http://dx.doi.org/10.1111/j.1365-2788.2006.00928.x

Gladding, S. T. (2003). *Group work: A counseling specialty*. Prentice Hall.

Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2011). The Mediating Effects of Family Functioning on Psychosocial Outcomes in Healthy Siblings of Children with Sickle Cell Disease. In (Vol. 57, pp. 1055-1061).

Goldbeck, L., & Braun, R. (2003). LQ-KID: A computer-assisted method to assess health-related quality of life of children and adolescents with chronic conditions. *Prävention und Rehabilitation*, *15*(3), 117-126.

Goodman, A., & Goodman, R. (2009). Strengths and difficulties questionnaire as a dimensional measure of child mental health. *Journal of the American Academy of Child & Adolescent Psychiatry*, *48*(4), 400-403.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: a research note. *Journal of Child Psychology and Psychiatry*, *38*(5), 581-586.

Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. Journal of the American Academy of Child & Adolescent Psychiatry, 40(11), 1337-1345.

Gowers, S. (2005). Development in adolescence. *Psychiatry*, *4*(6), 6-9.

Greening, L., Stoppelbein, L., Konishi, C., Jordan, S. S., & Moll, G. (2007). Child routines and youths' adherence to treatment for type 1 diabetes. *Journal of Pediatric Psychology*, *32*(4), 437-447.

Groop, P.-H., Thomas, M. C., Moran, J. L., Wadèn, J., Thorn, L. M., Mäkinen, V.-P., Rosengård-Bärlund, M., Saraheimo, M., Hietala, K., & Heikkilä, O. (2009). The presence and severity of chronic kidney disease predicts all-cause mortality in type 1 diabetes. *Diabetes*, *58*(7), 1651-1658.

Grych, J. H., & Fincham, F. D. (1990). Marital conflict and children's adjustment: a cognitive-contextual framework. *Psychological bulletin*, *108*(2), 267.

Guthrie, D. W., Bartsocas, C., Jarosz-Chabot, P., & Konstantinova, M. (2003). Psychosocial issues for children and adolescents with diabetes: Overview and recommendations. *Diabetes Spectrum*, *16*(1), 7-12.

Haggerty, R., & Mrazek, P. (1994). *Reducing risks for mental disorders: Frontiers for preventive intervention research*. National Academies Press.

Halfon, N., & Newacheck, P. W. (2010). Evolving notions of childhood chronic illness. *JAMA*, *303*(7), 665-666. https://doi.org/https://doi.org/10.1001/jama.2010.130

Hamama, L., Ronen, T., & Rahav, G. (2008). Self-Control, Self-Efficacy, Role Overload, and Stress Responses among Siblings of Children with Cancer [Article]. *Health & Social Work*, *33*(2), 121-132. https://doi.org/http://dx.doi.org/10.1093/hsw/33.2.121

Hamburg, B. A., & Inoff, G. E. (1983). Coping with predictable crises of diabetes. *Diabetes Care*, *6*(4), 409-416.

Harter, S. (1985a). *Manual for the self-perception profile for children*. Denver, Co: University of Denver.

Harter, S. (1985b) *Manual for the social support scale for children*. Denver, Co: University of Denver.

Harter, S. (1985c). *Manual for the self-perception profile for children☹revision of the perceived competence scale for children)*. University of Denver.

Hartling, L., Milne, A., Tjosvold, L., Wrightson, D., Gallivan, J., & Newton, A. (2014). A systematic review of interventions to support siblings of children with chronic illness or disability. *Journal of Paediatrics & Child Health*, *50*(10), E26-38. https://doi.org/10.1111/j.1440-1754.2010.01771.x

Hastings, S. E., Swales, M. A., Hughes, J. C., Jones, K., & Hastings, R. P. (2022). Universal delivery of a dialectical behaviour therapy skills programme (DBT STEPS-A) for adolescents in a mainstream school: feasibility study. *Discover Psychology*, *2*(1), 21.

Haukeland, Y. B., Czajkowski, N. O., Fjermestad, K. W., Silverman, W. K., Mossige, S., & Vatne, T. M. (2020). Evaluation o“ "SI”S", An Intervention for Siblings and Parents of Children with Chronic Disorders. *Journal of Child & Family Studies*, *29*(8), 2201-2217. https://doi.org/10.1007/s10826-020-01737-x

Havermans, T. (2015). Belgian siblings of children with a chronic illness: Is their quality of life different from their peers? (E. Goethals & I. Van Diest, Trans.). In I. De Croock (Ed.), (Vol. 19, pp. 154-166).

Havill, N., Fleming, L. K., & Knafl, K. (2019). Well siblings of children with chronic illness: A synthesis research study. *Research in Nursing & Health*, *42*(5), 334-348. https://doi.org/https://doi.org/10.1002/nur.21978

Hayes, S. C., & Hofmann, S. G. (2017). The third wave of cognitive behavioral therapy and the rise of process-based care. *World psychiatry*, *16*(3), 245.

Hayes, S. C., & Hofmann, S. G. (2021). “Third-wave” cognitive and behavioral therapies and the emergence of a process-based approach to intervention in psychiatry. *World psychiatry*, *20*(3), 363-375.

Heart Kids New Zealand. (n.d.). *Congenital heart conditions*. https://www.heartkids.org.nz/heart-conditions/congenital-heart-conditions/

Heiney, S., Goon-Johnson, K., Ettinger, R., & Ettinger, S. (1990). The effects of group therapy on siblings of pediatric oncology patients. *Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses*, *7*(3), 95-100. https://doi.org/10.1177/104345429000700303

Herrman, J. (2010). Sibling’s' Perceptions of the Costs and Rewards of Diabetes and its Treatment. *Journal of Pediatric Nursing*, *25*(5), 428-437. https://doi.org/https://doi.org/10.1016/j.pedn.2009.07.004

Hilário, A. P. (2022). Sibling caring roles and responsibilities when a child suffers from a chronic illness. *Sociology Compass*, *16*(1), e12950.

Hodgkinson, K., Butow, P., Hunt, G., Pendlebury, S., Hobbs, K., Lo, S. K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivor's' unmet supportive care needs: the CaSUN (Cancer Survivor's' Unmet Needs measure). *Psycho-Oncology*, *16*(9), 796-804. https://doi.org/https://doi.org/10.1002/pon.1137

Hollidge, C. (2001). Psychological adjustment of siblings to a child with diabetes [Article]. *Health & Social Work*, *26*(1), 15-25. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=eue&AN=507753263&site=eds-live&scope=site

Houtzager, B., Grootenhuis, M., Caron, H., & Last, B. (2005). SIBLING SELF-REPORT, PARENTAL PROXIES, AND QUALITY OF LIFE: The Importance of Multiple Informants for Siblings of a Critically III Child [Article]. *Pediatric Hematology & Oncology*, *22*(1), 25-40. https://doi.org/10.1080/08880010590896233

Houtzager, B., Grootenhuis, M., Caron, H., & Lasta, B. (2004). Quality of life and psychological adaptation in siblings of paediatric cancer patients, 2 years after diagnosis. *Psycho-Oncology*, *13*(8), 499-511. https://doi.org/https://doi.org/10.1002/pon.759

Houtzager, B., Grootenhuis, M., Hoekstra-Weebers, J., & Last, B. (2005). One month after diagnosis: quality of life, coping and previous functioning in siblings of children with cancer 1. *Child: care, health and development*, *31*(1), 75-87.

Houtzager, B., Grootenhuis, M., & Last, B. (2001). Supportive groups for siblings of pediatric oncology patients: impact on anxiety. *Psycho-Oncology*, *10*(4), 315-324. https://doi.org/10.1002/pon.528

Houtzager, B., Oort, F., Hoekstra-Weebers, J., Caron, H., Grootenhuis, M., & Last, B. (2004). Coping and family functioning predict longitudinal psychological adaptation of siblings of childhood cancer patients. *Journal of Pediatric Psychology*, *29*(8), 591-605. https://doi.org/https://doi.org/10.1093/jpepsy/jsh061

Huang, Y., Pan, Y., Chen, M., Jiang, H., Ren, L., Wang, Y., Zhang, L., & Dong, C. (2022). The resilient process of the family after diagnosis of childhood chronic illness: a qualitative meta-synthesis. *Journal of Pediatric Nursing*, *67*, e180-e190.

Im, Y.-M., Yun, T.-J., & Lee, S. (2018). Health condition and familial factors associated with health-related quality of life in adolescents with congenital heart disease: a cross sectional study. *Health and Quality of Life Outcomes*, *16*(1), 1-7.

Incledon, E., Williams, L., Hazell, T., Heard, T. R., Flowers, A., & Hiscock, H. (2015). A review of factors associated with mental health in siblings of children with chronic illness. *Journal of Child Health Care*, *19*(2), 182-194. https://doi.org/https://doi.org/10.1177/1367493513503584

Ingerski, L. M., Shaw, K., Gray, W. N., & Janicke, D. M. (2010). A pilot study comparing traumatic stress symptoms by child and parent report across pediatric chronic illness groups. *Journal of*

Developmental and Behavioral Pediatrics, *31*(9), 713-719. https://doi.org/https://doi.org/10.1097/DBP.0b013e3181f17c52

Iwakabe, S., Nakamura, K., & Thoma, N. C. (2023). Enhancing emotion regulation. *Psychotherapy Research*, *33*(7), 918-945.

Jackson, C., Richer, J., & Edge, J. A. (2008). Sibling psychological adjustment to type 1 diabetes mellitus. *Pediatric diabetes*, *9*(4pt1), 308-311.

Janssens, A., Peremans, L., & Deboutte, D. (2010). Conceptualizing collaboration between children's services and child and adolescent psychiatry: A bottom—up process based on a qualitative needs assessment among the professionals. *Clinical Child Psychology and Psychiatry*, *15*(2), 251-266. https://doi.org/https://doi.org/10.1177/1359104509340651

Jenholt Nolbris, M., & Ahlström, B. (2014). Siblings of children with cancer – Their experiences of participating in a person-centered support intervention combining education, learning and reflection: Pre- and post-intervention interviews [Article]. *European Journal of Oncology Nursing*, *18*, 254-260. https://doi.org/10.1016/j.ejon.2014.01.002

Jo, M. J., Hong, S., & Park, H. R. (2018). Effects of Art Intervention Program for Siblings of Children With Cancer: A Pilot Study [Article]. *Journal of Pediatric Oncology Nursing*, *35*(3), 178-187. https://doi.org/10.1177/1043454218762702

Kabat-Zinn, J. (2001). Mindfulness meditation for everyday life. *London, UK: Piatkus*.Minor, H. G., Carlson, L. E., Mackenzie, M. J., Zernicke, K., & Jones, L. (2006). Evaluation of a mindfulness-based stress reduction (MBSR) program for caregivers of children with chronic conditions. *Social work in health care*, *43*(1), 91-109

Kato, M., & Manabe, A. (2018). Treatment and biology of pediatric acute lymphoblastic leukemia. *Pediatrics International*, *60*(1), 4-12.

Katsarou, A., Gudbjörnsdottir, S., Rawshani, A., Dabelea, D., Bonifacio, E., Anderson, B. J., Jacobsen, L. M., Schatz, D. A., & Lernmark, Å. (2017). Type 1 diabetes mellitus. *Nature reviews Disease primers*, *3*(1), 1-17. https://doi.org/http://dx.doi.org/10.1038/nrdp.2017.16

Kazak, A., Alderfer, M., & Barakat, L. (2004). Treatment of Posttraumatic Stress Symptoms in Adolescent Survivors of Childhood Cancer and Their Families: A Randomized Clinical Trial [Article]. *Journal of Family Psychology*, *18*(3), 493-504. https://doi.org/10.1037/0893-3200.18.3.493

Kazak, A. E. (1989). Families of chronically ill children: A systems and social-ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology*, *57*(1), 25-30. https://doi.org/https://doi.org/10.1037/0022-006X.57.1.25

Kazak, A. E. (2001). Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice, and policy. *Children's Services: Social*

Policy, Research, and Practice, *4*(4), 217-233. https://doi.org/https://doi.org/10.1207/S15326918CS0404_05

Kearney, C. A., Drabman, R. S., & Beasley, J. F. (1993). The trials of childhood: The development, reliability, and validity of the Daily Life Stressors Scale. Journal of Child and Family Studies, 2, 371-388.

Kennedy, F., & Pearson, D. (2020). *Integrating CBT and third wave therapies: Distinctive features*. Routledge.

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L., ... & Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological medicine*, *32*(6), 959-976.

Kessler, R. C., & Wang, P. S. (2008). The descriptive epidemiology of commonly occurring mental disorders in the United States. *Annu. Rev. Public Health*, *29*, 115-129.

Kiburz, J. A. (1994). Perceptions and concerns of the school-age siblings of children with myelomeningocele. *Issues in Comprehensive Pediatric Nursing*, *17*(4), 223-231. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=107421876&site=eds-live&scope=site

Kim, S.-H., Yim, H.-W., Jo, S.-J., Jung, K.-I., Lee, K., & Park, M.-H. (2018). The effects of group cognitive behavioral therapy on the improvement of depression and anxiety in adolescents with problematic internet use. *Journal of the Korean Academy of Child and Adolescent Psychiatry*, *29*(2), 73.

Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of higher education*, *6*(5), 26-41. https://doi.org/http://dx.doi.org/10.5430/ijhe.v6n5p26

Knecht, C., Hellmers, C., & Metzing, S. (2015). The perspective of siblings of children with chronic illness: A literature review. *Journal of Pediatric Nursing*, *30*(1), 102-116. https://doi.org/https://doi.org/10.1016/j.pedn.2014.10.010

Kobayashi, K., Hayakawa, A., & Hohashi, N. (2015). Interrelations Between Siblings and Parents in Families Living With Children With Cancer [Article]. *Journal of Family Nursing*, *21*(1), 119-148. https://doi.org/10.1177/1074840714564061

Koenig, L. J., & Gladstone, T. R. (1998). Pubertal development and school transition: Joint influences on depressive symptoms in middle and late adolescents. *Behavior Modification*, *22*(3), 335-357.

Kuk, K., & Taylor-Cousar, J. L. (2015). Lumacaftor and ivacaftor in the management of patients with cystic fibrosis: current evidence and future prospects. *Therapeutic advances in respiratory disease*, *9*(6), 313-326.

Labay, L., & Walco, G. (2004). Brief Report: Empathy and psychological adjustment in siblings of children with cancer. *Journal of Pediatric Psychology*, *29*(4), 309-314. https://doi.org/10.1093/jpepsy/jsh032

Lamb, M. E., Sutton-Smith, B., Sutton-Smith, B., & Lamb, M. E. (2014). *Sibling relationships: Their nature and significance across the lifespan*. Psychology Press.

Langford, R. W. (1987). Chronic illness: A small group approach. *Rehabilitation Nursing*, *12*(4), 179-187.

Lantin-Hermoso, M. R., Berger, S., Bhatt, A. B., Richerson, J. E., Morrow, R., Freed, M. D., & Beekman, R. H. (2017). The care of children with congenital heart disease in their primary medical home. *Pediatrics*, *140*(5), e20172607.

Lavigne, J. V., Traisman, H. S., Marr, T. J., & Chasnoff, I. J. (1982). Parental perceptions of the psychological adjustment of children with diabetes and their siblings. *Diabetes Care*, *5*(4), 420-426.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer publishing company.

Leese, G. P., Wang, J., Broomhall, J., Kelly, P., Marsden, A., Morrison, W., Frier, B. M., & Morris, A. D. (2003). Frequency of severe hypoglycemia requiring emergency treatment in type 1 and type 2 diabetes: a population-based study of health service resource use. *Diabetes Care*, *26*(4), 1176-1180.

Leukaemia Foundation. (n.d.). *Childhood ALL: Treatment side effects*. Retrieved June 23, 2024, from https://www.leukaemia.org.au/blood-cancer/types-of-blood-cancer/childhood-blood-cancers/childhood-all/treatment-side-effects/

Limbers, C., & Skipper, S. (2014). Health-related quality of life measurement in siblings of children with physical chronic illness: a systematic review. *Families, Systems, & Health*, *32*(4), 408. https://doi.org/10.1037/fsh0000077

Lobato, D., & Kao, B. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, *27*(8), 711-716. https://doi.org/10.1093/jpepsy/27.8.711

Long, K., Lehmann, V., Gerhardt, C. A., Carpenter, A. L., Marsland, A. L., & Alderfer, M. A. (2018). Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review. *Psycho-Oncology*, *27*(6), 1467-1479. https://doi.org/10.1002/pon.4669

Long, K., Lown, E. A., Alderfer, M. A., Ring, S., Skala, S., Goldish, M., Ostrowski, N. L., Marsland, A. L., & Ewing, L. J. (2015). Major Lessons Learned From a Nationally-Based Community--Academic Partnership: Addressing Sibling Adjustment to Childhood Cancer [Article]. *Families, Systems & Health: The Journal of Collaborative Family HealthCare*, *33*(1), 61-67. https://doi.org/10.1037/fsh0000084

Long, K., Marsland, A. L., Wright, A., & Hinds, P. (2015). Creating a tenuous balance: Siblings' experience of a brother's or sister's childhood cancer diagnosis. *Journal of Pediatric Oncology Nursing*, *32*(1), 21-31. https://doi.org/10.1177/1043454214555194

Loup, O., von Weissenfluh, C., Gahl, B., Schwerzmann, M., Carrel, T., & Kadner, A. (2009). Quality of life of grown-up congenital heart disease patients after congenital cardiac surgery. *European journal of cardio-thoracic surgery*, *36*(1), 105-111.

Lummer-Aikey, S., & Goldstein, S. (2021). Sibling adjustment to childhood chronic illness: an integrative review. *Journal of Family Nursing*, *27*(2), 136-153.

Lundgren, T. (2004). *The Bull's-Eye Values Survey* [Unpublished manuscript]. Department of Behavioural Sciences, University of Linköping, Sweden.

Marsh, I. C., Chan, S. W., & MacBeth, A. (2018). Self-compassion and psychological distress in adolescents—a meta-analysis. *Mindfulness*, *9*, 1011-1027.

Martinez, B., Pechlivanoglou, P., Meng, D., Traubici, B., Mahood, Q., Korczak, D., Colasanto, M., Mahant, S., Orkin, J., & Cohen, E. (2022). Clinical health outcomes of siblings of children with chronic conditions: a systematic review and meta-analysis. *The Journal of pediatrics*, *250*, 83-92. e88.

Marusak, H. A., Iadipaolo, A. S., Cohen, C., Goldberg, E., Taub, J. W., Harper, F. W. K., Bluth, M. H., & Rabinak, C. A. (2020). Martial Arts-Based Therapy Reduces Pain and Distress Among Children with Chronic Health Conditions and Their Siblings [article]. *Journal of Pain Research*, *ume 13*, 3467-3478. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsdoj&AN=edsdoj.69c194f95a0d41f9915b07a05162aad9&site=eds-live&scope=site

Mayer-Davis, E. J., Kahkoska, A. R., Jefferies, C., Dabelea, D., Balde, N., Gong, C. X., Aschner, P., & Craig, M. E. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Definition, epidemiology, and classification of diabetes in children and adolescents. *Pediatric diabetes*, *19*, 7-19.

Mazur, M. (1998). The other children. *Diabetes Forecast*, *51*(8), 95-96.

Mazza, J. J., Dexter-Mazza, E. T., Miller, A. L., Rathus, J. H., & Murphy, H. E. (2016). *DBT? Skills in schools: Skills training for emotional problem solving for adolescents Dbt Steps-a*. Guilford Publications.

McCusker, C., & Casey, F. (2016). *Congenital heart disease and neurodevelopment: Understanding and improving outcomes*. Academic Press.

McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. *American Journal of Orthopsychiatry*, *53*(2), 209-218. https://doi.org/https://doi.org/10.1111/j.1939-0025.1983.tb03366.x

McKenzie Smith, M., Pinto Pereira, S., Chan, L., Rose, C., & Shafran, R. (2018). Impact of Well-being Interventions for Siblings of Children and Young People with a Chronic Physical or Mental Health Condition: A Systematic Review and Meta-Analysis. *Clinical child and family psychology review*, *21*(2), 246-265. https://doi.org/10.1007/s10567-018-0253-x

McLoone, J., Wakefield, C., & Cohn, R. (2013). Childhood cancer survivor’s' school (re) entry: A ustralian parents' perceptions. *European Journal of Cancer Care*, *22*(4), 484-492.

Meleis, A. I. (2010). *Transitions theory: Middle range and situation specific theories in nursing research and practice*. Springer.

Meltem, D., Kürşat Bora, Ç., Canan, Ö., Koray, H., Makbule, E., Birgül, K., Enver, Ş., Coşkun, Y., Aysu Duyan, Ç., & Figen Şahin, D. (2020). Quality-of-life Evaluation of Healthy Siblings of Children with Chronic Illness [article]. *Balkan Medical Journal*, *37*(1), 34-42. https://doi.org/10.4274/balkanmedj.galenos.2019.2019.7.142

Mencher, S. R., Frank, G., & Fishbein, J. (2019). Diabetic Ketoacidosis at Onset of Type 1 Diabetes: Rates and Risk Factors Today to 15 Years Ago. *Global Pediatric Health*, *6*, 2333794X19870394.

Merriman, B., & Guerin, S. (2006). Using children’s drawings as data in child-centred research. *The Irish journal of psychology*, *27*(1-2), 48-57.

Michaud, P., Suris, J., & Viner, R. (2004). The adolescent with a chronic condition. Part II: Healthcare provision. *Archives of Disease in Childhood*, *89*(10), 943-949. https://doi.org/https://doi.org/10.1136/adc.2003.045377

Midlarsky, E., Hannah, M. E., & Corley, R. (1995). Assessing adolescent’s' prosocial behavior: the family helping inventory. *Adolescence*, *30*(117), 141-155.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Bmj*, *339*.

Morgan, D. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of mixed methods research*, *1*(1), 48-76. https://doi.org/http://dx.doi.org/10.1177/2345678906292462

Morley, C., Jose, K., Hall, S. E., Shaw, K., McGowan, D., Wyss, M., & Winzenberg, T. (2024). Evidence-informed, experience-based co-design: a novel framework integrating research evidence and lived experience in priority-setting and co-design of health services. *BMJ open*, *14*(8), e084620. https://doi.org/http://dx.doi.org/10.1136/bmjopen-2024-084620. (CC BY- NC 4.0)

Mulvale, A., Miatello, A., Hackett, C., & Mulvale, G. (2016). Applying experience-based co-design with vulnerable populations: Lessons from a systematic review of methods to involve patients, families and service providers in child and youth mental health service improvement. *Patient Experience Journal*, *3*(1), 117-129. https://doi.org/http://dx.doi.org/10.35680/2372-0247.1104

Murray, J. (2000). Understanding sibling adaptation to childhood cancer. *Issues in Comprehensive Pediatric Nursing*, *23*(1), 39-47. https://doi.org/https://doi.org/10.1080/014608600265200

Murray, J. S. (1999). Siblings of children with cancer: A review of the literature [Review Article]. *Journal of Pediatric Oncology Nursing*, *16*, 25-34. https://doi.org/10.1016/S1043-4542(99)90004-8

Murray, J. S. (2002). Articles: A qualitative exploration of psychosocial support for siblings of children with cancer [Article]. *Journal of Pediatric Nursing*, *17*, 327-337. https://doi.org/10.1053/jpdn.2002.127177

Nabors, L., Ohms, M., Buchanan, N., Kirsh, K. L., Nash, T., Passik, S. D., Johnson, J. L., Snapp, J., & Brown, G. (2004). A pilot study of the impact of a grief camp for children. *Palliative & supportive care*, *2*(4), 403-408.

Naseri, A., Rahmanian, M., & Rafieipour, A. (2024). The Effectiveness of Acceptance and Commitment Therapy on Psychological Well-being, Resilience, and Hope for Life in Coronary Heart Disease Patients with High Blood Pressure Visiting Shahid Rajaei Hospital. *Health Nexus*, *2*(2), 57-67.

Network Waitangi. (2016). Treaty of Waitangi: *Questions and answers.* Network Waitangi.

Neville, A., Simard, M., Hancock, K., Rokeach, A., Saleh, A., & Barrera, M. (2016). The emotional experience and perceived changes in siblings of children with cancer reported during a group intervention. *Oncology Nursing Forum*, *43*(5), 188-194. https://doi.org/https://doi.org/10.1188/16.ONF.E188-E194

Newburger, J. W., Wypij, D., Bellinger, D. C., du Plessis, A. J., Kuban, K. C., Rappaport, L. A., Almirall, D., Wessel, D. L., Jonas, R. A., & Wernovsky, G. (2003). Length of stay after infant heart surgery is related to cognitive outcome at age 8 years. *The Journal of pediatrics*, *143*(1), 67-73.

Niemitz, M., & Goldbeck, L. (2018). Outcomes of an enhancement study with additional psychoeducational sessions for healthy siblings of a child with cancer during inpatient family-oriented rehabilitation [Article]. *Psycho-Oncology*, *27*(3), 892-899. https://doi.org/10.1002/pon.4599

Nolbris, J., & Nilsson, S. (2017). Sibling Supporters' Experiences of Giving Support to Siblings Who Have a Brother or a Sister With Cancer. In (Vol. 34, pp. 83-89).

Nolbris, M., Abrahamsson, J., Hellström, A., Olofsson, L., & Enskär, K. (2010). The Experience of Therapeutic Support Groups by Siblings of Children with Cancer. *Pediatric Nursing*, *36*(6), 298-304. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=104956383&site=eds-live&scope=site

Nolbris, M., Enskär, K., & Hellström, A.-L. (2007). Experience of siblings of children treated for cancer. *European Journal of Oncology Nursing*, *11*(2), 106-112.

O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: a literature review. *British Journal of Nursing*, *18*(22), 1358-1365. https://doi.org/https://doi.org/10.12968/bjon.2009.18.22.45562

Packman, W., Fine, J., Chesterman, B., vanZutphen, K., Golan, R., & Amylon, M. D. (2004). Camp Okizu: Preliminary investigation of a psychological intervention for siblings of pediatric cancer patients. *Children's Health Care*, *33*(3), 201-215. https://doi.org/https://doi.org/10.1177/1043454207311915

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., …& Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *bmj, 372.*

Pai, A. L., Patiño-Fernández, A. M., McSherry, M., Beele, D., Alderfer, M. A., Reilly, A. T., ... & Kazak, A. E. (2008). The Psychosocial Assessment Tool (PAT2. 0): Psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. Journal of pediatric psychology, 33(1), 50-62.

Parker, R., Houghton, S., Bichard, E., & McKeever, S. (2020). Impact of congenital heart disease on siblings: A review [Article]. *Journal of Child Health Care*, *24*(2), 297-316. https://doi.org/10.1177/1367493520914738

Patterson, P., McDonald, F. E. J., Butow, P., White, K. J., Costa, D. S. J., Millar, B., Bell, M. L., Wakefield, C. E., & Cohn, R. J. (2014). Psychometric evaluation of the Sibling Cancer Needs Instrument (SCNI): An instrument to assess the psychosocial unmet needs of young people who are siblings of cancer patients. *Supportive Care in Cancer*, *22*(3), 653-665. https://doi.org/10.1007/s00520-013-2020-3

Patterson, P., Millar, B., & Visser, A. (2011). The development of an instrument to assess the unmet needs of young people who have a sibling with cancer: Piloting the Sibling Cancer Needs Instrument (SCNI). *Journal of Pediatric Oncology Nursing*, *28*(1), 16-26. https://doi.org/https://doi.org/10.1177/1043454210377174

Pearson, N., Naylor, P. J., Ashe, M. C., Fernandez, M., Yoong, S. L., & Wolfenden, L. (2020). Guidance for conducting feasibility and pilot studies for implementation trials. *Pilot and feasibility studies*, *6*, 1-12.

Petersen, J. M., Ona, P. Z., & Twohig, M. P. (2022). A review of acceptance and commitment therapy for adolescents: developmental and contextual considerations. *Cognitive and Behavioral Practice*.

Piers, E. V., Herzberg, D. S., & Harris, D. B. (2002). PHCSCS-2: Piers-Harris Children's Self-Concept Scale. Western Psychological Services.

Pit-Ten Cate, G. L., Ineke. (2000). Experiences of siblings of children with physical disabilities: An empirical investigation. *Disability and Rehabilitation*, *22*(9), 399-408.

Pitama, S. G., Bennett, S. T., Waitoki, W., Haitana, T. N., Valentine, H., Pahiina, J., Taylor, J. E., Tassell-Matamua, N., Rowe, L., & Beckert, L. (2017). A proposed hauora Māori clinical guide for psychologists: Using the hui process and Meihana model in clinical assessment and formulation.

Porteous, E., Peterson, E. R., & Cartwright, C. (2019). Siblings of young people with cancer in NZ: Experiences that positively and negatively support well-being. *Journal of Pediatric Oncology Nursing*, *36*(2), 119-130. https://doi.org/https://doi.org/10.1177/1043454218819455

Prchal, A., Graf, A., Bergstraesser, E., & Landolt Markus, A. (2012). A two-session psychological intervention for siblings of pediatric cancer patients: a randomized controlled pilot trial. *Child and Adolescent Psychiatry and Mental Health*, *6*(1), 3-3. https://doi.org/10.1186/1753-2000-6-3

Prchal, A., & Landolt, M. (2009). Psychological interventions with siblings of pediatric cancer patients: a systematic review [Article]. *Psycho-Oncology*, *18*(12), 1241-1251. https://doi.org/10.1002/pon.1565

Prchal, A., & Landolt, M. A. (2012). How siblings of pediatric cancer patients experience the first time after diagnosis: a qualitative study. *Cancer Nursing*, *35*(2), 133-140. https://doi.org/10.1097/ncc.0b013e31821e0c59

Pugh, G., Bradbeer, P., Wood, A., Hunter, S., Cross, S., Denton, K., Copeland, K., & Laughton, S. (2023). Childhood cancer incidence & survival in Aotearoa, New Zealand 2010–2019. *Cancer Epidemiology*, *86*, 102433. https://doi.org/http://dx.doi.org/10.1016/j.canep.2023.102433

Pynoos, R. S., Frederick, C., Nader, K., Arroyo, W., Steinberg, A., Eth, S., Nunez, F., & Fairbanks, L. (1987). Life threat and posttraumatic stress in school-age children. *Archives of general psychiatry*, *44*(12), 1057-1063.

Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., ... & Kilroe, J. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. Expert review of pharmacoeconomics & outcomes research, 5(3), 353-364

Reynolds, C., & Kamphaus, R. (1992). BASC: Behavior Assessment System for Children Manual. American Guidance Service. *Inc., Circle Pines, MN.*

Reynolds, C., & Richmond, B. (1985). Revised children's manifest anxiety scale (RCMAS). Manual.

Reynolds, C. R., & Richmond, B. O. (1978). What I think and feel: A revised measure of children's manifest anxiety. *Journal of abnormal child psychology*, *6*(2), 271-280.

Reynolds, M. W., Nabors, L., & Quinlan, A. (2000). The effectiveness of art therapy: does it work? *Art Therapy*, *17*(3), 207-213.

Riddick, E. (2013). *Adolescent siblings of cancer survivors* The University of Auckland. http://hdl.handle.net/2292/21616

Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. Basic Books.

Rolland, J. S. (2018). *Helping couples and families navigate illness and disability: An integrated approach*. Guilford Publications. https://ebookcentral.proquest.com/lib/massey/detail.action?docID=5355420

Rosenberg, A. R., Yi-Frazier, J. P., Eaton, L., Wharton, C., Cochrane, K., Pihoker, C., Baker, K. S., & McCauley, E. (2015). Promoting resilience in stress management: A pilot study of a novel resilience-promoting intervention for adolescents and young adults with serious illness. *Journal of Pediatric Psychology*, *40*(9), 992-999. https://doi.org/https://doi.org/10.1093/jpepsy/jsv004

Rousseau, N., Turner, K. M., Duncan, E., O'Cathain, A., Croot, L., Yardley, L., & Hoddinott, P. (2019). Attending to design when developing complex health interventions: A qualitative interview study with intervention developers and associated stakeholders. *PLOS ONE*, *14*(10), e0223615. https://doi.org/http://dx.doi.org/10.1371/journal.pone.0223615

Sahler, O. J. Z., & Carpenter, P. J. (1989). Evaluation of a camp program for siblings of children with cancer. American journal of diseases of children, 143(6), 690-696.

Salavati, B., Seeman, M. V., Agha, M., Atenafu, E., Chung, J., Nathan, P. C., & Barrera, M. (2014). Which Siblings of Children with Cancer Benefit Most from Support Groups? *Children's Health Care*, *43*(3), 221-233. https://doi.org/10.1080/02739615.2013.837820

Samson, K., Rourke, M. T., & Alderfer, M. A. (2016). A qualitative analysis of the impact of childhood cancer on the lives of siblings at school, in extracurricular activities, and with friends. *Clinical Practice in Pediatric Psychology*, *4*(4), 362-372. https://doi.org/10.1037/cpp0000161

Sawicki, G. S., Rasouliyan, L., McMullen, A. H., Wagener, J. S., McColley, S. A., Pasta, D. J., & Quittner, A. L. (2011). Longitudinal assessment of health-related quality of life in an observational cohort of patients with cystic fibrosis. *Pediatric pulmonology*, *46*(1), 36-44.

Sawicki, G. S., & Tiddens, H. (2012). Managing treatment complexity in cystic fibrosis: challenges and opportunities. *Pediatric pulmonology*, *47*(6), 523-533.

Sawyer, M. G., Arney, F. M., Baghurst, P. A., Clark, J. J., Graetz, B. W., Kosky, R. J., Nurcombe, B., Patton, G. C., Prior, M. R., & Raphael, B. (2001). The mental health of young people in Australia: key findings from the child and adolescent component of the national survey of mental health and well-being. *Australian & New Zealand Journal of Psychiatry*, *35*(6), 806-814.

Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet*, *369*(9571), 1481-1489.

Schamong, A. S., Liebermann-Jordanidis, H., Brockmeier, K., Sticker, E., & Kalbe, E. (2022). Psychosocial well-being and quality of life in siblings of children with congenital heart disease: A systematic review. *Journal of Child Health Care*, *26*(2), 319-337.

Schoon, I., & Cook, R. (2021). Can individual agency compensate for background disadvantage? Predicting tertiary educational attainment among males and females. *Journal of youth and adolescence*, *50*(3), 408-422.

Sears, R. W. (2015). *Building competence in mindfulness-based cognitive therapy: Transcripts and insights for working with stress, anxiety, depression, and other problems*. Routledge.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, *27*(8), 699-710. https://doi.org/https://doi.org/10.1093/jpepsy/27.8.699

Shaw, A. M., Hare, M. M., Conroy, K., Kehrer, S. M., Cummings, L. R., Ramos, M. C., & Comer, J. S. (2024). An exploratory study of service user and clinical outcomes in telehealth-delivered dialectical behavior therapy for adolescents skills groups. *Psychological Services*.

Sholevar, G. P., & Perkel, R. (1990). Family systems intervention and physical illness. *General hospital psychiatry*, *12*(6), 363-372. https://doi.org/https://doi.org/10.1016/0163-8343(90)90003-U

Sidhu, R., Passmore, A., & Baker, D. (2005). An investigation into parent perceptions of the needs of siblings of children with cancer. *Journal of Pediatric Oncology Nursing*, *22*(5), 276-287. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=106521996&site=eds-live&scope=site

Sidhu, R., Passmore, A., & Baker, D. (2006). The effectiveness of a peer support camp for siblings of children with cancer. *Pediatric Blood & Cancer*, *47*(5), 580-588. https://doi.org/10.1002/pbc.20653

Siegel, D. J. (2001). Toward an interpersonal neurobiology of the developing mind: Attachment relationships,“mindsight,” and neural integration. *Infant Mental Health Journal: official publication of the world association for infant mental health*, *22*(1-2), 67-94.

Silver, R. (1993). Draw-a-Story: Screening for Depression and Age or Gender Differences. Ablin Press Distributors, 3332 Hadfield Greene, Sarasota FL 34235.

Sleeman, F., Northam, E., Crouch, W., & Cameron, F. (2010). Psychological adjustment of well siblings of children with Type 1 diabetes. *Diabetic Medicine*, *27*(9), 1084-1087. https://doi.org/http://dx.doi.org/10.1111/j.1464-5491.2010.03041.x

Sligo, J., Jones, B., Davies, C., Egan, R., Ingham, T., Hancox, R. J., & Richards, R. (2019). The experiences of young people with chronic illness in New Zealand: A qualitative study. *Child: care, health and development*, *45*(5), 660-669.

Sloper, P. (2000). Experiences and support needs of siblings of children with cancer. In (Vol. 8, pp. 298-306).

Sood, E., Karpyn, A., Demianczyk, A. C., Ryan, J., Delaplane, E. A., Neely, T., Frazier, A. H., & Kazak, A. E. (2018). Mothers and fathers experience stress of congenital heart disease differently: recommendations for pediatric critical care. *Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*, *19*(7), 626.

Spence, S. H. (1998). A measure of anxiety symptoms among children. Behaviour research and therapy, 36(5), 545-566.

Spielberger, C. D. (2010). State-Trait anxiety inventory. *The Corsini encyclopedia of psychology*, 1-1.

Stein, R., & Jessop, D. J. (1982). A noncategorical approach to chronic childhood illness. *Public health reports*, *97*(4), 354-362. https://www.jstor.org/stable/4596748

Steinberg, A. M., Brymer, M. J., Decker, K. B., & Pynoos, R. S. (2004). The University of California at Los Angeles post-traumatic stress disorder reaction index. *Current psychiatry reports*, *6*(2), 96-100.

Steinglass, P. (1998). Multiple family discussion groups for patients with chronic medical illness. *Families, Systems, & Health*, *16*(1-2), 55. https://doi.org/http://dx.doi.org/10.1037/h0089842

Strohm, K. (2008). Guest Editorial: Too important to ignore: Siblings of children with special needs. *Australian e-Journal for the Advancement of Mental Health*, *7*(2), 78-83. https://doi.org/https://doi.org/10.5172/jamh.7.2.78

Suris, J.-C., Michaud, P.-A., & Viner, R. (2004). The adolescent with a chronic condition. Part I: developmental issues. *Archives of Disease in Childhood*, *89*(10), 938-942. https://doi.org/https://doi.org/10.1136/adc.2003.045369

Takahashi, F., Ishizu, K., Matsubara, K., Ohtsuki, T., & Shimoda, Y. (2020). Acceptance and commitment therapy as a school-based group intervention for adolescents: An open-label trial. *Journal of Contextual Behavioral Science*, *16*, 71-79.

Tan, L. B., & Martin, G. (2016). Mind full or mindful: A report on mindfulness and psychological health in healthy adolescents. *International Journal of Adolescence and Youth*, *21*(1), 64-74.

Tarnowski, K. J., & Simonian, S. J. (1992). Assessing treatment acceptance: The abbreviated acceptability rating profile. *Journal of behavior therapy and experimental psychiatry*, *23*(2), 101-106.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004). Assessment of unmet needs among survivors of breast cancer. *Journal of Psychosocial Oncology*, *22*(1), 51-73. https://doi.org/https://doi.org/10.1300/J077v22n01_04

Toledano-Toledano, F., & Luna, D. (2020). The psychosocial profile of family caregivers of children with chronic diseases: A cross-sectional study. *BioPsychoSocial medicine*, *14*, 1-9. https://doi.org/http://dx.doi.org/10.1186/s13030-020-00201-y

Tsamparli, A., & Kounenou, K. (2004). The Greek family system when a child has diabetes mellitus type 1. *Acta Paediatrica*, *93*(12), 1646-1653.

van der Linde, D., Konings, E. E., Slager, M. A., Witsenburg, M., Helbing, W. A., Takkenberg, J. J., & Roos-Hesselink, J. W. (2011). Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *Journal of the American College of Cardiology*, *58*(21), 2241-2247.

Van Riper, M. (2003). The sibling experience of living with childhood chronic illness and disability. *Annual review of nursing research*, *21*(1), 279-302.

Vermaes, I. P., van Susante, A. M., & van Bakel, H. J. (2012). Psychological functioning of siblings in families of children with chronic health conditions: A meta-analysis. *Journal of Pediatric Psychology*, *37*(2), 166-184. https://doi.org/https://doi.org/10.1093/jpepsy/jsr081

Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: measurement model for the pediatric quality of life inventory. Medical care, 37(2), 126-139.

Wallace, J., Packman, W., Huffman, L. C., Horn, B., Cowan, M., Amylon, M. D., Kahn, C., Cordova, M., & Moses, J. (2014). Psychosocial changes associated with participation in art therapy interventions for siblings of pediatric hematopoietic stem cell transplant patients. *Art Therapy*, *31*(1), 4-11.

Wallander, J. L., & Varni, J. W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry*, *39*(1), 29-46. https://doi.org/https://doi.org/10.1017/S0021963097001741

Wasag, D. R., Gregory, J. W., Dayan, C., & Harvey, J. N. (2018). Excess all-cause mortality before age 30 in childhood onset type 1 diabetes: data from the Brecon Group Cohort in Wales. *Archives of Disease in Childhood*, *103*(1), 44-48.

Weersing, V. R., Jeffreys, M., Do, M.-C. T., Schwartz, K. T., & Bolano, C. (2017). Evidence base update of psychosocial treatments for child and adolescent depression. *Journal of Clinical Child & Adolescent Psychology*, *46*(1), 11-43.

Wei, H., Roscigno, C. I., Hanson, C. C., & Swanson, K. M. (2015). Families of children with congenital heart disease: A literature review. *Heart & Lung*, *44*(6), 494-511. https://doi.org/http://dx.doi.org/10.1016/j.hrtlng.2015.08.005

Weinberg, R. A. (1996). How cancer arises. *Scientific American*, *275*(3), 62-70.

Weiner, J. A., & Woodley, L. K. (2018). An integrative review of sibling responses to childhood cancer [Article]. *Journal of Child & Adolescent Psychiatric Nursing*, *31*(4), 109-119. https://doi.org/10.1111/jcap.12219

Weiss, D., Marmar, C., Wilson, J., & Keane, T. (1997). The impact of event scale—Revised, assessing psychological trauma and PTSD (pp. 399–411). *New York: Guilford*.

Weissman, M. M., & Bothwell, S. (1976). Assessment of social adjustment by patient self-report. Archives of general psychiatry, 33(9), 1111-1115.

Wen, K., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, *2*(1), 1-12. https://doi.org/https://doi.org/10.1186/1477-7525-2-11

Wennick, A., & Huus, K. (2012). What it is like being a sibling of a child newly diagnosed with type 1 diabetes: an interview study. *European Diabetes Nursing*, *9*(3), 88-92. https://doi.org/10.1002/edn.213

Wenzel, A. (2017). Basic strategies of cognitive behavioral therapy. *Psychiatric Clinics*, *40*(4), 597-609.

Whitener, M., Khazvand, S., Carson, I., Martin, A., Salyers, M., Cyders, M., ... & Zapolski, T. (2025). Acceptability and Efficacy of an Adapted School-Based Dialectical Behavioral Therapy Skills Group for Adolescents: A Qualitative Perspective. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, *62*, 00469580251314279.

Wilkins, K. L., & Woodgate, R. L. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. *Journal of Pediatric Oncology Nursing*, *22*(6), 305-319. https://doi.org/https://doi.org/10.1177/1043454205278035

Williams, P. (1997). Siblings and pediatric chronic illness: a review of the literature. *International journal of nursing studies*, *34*(4), 312-323. http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=107348610&site=eds-live&scope=site

Williams, P., Ridder, E., Setter, R., Liebergen, A., Curry, H., Piamjariyakul, U., & Williams, A. (2009). Pediatric Chronic Illness (Cancer, Cystic Fibrosis) Effects On Well Siblings: Parents' Voices [Article]. *Issues in Comprehensive Pediatric Nursing*, *32*(2), 94-113. https://doi.org/10.1080/01460860902740990

Williams, P., Williams, A., Graff, J., Hanson, S., Stanton, A., Hafeman, C., Liebergen, A., Leuenberg, K., Setter, R., Ridder, L., Curry, H., Barnard, M., & Sanders, S. (2003). A community-based intervention for siblings and parents of children with chronic illness or disability: the ISEE study [Article]. *The Journal of pediatrics*, *143*, 386-393. https://doi.org/10.1067/S0022-3476(03)00391-3

Williams, P. D., Hanson, S., Karlin, R., Ridder, L., Liebergen, A., Olson, J., Barnard, M. U., & Tobin-Rommelhart, S. (1997). Outcomes of a Nursing Intervention for Siblings of Chronically Ill Children: A Pilot Study. *Journal for Specialists in Pediatric Nursing*, *2*(3), 127.

http://ezproxy.massey.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edb&AN=65015595&site=eds-live&scope=site

Williams, P. D., Williams, A. R., Hanson, S., Gruff, C., Ridder, L., Curry, H., ... & Karlin-Setter, R. (1999). Maternal Mood, Family Functioning, and Perceptions of Social Support, Self-Esteem, and Mood Among.. Children's Health Care, 28(4), 297-310.

Woodgate, R. L. (2006). The importance of being there: Perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, *23*(3), 122-134. https://doi.org/10.1177/1043454206287396

Yalom, I. D., & Leszcz, M. (2020). *The theory and practice of group psychotherapy*. Hachette UK. https://doi.org/http://dx.doi.org/10.1192/S0007125000062723

Yang, H.-C., Mu, P.-F., Sheng, C.-C., Chen, Y.-W., & Hung, G.-Y. (2016). A systematic review of the experiences of siblings of children with cancer. *Cancer Nursing*, *39*(3), E12-E21. https://doi.org/10.1097/NCC.0000000000000258

Yvonne Feilzer, M. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of mixed methods research*, *4*(1), 6-16. https://doi.org/http://dx.doi.org/10.1177/1558689809349691

Zimmerman, B. J., & Cleary, T. J. (2006). Adolescents' development of personal agency: The role of self-efficacy beliefs and self-regulatory skill. *Self-efficacy beliefs of adolescents*, *5*, 45-69.

APPENDIX A: CLINICAL CASE STUDY

Research Case Study

How my doctoral thesis research has contributed to my clinical practice as an intern psychologist

A research case study in partial fulfilment of

The degree of Doctor of Clinical Psychology

Kathleen Sarah Armstrong

2022

Clinical Psychology Intern with Mental Health, Addictions & Intellectual Disability Services

and Specialist Maternal Mental Health, Te Whatu Ora

This case study represents the work of Kathleen Armstrong during her thesis from 2020 to 2022 and reflections as an intern psychologist in 2022.

Candidate: Kathleen Armstrong……K Armstrong……Date: 21/10/2022……

Supervisor: Kirsty Ross……KRoss……Date: 21/10/2022……

Abstract

This case study gives an overview of my research and provides my reflections on the transition from researcher to clinical psychology intern. The case study is organised into two main sections; the first section provides a summary of my research including: the rationale, aims, and methodology. The second section consists of my self-reflections on transitioning from a researcher into the role of intern psychologist at Addiction Services and the Specialist Maternal Mental Health service. These reflections include a discussion about the integration of emotion psychoeducation in therapeutic work with clients at Addictions Services, the application of Systems Theory to developing a deeper understanding of my clients' experiences at Specialist Maternal Mental Health, and the integration of values work early in therapy with clients at both services.

Keywords: Research, self-reflection, intern, clinical psychology

Research Overview

The aim of my doctoral thesis is to develop a needs-based psychosocial intervention that supports siblings of children with serious chronic health conditions in Aōtearoa New Zealand (NZ). This thesis is underpinned by the needs-based research I undertook on understanding the unmet needs of siblings of children with serious chronic health conditions for my Masters' thesis in 2019. This overview of my research will firstly include a summary of the development of the thesis followed by an overview of the aims, methodology and initial findings.

Thesis Topic Development

Sibling research is very important to me from a deeply personal perspective. My sister had cancer when I was a young child so I understand through my own experience the devastating impact such a diagnosis can have on families and siblings.

During my postgraduate studies I met Dr. Kirsty Ross, who expressed an interest in working with a student researching the needs of siblings of children with serious health conditions, and she became my supervisor in 2019. I completed my Masters' thesis on identifying the unmet needs of siblings of children with serious chronic health conditions the same year and the findings from that thesis have contributed to the development of the intervention I am currently working on. I am developing a psychosocial intervention for siblings, which allows them to access the support they need to help successfully adjust to the major adjustments a serious chronic illness diagnosis brings to a family.

Research Study Aims

Kirsty Ross had a strong interest in sibling support and through her clinical practice she identified a gap in sibling support services available in Aōtearoa New Zealand. With the aim of developing a psychosocial needs-based intervention that protects and promotes the health and wellbeing of siblings in Aōtearoa New Zealand together we developed a two-stage research plan. The first stage of the plan was to carry out needs-based research which would form a foundation for the development of an intervention. Needs-based research provides a direct link from the self-reported needs of a target population, to the development of an intervention, that aims to meets those needs. I identified the unmet needs of siblings of children with cancer, Type 1 diabetes mellitus, and cystic fibrosis in Aōtearoa/New Zealand which I completed as my Masters' thesis in 2020. The second stage of the planned course of study was to use the findings from the needs-based research, alongside existing literature, to inform the development of a psychosocial needs-based intervention for siblings which I am currently working toward for my doctoral thesis.

Summary of Literature

Chronic health conditions refer to a range of conditions that can be defined as being prolonged in duration, interfere with normal activities, and do not resolve spontaneously (Compas et al., 2012). The number of children and adolescents living with these conditions has increased dramatically in recent decades. This is partly due to medical advances in the diagnosis and treatment of pediatric chronic conditions which has led to increased survivorship of once fatal childhood diseases (Compas et al., 2012), and partly due to an increase in childhood incidences of chronic health conditions such as diabetes, asthma and obesity (Sawyer et al., 2007).

While accurate estimates of the prevalance of chronic childhood health conditions are elusive due to differences in the criteria used to define and categorise a chronic health conditions, it has been estimated that chronic conditions affect between 10 – 30% of children worldwide (Consolini, 2020). In Aōtearoa New Zealand, Denny and colleagues (2014) reported almost 20% of secondary school students lived with a chronic health condition and this prevalence is only expected to increase (Compas et al., 2012). These conditions present the affected child, their parents, and their siblings with significant long-term consequences and challenges.

Research has consistently found that the family environment is altered when a child is diagnosed with a chronic health condition; the focus of the family centres on the affected child, which leads to a reduced capacity for meeting the needs of siblings (Cohen et al., 1994; Janssens et al., 2010; Neville et al., 2016). Literature that investigates the effects of a child's chronic health condition on their siblings is compelling. While there is considerable heterogeneity in methodologies making it challenging to synthesise findings and draw overarching conclusions, it is clear there is a subgroup of siblings who experience significant psychosocial adjustment problems, in particular, anxiety, depression and post-traumatic stress symptoms (Alderfer et al., 2010; Sharpe & Rossiter, 2002). It is important these negative impacts are reduced as they can lead to long-term mental health problems (Kessler & Wang, 2008) and lower quality of life (Sawyer et al., 2001).

Despite the growing body of evidence pointing towards the potential negative impacts of chronic health conditions on siblings, the needs of siblings are currently inadequately met and seldom addressed. Consequently, there have been calls in the literature for the development and delivery of targeted support services that will protect this vulnerable population (Gerhardt et al., 2015; Havermans, 2015; Long et al., 2015).

With the goal of developing a support service for siblings of children with serious chronic health conditions, the current author carried out a study which identified the unmet needs of siblings in Aōtearoa New Zealand (Armstrong, 2020). This study provided valuable needs-based data which formed the foundation of the development of a sibling intervention and emphasised the urgent need to develop targeted support services that aim to protect the health and wellbeing of siblings.

The purpose of the following review was to identify existing interventions that have been developed to support siblings when a brother or sister is diagnosed with a chronic health condition and examine the characteristics of these program. Key research questions were:

- What interventions have been developed for siblings of children with chronic health conditions?
- Which interventions available to siblings have been evaluated and to what extent were the expected outcomes of the intervention achieved?
- What components of those interventions are important to consider in the development of an intervention for siblings who reside in Aōtearoa New Zealand?

To answer these questions a systematised review was carried out. A systematised review includes one or more elements of the systematic review process and are typically conducted in postgraduate student research. While these reviews possess a greater likelihood of bias than a full systematic review, they attempt to include one or more of the elements of systematisation and they model the systematic review process (Grant & Booth, 2009).

Methodology

Search Strategy

Study Selection

Studies were selected if:

a) they evaluated a psychosocial intervention developed for siblings of children or young people with cancer or a chronic health condition. This inclusion criteria did not exclude studies that had diverse samples (siblings of children with mental health conditions or developmental difficulties) to ensure studies that included any siblings of children with cancer and/or chronic illness were included.

b) the intervention included participants aged 18 years old or younger.

c) the intervention included a psychosocial outcome measure.

d) the intervention used a psychosocial approach (not primarily reliant on medication).

e) aimed to prevent or reduce psychosocial problems related to the health condition.

Studies were excluded for the following reasons:

a) the intervention was family-based but did not provide sibling self-report measures and/or siblings were not part of the family-based intervention.

b) the intervention did not target outcome(s) of interest.

c) the intervention targeted only siblings of youth with conditions that are not chronic medical conditions, such as acute medical illness (e.g., acute pain, broken bone) or neurodevelopmental disorders (e.g., autism spectrum disorder, intellectual disability)

d) the intervention was developed for bereaved siblings or siblings of children in palliative care.

e) the study was not reported in English.

Sources

The current author alongside a research librarian developed and implemented a search in the following databases: MedLine; Web of Science; SCOPUS; CINAHL; psychINFO; ERIC; and the Cochrane Library with the following:

sibling* OR brother* OR sister* AND "chronic illness*" OR "chronic disease*" OR “cancer*” OR “neoplasm*” OR “oncolog*” OR “tumor*” OR “tumour*” AND "child*" OR "pediatric*" OR "paediatric*" OR "teen*" OR "adoloescen*" OR

"youth*” AND intervention* OR therap*.

A total of 4261 studies were identified from the initial searches. After removal of duplicates, 2697 were screened at title and abstract level and 21 studies met criteria.

The results of the 21 studies were then analysed to identify intervention techniques that were found to be effective for supporting siblings following the diagnosis of a brother or sister with a chronic health condition. Evidence-based techniques include identifying values and psychoeducation about emotions, both of which will be discussed for their utility in my clinical practice in the following section.

Clinical Psychology Internship

In January 2022, I began my internship at Mental Health, Addiction & Intellectual Disability Service (MHAIDS) Capital, Coast, Hutt Valley, and Wairarapa as a clinical psychology intern. This 1500-hour internship was split across two mental health settings: six months at Addiction Services then six months at Specialist Maternal Mental Health. This research case study is written near the end of my internship and will include reflections about my transition from researcher to practitioner in both services. My reflections include the application of psychoeducation about emotions, systems theory, and values work.

Teaching emotion regulation skills

There are multiple challenges for siblings when a brother or sister is diagnosed with a chronic health condition and the associated emotions can feel overwhelming for siblings leading to emotional distress as illustrated in the figure below (Armstrong, 2020; Figure 1). Following a child's diagnosis with a serious chronic health condition siblings can feel strong negative emotions including fear, anxiety, sadness, resentment and distress. Parents focus on the affected child leading siblings to feel 'invisible' and 'forgotten' due to reduced parental attention. These feelings lead to jealousy of their affected sibling, then guilt for feeling jealous. This is emphasised when siblings feel 'left out' and 'unimportant' when information about their sibling's health condition is hidden from them by parents and health professionals trying to 'protect' them. Siblings also feel misunderstood and unsupported by friends and family who do not understand the full impact of the diagnosis on them. These complex emotions are suppressed due to siblings not wanting to overburden their parents, feeling 'selfish' for having needs of their own, and guilty for being the 'healthy' sibling. Adding to their distress, siblings can feel overwhelmed due to changes in family roles and relationships, and disruptions to family life (Armstrong, 2020).

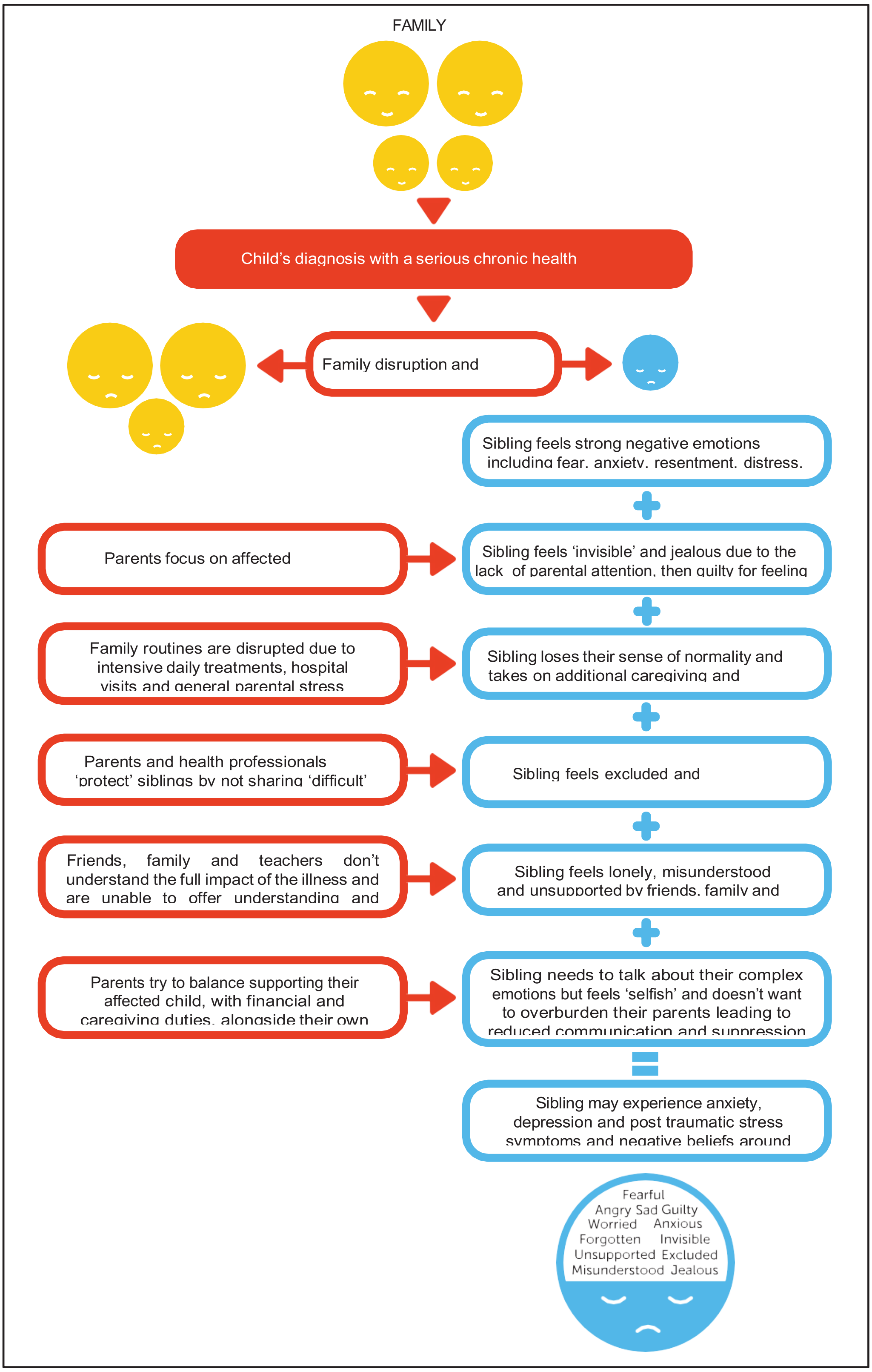

Figure 1. A typical pattern of a sibling's experiences following a child's diagnosis with a serious chronic health condition (Armstrong, 2020).

For these reasons psychoeducation about emotions is an important component of my research intervention to support the development of healthy coping strategies to manage difficult emotions. Working with clients at Addiction Services I became aware that unhelpful substance-use was at times, a maladaptive strategy for managing emotional distress and sometimes my clients needed support to develop emotional awareness and skills. My first client at Addiction services was a 66-year old male who was on the opioid substitution program, so I entered this therapeutic relation with very little expectation that my sibling research would be applicable. I discovered that my understanding of the importance of emotional awareness and associated skills and techniques crossed over with the work I did with almost all my clients at Addiction Services. One theory of substance-use is that it is a maladaptive coping strategy for managing emotional distress, hence developing an understanding of what emotions are, whey we have them, and learning the skills of being able to identify and name your emotions was an important step in the recovery process for most of my clients (Cavicchioli, 2018).

Values work

Through my research I developed an understanding of the clinical value of values work to support sibling adjustment to their sudden changes in circumstances. Values can be described as fundamental attitudes that guide our thoughts and behaviour, they influence our emotions and produce the belief that life is meaningful (Wilson & Murrell, 2004). Values act as a compass and an anchor, they help us recentre our emotions when we go off-track, and they keep us grounded in what really matters to us. Emotional distress can occur when there is a mismatch between how our life is at present and how we would like it to be. We never ‘arrive’ at our values, they are always a work in progress. Often, we will have some areas on track, and other areas not where we would like them to be but when we begin to move towards a value in one area of our life, it starts to recentre other areas of our life (Wilson & Murrell, 2004).

Early in my internship at Addiction services I began to understand the importance of values work for clients, and regularly integrated a session on values early in my therapeutic plan –

specifically the Bullseye values exercise (Lundgren, 2004). During this process I observed that values work is a very powerful technique for relapse prevention, as an example, three of my clients took their values home and put them on a wall as a daily reminder of the importance of acting in ways consistent with values to live a meaningful life. Values work was a powerful way of supporting my clients to focus on what was important to them, hold in their awareness why they want to make changes, and how to live a meaningful life.

I also integrated a values session into the treatment plans of some of my clients at Specialist Maternal Mental Health. I observed that this was particularly useful for a client who was being treated for post-partum obsessive compulsive disorder. Values work was very helpful for this client, it helped elicit motivation for the more challenging exposure response prevention tasks and it created a sense of hope for a better future.

Systems theory

I developed an understanding of systems theory through my research as systems theory helped explain the impact that a familial diagnosis of a chronic health condition has on siblings. I learnt that a system is defined as an interacting set of parts that make up a whole organisation, and that each part of the system is affected by what the other parts do (Bertalanffy, 1968). I also learnt that family therapists view families as complex, interacting systems, and that the actions and experiences of each family member have the potential to influence every other member, both directly and indirectly (Rolland, 2018).

Systems theory illustrates why family environments are important to examine following a major change to a family member such as a birth, death, or illness diagnosis. For example, in relationship to my research, when a child is diagnosed with a chronic health condition, treatment usually begins immediately and there is little time for adjustment as all family members have to adapt to a sudden transition in roles, priorities and routines. This can be a profoundly stressful experience and can destabilise the structure and functioning of the family (Rolland, 2018).

My understanding of systems theory and the interplay of our experiences within the systems we live in has been central to my work at Specialist Maternal Mental Health. Often I meet new mothers (and their partners) who feel like their world has been turned upside down. The structure of a family changes after the birth of a child, mothers almost solely focus on caring for their infant, and partners must adjust to new responsibilities, namely taking care of, and raising their child. Reflecting on how each part of a system is affected by the other parts, I began to think about the impact of maternal mental distress on baby. There is evidence in the literature that the attachment relationship that develops between a mother and her baby is strongly associated with the baby's outcomes (Schmid, 2011). For example, a mother who is less responsive to her baby due to psychological distress, may be less able to meet her baby's needs (Alhusen et al., 2013).

With this in mind, it seems a much lower threshold for providing support to a mother who is experiencing psychological distress would be appropriate, and that support should be freely available within the public health system. Rather than a mother needing a moderate to severe mental health diagnosis to meet criteria for support from a Specialist Maternal Mental Health service it would be protective for both mother and infant if a mother was offered support regardless of their level of psychological distress.

Supporting the family to develop a healthy attachment relationship between mother and infant could also be provided by the wider availability of education around the Circle of Security which is parenting support program grounded in Bowlby's attachment theory (Bretherton, 2013). When parents feel overwhelmed by the needs of their infant and unsure of their new role, education about attachment theory through the Circle of Security would help guide new parents and increase confidence and self-efficacy.

These thoughts led me to ponder the influence of the invisible but powerful societal systems that we live in and the impact they have on our health and wellbeing and that of our children. If societal systems prioritised the family systems in which there was *any level* of maternal psychological distress, the benefits could be exponential.

REFERENCES

Alhusen, J. L., Hayat, M. J., & Gross, D. (2013). A longitudinal study of maternal attachment and infant developmental outcomes. *Archives of women's mental health*, *16*, 521-529.

Armstrong, K. (2020). The Unmet Needs of Siblings of Children with Cancer and Serious Chronic Health Conditions in Aōtearoa/New Zealand [Master's thesis]. Massey University of New Zealand. http://hdl.handle.net/10179/15677

Alderfer, M. A., Long, K., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology*, *19*(8), 789-805. https://doi.org/https://doi.org/10.1002/pon.1638

Bertalanffy, L. (1968). *General system theory: Foundations, development, applications / Ludwig von Bertalanffy*. George Braziller.

Bretherton, I. (2013). The origins of attachment theory: John Bowlby and Mary Ainsworth. In *Attachment theory* (pp. 45-84). Routledge

Cavicchioli, M., Vassena, G., Movalli, M., & Maffei, C. (2018). Addictive behaviors in alcohol use disorder: dysregulation of reward processing systems and maladaptive coping strategies. *Journal of addictive diseases*, *37*(3-4), 173-184.

Cohen, D. S., Friedrich, W. N., Jaworski, T. M., Copeland, D., & Pendergrass, T. (1994). Pediatric cancer: Predicting sibling adjustment. *Journal of Clinical Psychology*, *50*(3), 303-319. https://doi.org/https://doi.org/10.1002/1097-4679(199405)50:3<303::AID- JCLP2270500302>3.0.CO;2-#

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual review of clinical psychology*, *8*, 455-480. https://doi.org/https://doi.org/10.1146/annurev-clinpsy-032511-143108 Consolini, M. (2020). *Children with Chronic Health Conditions*. https://www.msdmanuals.com/en-nz/professional/pediatrics/caring-for-sick-children-and-their-families/children-with-chronic-health-conditions?query=Chronic%20Health%20Problems%20in%20Children#v1084639

Gerhardt, C. A., Lehmann, V., Long, K. A., & Alderfer, M. A. (2015). Supporting siblings as a standard of care in pediatric oncology. *Pediatric blood & cancer*, *62*(S5), S750- S804.

Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, *26*(2), 91–108. https://doi.org/10.1111/j.1471-1842.2009.00848.x

Havermans, T., Croock, I. D., Vercruysse, T., Goethals, E., & Diest, I. V. (2015). Belgian siblings of children with a chronic illness: Is their quality of life different from their peers?. *Journal of Child Health Care*, *19*(2), 154-166.

Janssens, A., Peremans, L., & Deboutte, D. (2010). Conceptualizing collaboration between children's services and child and adolescent psychiatry: A bottom—up process based on a qualitative needs assessment among the professionals. *Clinical Child Psychology and Psychiatry*, *15*(2), 251-266. https://doi.org/https://doi.org/10.1177/1359104509340651

Kessler, R. C., & Wang, P. S. (2008). The descriptive epidemiology of commonly occurring mental disorders in the United States. *Annu. Rev. Public Health*, *29*, 115-129.

Lundgren, T. (2004). *The Bull's-Eye Values Survey* [Unpublished manuscript]. Department of Behavioural Sciences, University of Linköping, Sweden.

Long, K. A., Marsland, A. L., Wright, A., & Hinds, P. (2015). Creating a tenuous balance: Siblings' experience of a brother's or sister's childhood cancer diagnosis. *Journal of Pediatric Oncology Nursing*, *32*(1), 21-31.

Neville, A., Simard, M., Hancock, K., Rokeach, A., Saleh, A., & Barrera, M. (2016). The emotional experience and perceived changes in siblings of children with cancer reported during a group intervention. *Oncology Nursing Forum*, *43*(5), 188-194. https://doi.org/https://doi.org/10.1188/16.ONF.E188-E194

Rolland, J. S. (2018). *Helping couples and families navigate illness and disability: An integrated approach*. Guilford Publications. https://ebookcentral.proquest.com/lib/massey/detail.action?docID=5355420

Sawyer, M. G., Arney, F. M., Baghurst, P. A., Clark, J. J., Graetz, B. W., Kosky, R. J., ... & Rey, J. M. (2001). The mental health of young people in Australia: key findings from the child and adolescent component of the national survey of mental health and well- being. *Australian and New Zealand Journal of Psychiatry*, *35*(6), 806-814.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta- analysis. *Journal of Pediatric Psychology*, *27*(8), 699-710. https://doi.org/https://doi.org/10.1093/jpepsy/27.8.699

Schmid, B., Blomeyer, D., Buchmann, A. F., Trautmann-Villalba, P., Zimmermann, U. S., Schmidt, M. H., ... & Laucht, M. (2011). Quality of early mother–child interaction associated with depressive psychopathology in the offspring: A prospective study from infancy to adulthood. *Journal of Psychiatric Research*, *45*(10), 1387-1394.

Wilson, K. G., & Murrell, A. R. (2004). Values work in acceptance and commitment therapy. *Mindfulness and acceptance: Expanding the cognitive-behavioral tradition*, 120-151.