The unmet needs of siblings of children with cancer and serious chronic health conditions in Aōtearoa/New Zealand

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Abstract

There is evidence to suggest a subset of siblings of children with serious chronic health conditions have a range of unmet psychosocial needs which can lead to adjustment difficulties and mental health problems. A review of needs-based support services available to siblings in Aōtearoa/New Zealand found this is an under-serviced area. The current research aimed to identify the unmet needs of siblings of children with cancer and serious chronic health conditions and contribute to the development of targeted support services that protect and promote health and wellbeing in siblings.

An online survey design was used to identify the unmet needs of siblings of children with cancer, cystic fibrosis, and Type 1 diabetes mellitus. The final sample included 204 respondents across the three health conditions (cancer: *n*=84, cystic fibrosis: *n*=47, diabetes: *n*=73).

Quantitative results show the average percentage of unmet needs for the total sample was very high (57.8%). Of the three health conditions, cancer had the highest average percentage of unmet needs (66.3%), followed by cystic fibrosis (53.0%), then Type 1 diabetes mellitus (48.6%). Of the seven domains 'Information about my sibling/whānau member's health condition' had the highest number of unmet needs. A significant difference was found between the total mean percentage scores of males and females (p=.001). A comparison of siblings in the 'cancer' health condition with an Australian study found the domains were strongly correlated but the New Zealand sample was systematically higher.

The qualitative results showed siblings were affected negatively (and potentially long-term) from: a lack of information; feeling 'invisible' and forgotten; feeling guilty for being the 'healthy' sibling; suppression of needs; disruption to the family; a lack of peer and familial support; and additional care-giving roles. The impacts of these issues can lead to depression, anxiety, post-traumatic stress symptoms and affect beliefs around self-worth.

Recommendations arising from these findings point to the need for effective support for siblings including: information about their sibling's health condition; professional support offered to them; support and understanding from peers, family and teachers; time with parents to feel valued and included; guidance on how to support their affected sibling; a safe space where they feel validated and can speak freely; and 'time out' with other siblings.

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Chapter One – Introduction

> *My whole life I've felt forgotten. My parents tried to lessen the impact on my brother and I growing up but I've always known that my sisters health comes first. Being a sibling is incredibly lonely and dealing with chronic sadness has always been there*
>
> Sibling of a child living with a chronic illness (SibStars, unpublished)

An estimated 80% of people in western countries grow up with a sibling (Dunn, 2000). Siblings share an intensive and usually lifelong relationship which is one of the most important relationships in a child's life (Hackenberg, 2008; Noller, 2005). Sibling relationships model future interactions with peers, serving as a child's first social network, and teaching them about social norms and conflict resolution (Dunne & McGuire, 1992; Lamb & Sutton-Smith, 2014). Research shows siblings play a key role in each other's emotional, social and cognitive adjustment, and peer relationships (Dunn, 1992; Kim, McHale, Crouter & Osgood, 2007; Noller, 2005; Waldinger, Vaillant & Orav, 2007).

There is evidence that positive sibling relationships are a protective factor after stressful life events (Gass, Jenkins & Dunn, 2007), and a source of emotional security across the life span (Voorpostel & Blieszner, 2008). Siblings' experience intense emotions including envy, empathy, love, and companionship; these tend to be exaggerated when one sibling is diagnosed with a serious chronic illness (Vermaes, van Susante, & van Bakel, 2012).

A chronic illness is defined as a pervasive, longlasting health condition that requires longterm care (greater than six months). In Aōtearoa/New Zealand, it has been estimated that chronic health conditions affect between 10 – 30% of children (depending on the criteria of what is a chronic health condition), many of whom have siblings (Blatt, 2018). These include

(but are not limited to) cancer, diabetes mellitus (diabetes), cystic fibrosis (CF), asthma, cerebral palsy, congenital heart disease, attention-deficit/hyperactivity disorder, eczema and dermatitis (Dell et al., 2013; Blatt, 2018).

Due to recent advances in pediatric illness diagnosis, medical knowledge, and more sophisticated technical equipment, pediatric illnesses which were once fatal are now able to be successfully treated or readily managed (Compas, Jaser, Dunn, & Rodriguez, 2012; Maddox and Pontin, 2013). Better survival (along with other factors) has led to significant increases in the prevalence of child chronic illness. This presents these children, their parents, and their siblings with significant longterm consequences and challenges. Research has consistently found that the family environment is altered by a child's chronic illness diagnosis; the focus of the family centres on the ill child, leading to reduced capacity for dealing with siblings needs (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Houtzager et al., 2004; Janssens, Peremans, & Deboutte, 2010; Murray, 2000; Neville, Hancock, & Rokeach, 2016; Patterson, Millar, & Visser, 2011; Long et al., 2018).

International literature on the effect of childhood chronic illnesses on siblings is compelling. Despite the complication of heterogenous methodologies (which make it difficult to compare studies), it is clear there is a subgroup of siblings who experience significant psychosocial adjustment difficulties, in particular, depression, anxiety, and post traumatic stress symptoms (Alderfer et al., 2010; Long, Marsden, Wright & Hinds, 2015; Sharpe & Rossiter, 2002).

It is important to reduce the negative impacts of chronic illnesses on the psychosocial functioning and adjustment of siblings, as these difficulties 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 to the potential negative impact of serious chronic illness on siblings, the needs of siblings appear to be overlooked and inadequately

met. Consequently, there have been repeated calls in the literature for targeted support services to be developed that will benefit and protect this vulnerable population (Gerhardt, Lehmann, Long, & Alderfer, 2015; Havermans, De Croock, Vercruyesse, & Goethals, 2015; Long et al., 2015;).

1.2 Systems theory

The impact of a child's chronic illness on their healthy siblings is best understood by systems theory. A system is defined as an interacting set of parts that make up a whole organization, each part of the system is affected by what the other parts do (Ludwig von Bertalanffy, 1968). Systems theory can be applied to all living organisms; systems are defined as "a form of life composed of mutually dependent parts and processes standing in mutual interaction" (von Bertlanaffy, 1968, p. 33). In accordance with the theoretical rationale of systems theory, family therapists view families as complex, interacting systems, in which the actions and experiences of each family member have the potential to influence every other member, both directly and indirectly (Lamb & Sutton-Smith, 2014).

Systems theory illustrates why family environments are important to examine following a child's chronic illness diagnosis. Because treatment usually begins immediately, there is little time for adjustment and all family members have to adapt to a sudden transition in roles, priorities and routines with no preparation (McCubbin, Balling, Possin, Frierdich, & Brybe, 2002). It is a profoundly stressful experience and can destabilise the structure and functioning of the family (Gannoni & Shute, 2010; Murray, 1995; O'Shea, Shea, Robert, & Cavanaugh, 2012). When a child is diagnosed with a chronic illness, their relationship with their siblings can change, as might each of the children's relationships with their parents, and each other. Thus, the closest and longest lasting relationships in a child's life may all change

in unison as the family re-stabilises itself and seeks to find equilibrium at a time of chaos and disruption.

1.3 Health and Culture in Aōtearoa/New Zealand and Australia

The experiences of siblings of children with cancer and serious chronic health conditions are set within a cultural context. Differences in cultural norms, service provision, and the accessibility and quality of support services, mean sibling's experiences are strongly influenced by the country they reside in. The applicability of international sibling research to an Aōtearoa/New Zealand population has yet to be established, as only a handful of studies investigating the experiences of siblings have been carried out on in Aōtearoa/New Zealand.

One of the first studies into this area indicated siblings from Aōtearoa/New Zealand may experience more problems with negative adjustment than siblings studied in international literature (Dobson, 2007). This unpublished Master's thesis interviewed thirty seven healthy siblings of children with cancer (aged 8-15 years) who lived in the North Island of Aōtearoa/New Zealand (Dobson, 2007). The findings showed 62% of siblings of children who were diagnosed with cancer within the last eighteen months scored above the cut-off in an epidemiological depression scale (Dobson, 2007).

These results were supported by a doctoral thesis written on the psychological adjustment of adolescent siblings of cancer survivors; this thesis focused on recognising the needs and perspective of siblings of children with cancer using both qualitative and quantitative methods (Riddick, 2013). Although it was a self-selected study with a small sample size (n=31), quantitative research findings indicated depression scores on the Centre for Epidemiological Studies Depression Scale for Children (CES-DC) were above the cut-off for 76% of the sample, meaning they reported levels of depressive symptoms that indicated probable mood problems. Parental differential treatment, peer alienation and lower optimism

were all found to be significant predictors of depression (Riddick, 2013). Both Dobson and Riddick suggested travel time to treatment facilities and the need to live away from home for extended periods during treatment added additional strain to siblings. This suggestion was also supported by research by Scott-Findlay and Chalmers (2001).

A recent qualitative study (n =10) investigated the experiences that positively and negatively impact the well-being of siblings (aged 12-18) of paediatric cancer survivors in Aōtearoa/New Zealand (Porteous, Peterson & Cartwright, 2019). Their findings showed multiple experiences of distress amongst siblings that negatively influenced their psychosocial adjustment. The experiences relating to the most distress were 'feeling left out' and having 'multiple concurrent stressors'. The majority of participants reported parental differential treatment and feelings of shame and guilt for feeling jealous of their sibling. Experiences that were helpful to wellbeing were knowing they were still a priority for their parents, focusing on positive experiences, connecting with people through their experiences, and feeling involved (Porteous et al., 2019). The authors concluded that the results support the review by Long et al., (2018) that there is a strong need for sibling support.

In Aōtearoa/New Zealand, there are some supports available for siblings, but these are limited and vary across health conditions and geography. An overview of existing support services is discussed below (see section 1.3.4 Regional and national support services in Aōteraoa/New Zealand). However, those who work clinically with paediatric patients and their families are aware of the needs of siblings and the gaps in current services in NZ (Dr Ross, personal communication). This observation is supported by the existing literature in Aōtearoa/New Zealand, which advocates for siblings to be the focus of more research (Lamb, 2015; Porteous, 2019; Riddick, 2013).

Australia appears to have more resources available and research underway for siblings than Aōtearoa/New Zealand, but individual state-run sibling support initiatives can be

difficult to identify. In terms of national sibling support in Australia, a charitable organisation called 'Siblings Australia Inc' was established in 1999 (Strohm, K, 1999). 'Siblings Australia Inc' is committed to improving the support available for siblings of children with chronic conditions. They offer a range of resources including workshops for parents and professionals, as well as the SibWorks Programme, which is a support group for primary school age siblings.

In 2011, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) launched the position statement: Addressing the needs of siblings of children with disability or chronic illness. This statement acknowledged that siblings are largely neglected within the health care system, and that the challenges siblings face can lead to long-term mental health difficulties. The RANZCP identified a number of systemic gaps that contribute toward the inadequacy of services for siblings and the existing lack of sibling support programmes (Royal Australian and NZ College of Psychiatrists, 2011). Despite identifying and committing to addressing the needs of Australian siblings in 2011, in 2018 a mapping project of sibling support carried out by 'Siblings Australia Inc', identified little recognition of the needs of siblings by professionals and by policy makers and no improvement in the significant gap in support services for siblings (Siblings Australia, 2018).

Concerned that the needs of adolescent and young adult (AYA) siblings appear were being inadequately met by the Australian Healthcare system, Franklin and colleagues (2018) conducted qualitative research on the perspective of health care professionals on how AYA siblings are catered for in hospital-based cancer care (Franklin, Patterson, Allison, Rosso-Buckton, Walczak, 2018). Findings showed current approaches to psychosocial support are not adequately addressing the needs of AYA siblings due to difficulty in accessing siblings, a lack of assessment procedures, and service management. They called for improvements in the model of care that delivers AYAs psychosocial support (Franklin et al., 2018).

Despite these findings, valuable research with siblings is being carried out in Australia. A large-scale national research project is currently underway in Australia called 'SibStars' which is run through the University of New South Wales. The developers of SibStars have identified a need for sibling support and a gap in services for siblings in Australia. The study aims to better understand siblings' experiences of growing up with a sister or a brother with a chronic illness, identify the siblings' information and support needs, and identify factors that impact on siblings' quality of life (SibStars Study).

Overall there appears to be a gradual increase in the focus on needs-based support service for siblings in Australia and research is being carried out in this area. This may be influenced by the increase in young people living with chronic illness, leading to more siblings potentially experiencing psychosocial and adjustment difficulties. Having identified that a subset of siblings are vulnerable, one of the challenges in the provision of needs-based support services to siblings is having access to an effective needs-based instrument that enables targeted effective support services, and accurately identifies those needing support in a timely way.

Needs-based measures for siblings

There have been a limited number of measures developed to understand the impact of having a sibling with cancer or a chronic illness but most of these do not produce specific needs-based information aimed at developing targeted health care services for siblings. Needs assessment is beneficial for the development of services as described by Thewes, Butow, Girgis, and Pendlebury (2004):

"Needs assessment yields a direct index of what [people] perceive they need help with and indirectly measures the perceived efficacy of a health service by its users… and differs from related assessment constructs such as "quality of life" and "patient satisfaction" surveys,

in that it directly links services with [people's] desires and is more focused on solutions. (p.54)."

Aware of the lack of needs-based measures, CanTeen Australia developed the Sibling Cancer Needs Instrument (SCNI) to identify specific unmet needs in healthy siblings of children with cancer, and facilitate health services and support organisations developing targeted interventions and resources (Patterson, Millar, & Visser, 2011). The instrument has seven domains of need which include: 1) Information about my sibling's cancer; 2) 'Time out' and recreation; 3) Practical assistance; 4) Dealing with feelings; 5) Support from my friends and other young people; 6) Understanding from my family; and 7) Relationship with my sibling with cancer. The study found the top three reported unmet needs were: 1) coping with the feeling that their sibling may die; 2) access to professional support to cope with family stress; and 3) to be able to talk to their siblings about their feelings (Patterson et al., 2011). A larger and more recent study (n=106) using the SCNI to identify the unmet needs of siblings of children with cancer, found the domains with the highest percentages of unmet needs were: 'Information about my sibling's cancer' and 'Support from my friends and other young people'. Overall the findings showed 44% of sibling's needs were unmet on average which emphasised the need for support services for siblings (Patterson et al., 2017).

This section has outlined existing research on siblings with cancer and chronic illness in Aōtearoa/New Zealand, and touched on sibling support provision and research in Australia. The next section will explore common needs of siblings across multiple serious chronic health conditions that affect people in childhood. These conditions will be discussed in the following section with a focus on the impact on siblings.

1.3.1 Child Cancer in Aōtearoa/New Zealand

The New Zealand Cancer Registry (NZCR) collects and records information on all cancer diagnoses in New Zealand. In 2018, there were 197 registrations of cancer for children and adolescents (age 0-18 years) many of whom will have siblings (C. Lewis, personal communication, July 24, 2019).

Cancer is a term that is given to a number of related diseases, but in all types, it begins when body cells divide without stopping. These cells form tumours or spread into surrounding tissue. Treatment types vary significantly, with the most common types being bone marrow or stem-cell transplants, surgery, chemotherapy, and radiation therapy (Dixon-Woods, Young, & Heney, 2005). Different types of cancer have different causes, treatment, and prognosis (Di-Gallo, 2006). Sibling's lives often change dramatically during the diagnosis and treatment of their brother or sister and there are some disease-related stresses they find particularly difficult. These include seeing their sibling in pain (Woodgate, 2006), fear about the possibility of their sibling dying (Nolbris, Enskar, & Hellstrom, 2007), and physical changes for the cancer patient such as hair and weight loss (Nolbris et al., 2007; Woodgate, 2006).

While children are considered 'cured' following five years of remission after treatment, they are at greater risk (than the general population) of developing a subsequent cancer or chronic health problems; understandably, this can cause anxiety for both cancer survivors and their family members (Riddick, 2013).

In 1995, the number of paediatric oncology treatment centres in New Zealand reduced from five to two: Starship Children's Hospital in Auckland, and Christchurch Hospital in Christchurch. Consequently, families who have a child with cancer often have to travel long distances for treatment, forcing families to live apart, leading to additional strain in their cancer journey.

1.3.2 Cystic Fibrosis in Aōtearoa/New Zealand

Cystic Fibrosis (CF) is the most common life-limiting genetic condition in New Zealand, Australia, North America, and Europe. It has a worldwide prevalence of 1 in 2500 births (Elborn, 2016). There are over 500 people living with CF in Aotearoa/New Zealand; this includes 270 children between the ages of 0 and 17 years (Personal communication, Cystic Fibrosis New Zealand). Newborn screening through the heel prick blood test facilitates early diagnosis of CF in Aōtearoa/New Zealand babies, although some children who have rare CF genes or were born overseas receive a late diagnosis (Cystic Fibrosis NZ).

An autosomal disorder, CF is caused by a mutation of the cystic fibrosis transmembrane conductance regulator which leads to epithelial cell dysfunction (Elborn, 2016). This causes problems with mucociliary clearance, leading to chronic respiratory infections and eventual loss of lung function. Epithelial cell dysfunction also leads to comorbidities in other organs including the liver, sweat glands, pancreas, and causes infertility in males (Elborn, 2016).

While there is no cure for CF, there are daily treatments and medications that help control CF symptoms, in particular the sticky mucus in the lungs. It is estimated the daily treatment routine is between 2 to 4 hours per day (Sawicki et al., 2011). Chest physiotherapy, or airway clearance, needs to be performed for 20 – 40 minutes twice daily. In younger children, this is performed by parents (Glazner, 2017).

In addition to airway clearance techniques, mucolytics and hypertonic saline are used to make the mucus easier to remove. Thick secretions in the digestive system cause malabsorption, so taking pancreatic enzymes with food helps the body absorb nutrients (including fat) and maintain weight. Children who live with CF need an energy-rich diet which includes chocolate and chips and other ‘treat’ foods. This can cause tension with healthy siblings who are not required to eat such foods. Meal times are often reported to be

one of the most stressful times of day by parents of children with CF (Branstetter et al., 2008; Glazner, 2017).

Infections are a constant threat to people with CF who are highly susceptible to respiratory pathogens which are associated with reduced survival. These pathogens can be easily transmitted between people with CF in a process called cross-infection. To avoid the risk of cross infection, Cystic Fibrosis New Zealand recommends people with CF keep a distance of at least four metres between each other and wear masks when visiting treatment centres (Glazner, 2017). Medications such as antibiotics, vitamin supplements, and bronchodilators are also key parts of treatment.

People living with CF benefit from regular visits to specialised CF treatment centres, where it's been shown that more frequent visits, monitoring adherence to therapy, periodic testing and more antibiotic use lead to better lung function. While CF is incurable, due to improvements in treatment and specialist care centres, the prognosis for children born with CF continues to improve. Recently, both gene correctors and potentiators have been approved for certain individuals with CF, which is expected to further decrease mortality. The median life expectancy for individuals for CF is now late forties to early fifties – this has increased dramatically in the past 20 years (Burgel et al., 2015).

Dr Judith Glazner wrote a PhD thesis on siblings of children with CF, with the support of The Royal Children's Hospital in Melbourne, Australia. Her focus was on assessing the impact of parental differential treatment in families with a child with CF. The study found evidence of paternal parental differentiation only (Glazner, 2011).

There have been no known studies carried out on siblings of children with CF in Aotearoa/New Zealand. This is possibly due to the relatively small number of children living with CF, making funding for research difficult to secure.

1.3.3 Type 1 Diabetes Mellitus in Aōtearoa/New Zealand

Type 1 Diabetes Mellitus (diabetes) is a serious chronic illness and has treatment and daily care needs that place significant strain on the entire family (Jackson, Richer & Edge, 2008; Loos & Kelly, 2006). It is an autoimmune condition in which the immune system attacks the insulin-producing beta cells. Over time, people with diabetes cannot produce their own insulin which is the hormone that regulates blood sugar. Diabetes is managed though continuous glucose management; this is a balancing act that requires constant attention to hypoglycaemia (low blood sugar; which is acute and immediately life-threatening), and the long-term damage that can be caused by hyperglycaemia (high blood sugar; What is Type 1 diabetes?, 2019).

There are approximately 2500 children, aged 0-18, living with diabetes in New Zealand (Cure Kids, n.d.). There is evidence the incidence of diabetes in children is increasing and becoming the one of the most common paediatric chronic health conditions (Ministry of Health, 2013). An analysis of the existing literature shows conflicting results on the outcomes for siblings of children with diabetes; some show they are at risk of developing social, emotional and behavioural problems (Adams, Peveler, Stein & Dunger, 1991; Ferrari, 1984); others found no increase in adjustment difficulties (Hollidge, 2001; Lavigne, Traisman, Marr & Chasnoff, 1982; Sleeman, Northam, Crouch & Cameron, 2010); and at least one study concluded siblings of children with diabetes are better adjusted than their peers (Jackson et al., 2008).

Siblings of children with diabetes are often involved in the daily dietary management and insulin treatment of the ill child and they often take on parental roles (Tsamparli & Kounenou, 2004). They can experience feelings of resentment for the removal of certain foods from the family diet and jealousy at the attention given to the ill child. Furthermore, because diabetes is known to have a genetic component, siblings of children with diabetes

may also have inherited a predisposition for the illness, increasing their risk of developing the illness themselves (Hamburg & Inoff, 1983).

1.3.4 Regional and national support services in Aōteraoa/New Zealand

Other than limited support services for siblings of children with cancer, Aōtearoa/New Zealand does not offer needs-based support services nationwide to siblings of children with other serious chronic health conditions. This section outlines the organisations that currently offer support to siblings:

1) The Child Cancer Foundation supports families of children with cancer. When a child in Aōtearoa/New Zealand is diagnosed with cancer, the family is assigned a personal Family Support Coordinator. The role of the coordinator is to ensure the needs of the family are met regardless of location, and they will support the family through their child's cancer diagnosis and in the future. Some areas in New Zealand run camps for siblings and parents of children with cancer (Family Support, n.d.);

2) CanTeen supports young people between the ages of 12 and 25 years who are living with their own cancer, their parent's cancer, or their sibling's cancer. Canteen is a national organisation that has recently changed to an online service model operating from three hubs which are located in Auckland, Wellington and Christchurch. When a young person signs up to CanTeen online, they are contacted by a psychosocial worker to discuss their personal situation and to assess their level of need. Depending on their needs, they are assigned either a youth worker, a psychosocial worker, a counsellor, or are referred to an external mental health service. CanTeen also runs workshops titled 'Youth Leadership' and 'Dealing with Grief' which are available to all members (Canteen, Personal communication, August 8, 2019);

3) The Cancer Psychology Service is a joint venture between the MidCentral District Health Board and the Massey University Psychology Clinic in Palmerston North. It provides psychological therapy and support for patients with cancer and their family/whānau (including siblings) living in the MidCentral and Whanganui regions. It is a free service which is funded by the District Health Boards. Dr Kirsty Ross (supervisor of this research) is a senior clinical psychologist and senior lecturer at the Massey University Psychology Clinic and has worked in this service from its inception;

4) The Health Conditions Psychology Service is also a venture between the MidCentral District Health Board and the Massey University Psychology Clinic in Palmerston North. The service works with adults, children and families who live in the MidCentral Health Board region offering short to medium term psychology services for patients and their family/whānau live with a range of qualifying medical conditions, which include (for children and youth) CF and Type 1 diabetes. It is a free service which is funded by the District Health Board;

5) The True Colours Children's Health Trust is a Waikato-based health care organisation. It supports children and young people (age 0-18) with a complex serious illness and their families. It is funded by the community and provides a free service for families who live in the greater Waikato region. They offer psychosocial, nursing and education support for the affected child, their siblings, and their parents, from diagnosis through to cure;

6) 'Parent to parent' is a national charitable organization which offers support to the families of babies, children, teens, and adults with any type of disability or health impairment. With eleven regional offices nationwide, they run free programmes to support siblings to thrive 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 Aōtearoa/New Zealand that offers support services to siblings. From July, 2018 – June, 2019, 83 siblings attended

SibCamps, 106 siblings attended SibShops, and 51 siblings attended SibDays. The organisation 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);

7) There are also generic mental health support services for children and young people in Aōtearoa/New Zealand. Organisations such as 'What's Up', 'Kidsline', and 'Youthline' offer free counselling services (online, telephone or text support) and can be easily accessed by young people.

While all of these services are valuable, they are either not available nationwide or they do not offer specific needs-based support for siblings of children with a serious chronic health condition. For example, while the 'Parent to Parent' programme offers a generic service to siblings of children with any disability, they do not offer support services that have been developed for siblings of children with serious chronic health conditions who potentially face the greatest challenges. Furthermore, while younger siblings of children with cancer receive family support through the Child Cancer Foundation, and older siblings receive support services through CanTeen NZ, there are limits to what these organisations can offer siblings of children with cancer particularly in regard to targeted emotional support and strategies.

This overview of support services that are available to siblings of children with cancer and other serious chronic health conditions identifies this area is under serviced and there is a need for targeted support services for siblings of serious chronic health conditions that is available nationwide.

Chapter Two – Literature Review

Chapter overview

This chapter will review the existing literature on siblings of children with cancer and chronic health conditions and describe findings on the impact on siblings, and the variables that effect sibling adjustment.

2.1 The impact of childhood cancer and chronic health conditions on siblings

2.1.1 Chronic illness

One of the earliest literature reviews regarding the impact on siblings (of having a young person diagnosed with a chronic illness) concluded that siblings were an 'at-risk population' (McKeever, 1983). Subsequent reviews found siblings to be at risk for experiencing psychological difficulties; however, there was also suggestion of positive outcomes to growing up with a chronically ill sibling (Faux, 1993; Midlarsky, Hannah & Corley, 1995; Packman, 1999; Williams, 1997).

More recent reviews that examine the psychosocial functioning of siblings with serious chronic health conditions have broadly found: an increase in low mood (Hartling et al., 2014); somatic symptoms and internalising problems (Incledon, 2015); post-traumatic stress symptoms (Ingerski, Shaw, Gray, & Janicke, 2010); lower scores for quality of life measures (Knecht, Helmers, & Metzing, 2015); and in qualitative research, adjustment problems following a child's diagnosis (Vermae, van Susante, & van Bakel, 2012).

A meta-analysis of fifty one quantitative studies published between 1976 and 2000, representing over 2,500 siblings, examined siblings of children with chronic illness (Sharpe & Rossiter, 2002). The analysis found a statistically significant and negative overall effect for

siblings and that internalizing behaviours (such as anxiety and depression) were associated with larger negative effects than externalising behaviours. This was consistent with previous reviews (Howe, 1993; Rossiter & Sharpe, 2001). Sharpe and Rossiter (2002) speculated that siblings of children with chronic illness have increased frustrations due to an increase in caretaking responsibilities and parental inattention, which may not be easy to externalise considering the precarious state of their ill sibling.

In 2012, Vermaes et al., conducted an up-to-date systematic review that updated the meta-analysis by Sharpe and Rossiter (2002), through the addition of thirteen new research reports. The review confirmed a relatively stable overall negative effect of chronic health conditions on siblings; this was almost an identical finding to the previous meta-analysis (Sharpe & Rossiter, 2002). Findings showed siblings were more at risk of internalising than externalising problems which the authors suggested may be due to siblings suppressing their emotions and feelings rather than asking for attention from their overburdened parents (Vermaes et al., 2012). This review also found siblings of children with more intrusive and/or life-threatening health conditions were at greater risk of developing psychological problems.

A recent review of literature on siblings' perspectives on living with a child with a serious chronic illness (excluding cancer), carried out a thematic synthesis. This meta-synthesis analysed qualitative research studies that focused on the psychosocial commonalities across chronic illnesses, using direct reports from siblings (Deavin, Greasley, & Dixon, 2018). Two main themes were identified. The first theme was 'Changing relationships', which had subthemes of 'Changing family relationships', and 'Changing relationship to self'. The second theme was 'Managing changes', which had subthemes of 'Coping, acceptance, and adjustment', 'Support from friends, peers and support groups', and 'Negative reactions from others' (Deavin et al., 2018).

Findings showed siblings alter their behaviour by taking on caring goals to meet both their own needs and the needs of the family; with positive feedback, these behaviours become reinforced and internalised, and are synonymous with post traumatic growth (discussed further below). The meta-synthesis also found that some siblings use active adaptive coping strategies, while others relied on passive coping which was associated with poorer outcomes. Siblings reported that worrying about their sibling was pervasive and some recognised their worrying negatively impacted other areas of their life and concentration at school. Other emotions siblings reported were: loneliness as a result of familial and peer isolation; jealousy due to reduced parental attention; and feelings of 'survivor guilt' (Deavin et al., 2018).

Overall the findings suggested healthy siblings (on the whole) did not experience significantly higher levels of psychiatric disorders; however, a subset of siblings experienced strong negative emotional reactions which impacted their emotional and social wellbeing (Deavin et al., 2018). These findings are similar to those of siblings of children with cancer. A detailed discussion of the specific impacts on siblings and variables that influence adjustment and coping follows below.

One of the complications in identifying the impact of a serious chronic health condition diagnosis on siblings, are the heterogeneous research approaches and measures used in existing studies. To overcome this problem of inconsistent methodologies, a grounded theory framework was used to synthesize results of both qualitative and quantitative research (Havill, Fleming, & Knafl, 2019). A grounded theory framework does not restrict the sample to a specific study design, rather it aims to synthesize results across multiple studies to extend the current body of knowledge on a specific topic (Knafl & Whittemore, 2017). This method was used for synthesizing the results of 78 international research reports on siblings of children with a chronic illness (including cancer) published

between 2010 and 2014. It included data from the literature on fourteen chronic health conditions (see Table 1; Havill et al., 2019).

The study used thematic analysis to identify four broad patterns of sibling behaviour, including; knowing something is seriously wrong; figuring out the meaning of the disease; adapting to changes in personal and family life; and handling emotional reactions to disease. These patterns were comprised of fifteen sibling responses and the sibling literature was analysed to identify which chronic conditions each sibling response was associated with (see Table 1).

Table 1

The chronic conditions with supporting evidence for each pattern of sibling behaviour and category of sibling response (Havill et al., 2019)

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/Spina Bifida/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

Overall, the most common sibling responses were ‘experiencing fear’ (supported by 20 reports), assuming a parent-like role and taking an active role in treatment of ill child (20 reports), experiencing other negative emotions (12 reports), disrupting family relationships (12 reports), changing family activities and routines (11 reports), experiencing positive emotions (9 reports), experiencing anger (8 reports), and seeking more information (8 reports; Havill et al., 2019).

The findings of this synthesis show similarities in sibling experiences across all chronic conditions, with the strongest similarities between siblings of children with cancer and Type 1 diabetes. These shared experiences suggest there is value in looking across serious chronic health conditions to identify whether the needs of siblings can be met together regardless of the specific illness.

2.1.2 Cancer

A 2010 systematic review of 65 qualitative, quantitative and mixed methods papers on the psychosocial adjustment of siblings of children with cancer represented data from a variety of countries, cultures, socioeconomic groups, and health systems (Alderfer et al.,

2010). Findings showed siblings do not experience higher mean rates of psychiatric disorders than the normative population. However, findings also showed when rates of siblings in clinical ranges were investigated (instead of group means), the number of siblings in clinical ranges were often significantly higher than group norms. This shows that while most siblings are well-adjusted, there is a significant subset of siblings who experience poorer emotional functioning, quality of life, and post-traumatic stress symptoms. The findings of the qualitative studies revealed siblings experience a loss of attention and status within the family, disruptions in normalcy and their sense of security, and changes in family roles and relationships (Alderfer et al., 2010).

This review was updated by a large-scale systematic review on the psychosocial functioning and risk factors of siblings of children with cancer, which summarised the findings on sibling literature since 2008 (Long et al., 2018). It updated the authors' previous review on siblings (Alderfer et al., 2010) and included 102 studies (63 quantitative, 35 qualitative, and 4 mixed-methods). Siblings reported no significant difference for emotional and behavioural functioning than the normative population; however, two-thirds of siblings endorsed moderate to severe levels of post-traumatic stress symptoms, and one quarter of siblings met full criteria for post-traumatic stress disorder. This review considered siblings to be at increased risk of some emotional/behavioural problems, risky behaviour, and stress-related medical conditions. Despite methodological limitations, the authors concluded 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).

Qualitative data from this review showed some siblings felt overwhelmed by strong negative emotions including loneliness, jealously, shock, isolation, sadness, fear, anxiety, anger, guilt, depression, worry, and helplessness (Long et al., 2018). This echoes findings from an earlier Canadian qualitative review of siblings of children with cancer aged 6 – 21

years (*n*=30), which found a core theme was 'enduring sadness' (Woodgate, 2006). This review found feelings of sadness remained even after successful treatment, as if the sadness had become an enduring part of siblings' personality and of their lives (Woodgate, 2006).

An integrative review on sibling responses to childhood cancer between 2012 and 2017, included eighteen studies and one systematic review (Weiner & Woodley, 2018). This study used Meleis' Transition Theory as a framework for understanding the holistic experiences of siblings of children with cancer or serious chronic illness (Meleis, 2010). Meleis described four types of life transitions; these include developmental, health/illness, situational, and organizational. Based on transition theory, adolescent siblings whose sister or brother is diagnosed with cancer (or chronic illness) experience an intersection of simultaneous transitions. They undergo a health/illness transition as a result of their sibling's illness; a developmental transition as they simultaneously navigate the complexities of adolescence; and a situational transition as their family and home life changes as a result of the diagnosis.

Seven categories of major changes for siblings were identified in this extensive review. In the 'emotional change' category, the following emotions were reported: shock, fear, and uncertainty at the time a child is diagnosed; anger and jealousy throughout the treatment period (due to the ill child receiving increased attention); uncertainty and anxiety (especially while waiting for an accurate diagnosis); depression, fear, anger and isolation during the course of the illness; and loss of identity and feelings of insecurity throughout the cancer experience. Grief and guilt were commonly reported by siblings as they watched the ill child undergo physical changes and lose the ability to engage in normal activities. Not all emotions were negative however; some siblings experienced a change of emotions over time using coping strategies that turned negative feelings into more positive ones with the support

of friends and family (Weiner & Woodley, 2018). This support other studies' findings around the emotions siblings experience.

2.1.3 Family functioning

Research suggests children's social and emotional development is influenced by the family environment (Grych & Fincham, 1990). Family dynamics involve a complex set of relationships which are even more so when a child is born with or diagnosed a chronic illness (Sharpe & Rossiter, 2002). Family life is significantly disrupted due to intensive daily treatments, hospital visits, and general parental stress. Parents are often absent from home (while they are at hospital with the ill child), and when they are home, siblings notice their exhaustion. Family occasions are also impacted and social activities are reduced (Prchl & Landolt, 2012; Weiner & Woodley, 2018). It is well supported in existing literature that a child's diagnosis with a serious chronic illness leads to significant disruptions in family roles and routines.

One of the role changes that impacts the functioning of a family is that fathers have been shown to take on more responsibilities caring for siblings (Alderfer et al., 2010). This is due to mothers being the parent who is more likely to take the affected child to hospital and treatments. Communication patterns also change in families with a child with a chronic illness. Siblings are often aware of the challenges the affected child faces, and tend to repress their feelings, believing they are insignificant, and not wanting to share their problems for fear they will add to parental burden (Vermae et al., 2010; Kobayashi, Hayakawa & Hohashi, 2015; Prchal & Landolt, 2012). They also observe their ill sibling in emotional and physical pain as they fight the disease and tolerate treatments. This can cause a disrupted sense of normalcy leading to siblings taking on both practical and emotional support roles in the

family (D'Urso, Mastroyannopoulou, & Kirby, 2017; Long et al., 2015; Nolbris, Abrahamsson, Hellström, Olofsson, & Enskär, 2010).

2.1.4 School Functioning

School life is central to a child's social and academic development; relationships with peers and teachers play an important role in children's overall psychosocial adjustment (Roeser, Eccles, & Sameroff, 2000). A review of the literature on the school experiences of siblings of children with chronic illness found siblings who miss regular school attendance struggle to keep up with their academic work and have poorer social functioning (Alderfer et al., 2010). Parents of children with cancer report that siblings typically have more absenteeism from school following their brother or sister's cancer diagnosis (Donnan et al., 2015); this can lead to sibling distress if they experience disconnection from their peers at school (Williams et al., 2009).

Further research has found that interruptions to attendance leads to a loss of the 'normalcy' that regular school routines add to siblings' lives (Gerhardt, Lehmann, Long, & Alderfer, 2015; Long et al., 2018). Studies that examined academic functioning in siblings found many siblings reported academic difficulties when they have a sibling with a chronic illness. These difficulties included: a decline in academic performance; difficulty concentrating due to worry; frequent absenteeism; and school aversion (Donnan, et al., 2015; Gan, Lum, Wakefield, Nandakumar, & Fardell, 2017; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005; Long et al., 2018; Prchl and Landolt, 2012).

However, the negative impacts on siblings' schooling and social connection with peers are not a universal finding. A recent systematic literature review on the school experiences of children with chronic illness (which represented over 1400 siblings), showed some sibling's reported positive impacts such as social resilience, positive self-esteem, and

maturity (Gan et al., 2017). The authors suggested siblings perceived that changes in self-identity can impact on how they interact with their peers and teachers and while siblings may experience negative effects in academic, social, and psychological domains of school functioning, they are a socially resilient population (Gan et al., 2017).

Turning to local research, a recent Master's thesis investigated school support structures for siblings of patients with cancer in New Zealand. Findings showed sibling's everyday lives are disrupted by a brother or sister's cancer diagnosis and that there is a need for home-school partnerships to achieve the best outcomes for siblings (Lamb, 2015). Further work by Lamb acknowledged how important school support is for siblings of children with cancer, and the need to educate school personnel so they can answer questions from students or direct them to appropriate resources. This small qualitative study also emphasised that the school community is the perfect place to provide attention and support to siblings due to the large amount of time spent at school and that guidance counsellors are pivotal in providing consistent, effective, sustainable support for siblings (Lamb & Holley-Boen, 2016).

2.1.5 Post traumatic growth

While literature points to numerous negative impacts for siblings around their emotional needs, family functioning, and school engagement and achievement, it is also evident that there are positive impacts reported in each of these areas. Post traumatic growth (PTG) is the experience of positive psychological change following the struggle with a highly stressful life experience (Tedechi & Calhoun, 2004). It has been defined as the ability to master a traumatic experience, perceive benefits from it, then develop beyond the original level of psychological functioning (Tedechi, Park & Calhoun, 1998). Literature has identified a wide array of traumatic experiences which can act as a catalyst for post traumatic growth. These include bereavement, cancer diagnosis, heart attacks, serious illness, house

fires, sexual assault, refugee experiences, being taken hostage, automobile accidents and coping with the medical problems of children (Tedechi & Calhoun, 2004).

Sibling literature commonly reports positive outcomes for siblings, including PTG. Berbis et al. (2013), found some healthy siblings of chronically ill children have better self-perception of their psychological functioning and self-esteem when compared to age and gender matched children. Studies have also found some siblings report an increase in feelings of self-worth, empathy, enhanced prosocial behaviours, independence, personal growth, maturity, responsibility, understanding, and family cohesion (Adams et al., 1991; Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Batte, Watson, & Amess, 2006; Brennan Hugh-Jones, & Aldridge, 2013; Snethen & Broome, 2001; Turner-Sack, Menna, Setchell, Maan & Cataudella, 2015; Woodgate, 2006). Silver and Frohlinger-Graham (2000) found female siblings reported greater interpersonal sensitivity than siblings of children without a chronic illness which suggests there may be gender differences in effects and coping.

A doctoral thesis on the experiences of siblings of children with cancer in Aōtearoa/New Zealand conducted a thematic analysis on the interviews of eleven participants between the ages of 12 and 18 years old (Riddick (2013). All participants reported they had changed as a result of their sister or brother's cancer, and that the change was mostly positive. The changes reported were increased maturity, being more responsible and independent, and being emotionally stronger. They also reported having fun through, and because of, their siblings cancer; additionally, they described an improved desire to see the bright-side of difficult situations, a desire to make the most of life and relationships, and the majority of participants reported feeling their family had grown closer (Riddick, 2013). It is important to note this was a small self-selected study and that further research is needed to establish whether these results are representative.

Another qualitative New Zealand study reported a number of positive outcomes from participant's experiences of being a sibling of a child with cancer, and all siblings were able to describe some positive elements of their experiences (Porteous et al., 2019). These outcomes included spending quality time with family members, closer family relationships, and personal growth - all themes which fit with the PTG model which encourages reflection on the positive outcomes of a traumatic experience (Tedechi & Calhoun, 2004).

2.2 Variables that effect sibling adjustment

The mechanisms of why some siblings of children with serious chronic health conditions have adjustment difficulties, while others experience positive personal growth, has not been adequately explored internationally, and even less so in an Aōtearoa/New Zealand population.

Understanding sibling adjustment to a child's serious chronic health condition diagnosis is a complex task due to the multitude of personal, family, and system variables that mediate the impact of the diagnosis. This section will identify some key variables that have been investigated for the impact they have on sibling adjustment. These include: cultural context; time since diagnosis; age; gender; the sibling relationship; parental differentiation; individual coping style, and illness variables.

2.2.1 Cultural context

International literature on siblings experiences needs to account for (and take into consideration) variations in health service provision and accessibility of services and support across countries. For example, initial New Zealand studies on siblings of children with cancer suggest they may experience more psychosocial adjustment problems than their overseas counterparts (Dobson, 2007; Riddick, 2013).

It is also important to consider that the impact of serious chronic health conditions on siblings who are raised within a western cultural context may have differences to siblings who belong to non-western cultural groups. Indigenous models of health are influenced by values, beliefs and traditions which focus on spirituality, holism and wellbeing. These perspectives differ from western culture's biomedical model of health (Durie, 1985).

In New Zealand, the indigenous culture is Māori, who comprise almost 16.5% of Aōtearoa/New Zealand's population (Statistics New Zealand, 2018). In Te Ao Māori (the Māori world view), the role of whānau (family) is broader than the western concept of family and Māori children are more likely to grow up with whāngai and/or extended family living together (whāngai is a customary Māori practice when a child is raised by someone other than their birth parents). In Māori families, cousins and whāngai have the same status and closeness as siblings (Edwards, McCreanor & Moewaka-Barnes, 2007).

For these reasons, the current research will investigate the impact of serious chronic health conditions on Māori siblings/cousins/whāngai. This is in adherence to the 'Treaty of Waitangi' (New Zealand's founding document which underpins the Code of Ethics for Psychologists working in Aōtearoa/New Zealand), which promotes the principles of participation, protection, and partnership for (and with) Māori (New Zealand Psychological Society, 2002).

2.2.2 Time since diagnosis

Studies have shown time since diagnosis is associated with better adjustment and fewer difficulties, as siblings get used to the situation (Alderfer et al., 2010; Houtzager et al., 2004). Higher distress occurs at diagnosis and then adjustment typically occurs over time allowing for the development of coping and acceptance, especially with good support

(Deavin et al., 2018; Hamama, Ronen, & Rahav, 2008; Houtzager et al., 2004; Havermans et al., 2015; Sleeman, Northam, Crouch, & Cameron, 2010; Weiner & Woodley, 2019).

While research investigating the average outcomes for siblings show a trend toward an improvement over time, a longitudinal study by Houtzager et al., (2004) found 26% of siblings reported clinically relevant emotional problems two years after their sibling's diagnosis. This emphasises that despite the majority of siblings experiencing an improvement in symptoms over time, there is a significant subgroup of siblings who experience long-term adjustment problems.

In summary, literature suggests sibling distress may be greater closer to the time of diagnosis; hence, it may be valuable to provide support services to siblings in these early stages as they adjust to the significant changes they face. An early intervention may also help ameliorate the risk for the vulnerable subgroup of siblings who may otherwise suffer long-term negative impacts.

2.2.3 Parental Differential Treatment

Studies on intra-familial variance in children's social and emotional adjustment have identified several non-shared influences: variations in temperament; different peer groups; and parental differential treatment (Brody, Stoneman & McCoy, 1992; Volling & Belsky, 1992). Of these non-shared experiences, parental differential treatment is most commonly linked with child outcomes and has been shown to be strongly associated with the psychological wellbeing of siblings (McHale & Pawletko, 1992).

Parental differential treatment refers to inequities in parental behaviour directed at siblings living in the same household. They can be expressed through tangible rewards (money, food, clothes, gifts), expressions of affection, inconsistent punishment, and the amount of time a parent spends with a child (Opipar, 1997). Increasingly, evidence suggests a

relationship between parental differential treatment and less positive sibling relationships, as well as sibling resentment, and lower levels of psychological adjustment in the less favoured child (Brody, Stoneman & Burke, 1987; Noller, 2005; Shanahan, McHale, Crouter, & Osgood, 2008).

Parental differentiation is discussed repeatedly in the literature on siblings of children with cancer and serious chronic health conditions (Chesler, Allswede, & Barbarin, 1992; Glazner, 2017; Marciel, 2004; Sloper 2000). When one sibling has a chronic health condition, the additional physical and emotional demands placed on parents make differential treatment of a child difficult to avoid. In families with a chronically ill child, the amount of time parents spend with the affected child is often greater than time spent with their other children due to increased care needs, this can lead to parental differential treatment. This can also be motivated by parental guilt, especially if their child's condition is genetically inherited such as cystic fibrosis (Priddis, Dunwoodie, Balding, Barrett, & Douglas, 2010).

Findings from twin studies where parental differential treatment was reported showed more negative behaviour and more negative communication than families where equal treatment was reported. Naturally, having a warm and supportive sibling relationship is difficult when it is undermined by pervasive differential treatment (Noller, 2005). Further research by Noller (2005), found evidence that less favoured siblings are more likely to be lower in self-esteem, higher in anxiety, and more insecure in attachment than their favoured siblings.

This, however, was not found to be the case with siblings of child cancer survivors. Riddick (2013) found parental differential treatment was a predictor of depression but did not influence self-esteem or wellbeing. The author suggested this could be because siblings interpret parental differentiation differently when it is in the context of their sibling's illness. This could also explain the findings of a recent Australian study on the impact of CF on

siblings which found evidence of parental differential treatment with fathers but not mothers (Glazner, 2018).

Conversely, a qualitative study of families with a child living with CF, found mothers had high levels of involvement in treatment, preferential treatment towards the ill child, and were less tolerant of siblings misbehaviour (Foster et al., 2001). Parents in this study described parental differentiation as unintentional and both children with CF and their parents reported sibling resentment to the differential treatment.

Thus, research suggests that parental differentiation does occur within the context of childhood chronic illness and can impact negatively on siblings, but further investigation is required to understand the effect on siblings and how this could be mediated.

2.2.4 Age and developmental stage

Despite the effect of age being investigated a number of times, results are varied. There is some evidence of an increase in adjustment problems and psychological distress in older siblings, as well as siblings who are older in relation to their ill sibling (Alderfer et al., 2010; Grootenhuis et al., 2004; Havermans et al., 2015; Houtzager, Grootenhuis, Hoekstra-Weebers & Last, 2005; Labay & Walco, 2004; Silver & Frohlinger-Graham, 2000). These results have been shown at both four to eight weeks post diagnosis and two years post diagnosis in a study with Dutch participants aged 7-18 years (Houtzager et al., 2005).

In 2018, Deavin et al., conducted a meta-synthesis which found younger siblings often reported somatic complaints, while adolescents had more psychosocial adjustment problems. These results are representative of typical manifestations of distress based on developmental stage. The increase in psychosocial adjustment problems in adolescence has been linked to the increase in caregiving duties older children tend to take on (Labay & Walco, 2004). They have also been linked to the developmental stage of adolescence which

is characterised by a young person's identity development as well as significant social, cognitive and developmental milestones (Arnett, 2000). In adolescence, functional family relationships, self esteem and social connection have great importance; these factors have been shown to be negatively impacted by a family member's cancer diagnosis (Knecht, Hellmers, & Metzing, 2015).

In contrast to these difficulties, older siblings also reported more positive outcomes of cancer or post-traumatic growth (Sargent et al., 1995). An Aōtearoa/New Zealand study found anxiety and depression levels of siblings of children with cancer (aged 8-15) had a negative correlation with age between two and seventeen months post diagnosis - meaning the older sibling participants had fewer adjustment difficulties than younger siblings (Dobson, 2007).

This research indicates a child's chronic health condition diagnosis impacts siblings differently depending on their age and developmental stage, but further investigation is needed in this area to identify and clarify what these impacts are.

2.2.5 Gender

An investigation into the literature on the moderating effects of gender show varied results. Some studies found female adolescent siblings of chronically unwell children experience greater adjustment problems (higher levels of anxiety, insecurity, and loneliness) than both males, and younger children (Barrera, Fleming, & Khan, 2004; Hamama, Ronen, & Feigin, 2000; Houtzager et al., (2015). Hamama et al. (2000) found sisters experienced an increase in feelings of loneliness.

In contrast, neither the meta-analyses by Sharpe and Rossiter (2002) nor Vermaes et al. (2011) found a significant effect for gender. When investigating the quality of life between siblings of children with CF, Type 1 diabetes, cancer and congenital heart disease

(CHD) Havermans et al. (2015) found no difference between the health conditions for gender. However when they combined illness groups, they found girls scored lower than boys on the Child Health Questionnaire mental domain.

While these findings on the effect of gender on sibling adjustment are inconclusive there is enough evidence to suggest the impact on female siblings may be greater than the impact on male siblings, further investigation is needed.

2.2.6 Sibling relationships

There is some evidence the sibling relationship is a moderator in the impact of a chronic illness, although very little research has been carried out in this area. Sloper (2000) found decreases in intimacy and companionship when one sibling is diagnosed with cancer; and Chesler et al., (1992) found the healthy sibling reported a loss of status compared to the ill sibling. Vogt (2000) studied the sibling relationship between children with Type 1 diabetes and their well siblings (n=53). Findings showed the warmth factor of the Sibling Relationship Questionnaire was positively correlated with coping for both the affected children and their well siblings, and negatively correlated with the conflict factor (Vogt, 2000).

In contrast, surprising findings by Labay and Walco, (2004) found evidence that a caring, warm sibling relationship was correlated with greater adjustment problems and decreased social competence for both siblings. The authors suggested this effect could be due to closer, more intimate relationships' amplifying stressors and leading to greater vulnerability to periods of separation and change, as well as a heightened impact of exposure to the suffering of the ill child (Labay & Walco, 2004).

Investigations of sibling warmth in relation to the adjustment of siblings have shown different outcomes for different health conditions. For example, poorer outcomes were found in siblings of children with pervasive developmental disorders, whereas siblings of children

with Spina Bifida, Down Syndrome and Attention Deficit Hyperactivity Disorder have shown non-significant or improved outcomes (Riddick, 2013). Hence, the effect of sibling warmth may vary depending on the health condition.

The lack of conclusive findings on sibling relationships highlights the need for further investigation in this area as it is a variable that is likely to impact sibling adjustment.

2.2.7 Individual coping style

The impact of a chronic condition on siblings has been shown to be mediated to some degree by individual coping style. Fletes (2016) investigated how coping skills are related to feelings of loneliness and symptoms of anxiety in healthy siblings' of children with cancer (n=62). The findings showed increased self-control was related to decreased anxiety and feelings of loneliness. This was congruent with previous research by Hamama, Ronen, and Rahav (2008) and indicates a strong need for support services that promote self-control and other coping skills. Coping strategies such as optimism for the future, gathering information about the illness, contributing to the family, and problem minimisation are associated with fewer adjustment problems in siblings and require further exploration (Deavin et al., 2018; Houtzager et al., 2004; Nolbris, Enskar, & Hellstrom, 2007; Prchal & Landolt, 2009; Woodgate, 2006).

Siblings have described the process of information accrual, over time, leading to changing attitudes about the disease and its impacts. This improved insight led to greater understanding of the illness and empathy for their siblings experiences. Siblings in a recent meta-synthesis expressed that a lack of information, particularly around symptom management, could lead to fear (Deavin et al., 2018). The findings in this meta-synthesis suggested siblings would benefit from information about the illness and it's impacts closer to the time of diagnosis, which may help them build empathy and understanding and help them

accept the situation (Deavin et al., 2018). This supports earlier research which showed a strong association between sibling knowledge, positive sibling attitude toward the illness, and sibling behaviour; however it is important that the information siblings are provided is age appropriate (Williams et al, 2002).

Hamama et al., (2008) found when self-control and self-efficacy were greater in siblings, their psychosomatic symptoms and anxiety were milder. Self-control helps change the perception of a difficult situation, leading to a shift from helplessness to resourcefulness (Meichenbaum, 1995). Resourcefulness encompasses beliefs, skills and behaviour which an individual develops to cope with disruptive situations and is linked with greater feelings of control (Rosenbaum, 2000). When a child feels confident in their ability to cope with adverse circumstances (such as a siblings chronic illness), they are more likely to implement more active coping patterns (McKernon et al., 2001).

As with any significant life experience, individual coping styles are likely to impact on sibling adjustment following a brother or sister's diagnosis with a serious chronic health condition. Further investigations into which coping styles are protective factors for siblings are important to identify in order to effectively inform the development of support services.

2.2.8 Health condition variables

Within the field of sibling literature, there have been studies that investigate the psychosocial adjustment and needs of healthy siblings of children with specific diseases, as well as studies that take a non-categorical approach by grouping together a range of chronic conditions.

The justification for a non-categorical 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 (Fanos et al., 2005; Gannoni & Shute, 2010; Lavigne & Faier-Routman, 1992; Stein & Jessop, 1982; Van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004; Young, Dixon-Woods, Findlay, & Heney, 2002). Pless and Pinkerton (1976), support taking the non-categorical approach. They argue that the chronicity of the illness, and the impact it has on the ill child's siblings and parents, is more significant than the effects of a specific illness, due to the common problems of all chronic illnesses.

This perspective is underpinned by the understanding that chronically unwell children face common life experiences based on the generic dimensions of their illness. If their illness is potentially life threatening and characterised by intermittent crises, this influences the intensity and frequency of treatment; thus, this has more impact on their experiences than the specific characteristics of the illness they have (Stein & Jessop, 1982). Furthermore, because some kinds of serious chronic health condition (such as cancer) have so many variations (depending on the type and prognosis, as well as variations in treatment), the experiences of siblings of children with cancer are very individual.

A benefit of the non-categorical approach is that it facilitates the development of services that meet the needs of a broad range of siblings, as opposed to services tailored to individual chronic health conditions. In a study on siblings of children with cancer and cystic fibrosis, similarities between the two health groups were found which supported the argument for Stein and Jessop's (1982) non-categorical approach. Regardless of the diagnosis, parent respondents reported the negative manifestations in siblings included upset/anger/resentment; worry/fear/anxiety; loneliness/sadness/depression; and negative behaviours. Academic problems, low self-esteem, and guilt were also reported for both groups (Williams et al., 2009).

A meta-analysis on siblings of children with chronic illness by Sharpe and Rossiter (2002), found no difference in siblings psychological functioning across a range of illness severity (based on mortality rates), but they did find siblings of children with illnesses that require more intensive daily treatment were more negatively affected. Sharpe and Rossiter (2002) called for further investigation into the impact of disease factors on the psychological functioning of siblings.

In contrast, other studies contradict the non-categorical approach arguing that illness-specific factors influence the healthy siblings experience (Dougherty, 2015; Long et al., 2015; Knecht, Helmers, & Metzing, 2015; Bellin & Kovacs, 2006; Vermaes et al., 2012). The rationale underpinning this theory is that family relationships, daily experiences, behavioural issues, and care needs differ between health conditions.

In 2012, Vermaes et al., conducted a meta-analysis which found that siblings of children with health conditions that were life-threatening and/or required intensive daily treatments had significantly more internalising and externalising problems. Another meta-review by Long et al., (2018), found siblings of children with cancer reported greater impact of the illness than siblings of children with other illnesses.

A study that compared the Quality of Life between siblings of children with Type 1 diabetes, cancer, cystic fibrosis and congenital heart disease (CHD) found siblings of children with cancer and CHD reported more internalising and behavioural problems than siblings of children with CF and diabetes (Havermans et al., 2015). The authors discussed the importance of taking into account illness specific factors such as hidden stressors, society's concept of the illness, uncertainty and perceived uncontrollability when assessing illness-specific impacts on siblings.

Another factor to consider in Aōtearoa/New Zealand, is that the number of children with the less common serious chronic health conditions is relatively small. For example, there

are approximately 187 young people between the ages of 0 and 17 years old living with cystic fibrosis in Aōtearoa/New Zealand (Cystic Fibrosis NZ, Personal communication, August 10, 2019). The resources available for the research and development of targeted support services for the CF sibling population are less than those available for the more common or well-known health conditions, such as cancer. Accordingly, it is important that research is carried out that investigates the extent of similarities of unmet needs across different types of chronic health conditions, to ensure efficient use of limited resources and to maximise the benefits to the sibling population.

2.3 Limitations

A critique of the empirical literature on the impact of chronic health conditions on siblings show conflicting results and several limitations; however, the majority of studies find adverse effects on a subset of siblings. Findings indicate that gender, age, time since diagnosis, parental differential treatment, sibling relationship, individual coping style, and health condition variables may impact on sibling adjustment and should be further investigated in an Aōtearoa/New Zealand sibling population.

One significant limitation of the existing literature is the reliance on investigating siblings' experiences from the view of a parental proxy (Knecht, Hellmers & Metzing, 2015). Recent research shows there is a difference in sibling self-reports and parental proxy reports, with maternal overestimation of sibling coping being found repeatedly (Kobayashi et al., 2015; Sharpe & Rossiter, 2002; Upton, Lawford & Eiser, 2008).

Another limitation of the existing literature is the heterogeneous instruments used to measure sibling's psychosocial adjustment and wellbeing which makes it difficult to accurately compare results and draw conclusions.

2.4 Study rationale and aims

The first two chapters of this study have reviewed the literature and: described the negative impact of serious chronic health conditions on a subset of siblings; summarised the variables that affect sibling adjustment; and described the gap in existing support services available for siblings of children with serious chronic health conditions in Aotearoa/New Zealand.

Together, these topics point to the neccessity and urgency of developing targeted, needs-based support services for the sibling population. This conclusion is supported by the many studies that have called for an improvement in support services for siblings of children with chronic illness (Brennan et al., 2013; Gerhardt et al., 2015; Hallion, Taylor, & Roberts, 2018; Havermans et al., 2015; Long et al., 2017; Woodgate, 2005).

The initial stage of developing needs-based support services for siblings is conducting research that identifies their unmet needs. Thus, the goal of this research is to identify and explore the unmet needs of siblings of children with serious chronic health conditions in Aōtearoa/New Zealand. The aim is that the findings will contribute to the development of targeted needs-based psychosocial support services which will help protect and promote the health and wellbeing siblings.

Because the literature is inconclusive on whether a non-categorical versus illness-specific approach is beneficial in the context of childhood chronic illness, this study will investigate the unmet needs of three serious chronic health conditions that are broadly similar in severity, chronicity, impact on daily functioning, and likelihood of death; cancer; Type 1 diabetes; and cystic fibrosis. As resources are not infinite in Aōtearoa/New Zealand, it is our ethical responsibility to investigate the unmet needs of siblings of children with a range of serious health conditions to maximise the benefits for our vulnerable sibling population. This

information will be valuable in establishing whether services can be developed taking a non-categorical approach.

A significant proportion of existing international literature concerning siblings' experiences were conducted through proxy perspectives. These rely on an outside view of siblings experiences from parents, professionals and researchers rather than from the siblings' perspectives. To avoid this potentially distorted view, this research will focus on the perspective of siblings through direct report.

Literature on the association of distress levels and time since diagnosis show a positive correlation between higher levels of distress and closeness to diagnosis. Accordingly, this study will investigate the unmet needs of siblings during the time immediately following diagnosis from a retrospective perspective.

Because Aōtearoa/New Zealand and Australia both have government supported healthcare systems, are relatively sparsely populated, geographically close, and have cultural similarities, this study will compare the unmet needs of siblings of children with cancer in Aōtearoa/New Zealand with siblings in an Australian population. This will be valuable for understanding whether there are differences in the unmet needs of siblings in Aōtearoa/New Zealand and Australia, and whether research on siblings can generalise between the two countries.

The influence of culture on the impact of serious chronic illness on siblings means we cannot be sure of the representativeness of international literature for an Aōtearoa/ New Zealand population. While no known studies have investigated the impact of culture on siblings experiences (specifically western compared to non-western cultures), in alignment with the three principles of the Treaty of Waitangi, this study will also investigate the impact of serious chronic illness on siblings who identify as Māori (the indigenous people of Aōtearoa/New Zealand).

Research aims:

- Identify whether siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aotearoa have unmet needs, and if so, identify what these needs are.
- Identify the similarities and differences in unmet needs between siblings of children with cancer, cystic fibrosis, and diabetes in New Zealand/Aotearoa.
- Identify whether there are any differences in unmet needs between female siblings and male siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aotearoa and if so, identify what these needs are.
- Identify whether there are any differences in unmet needs between older siblings (>12 years old) and younger siblings (≤12 years old) of children with cancer, cystic fibrosis and diabetes in New Zealand/Aotearoa and if so, identify what these needs are.
- Identify if there are any differences in unmet needs between Māori and non-Māori siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aotearoa and if so, identify what these needs are.
- Compare the mean percentage of unmet needs of siblings of children with cancer in New Zealand/Aotearoa with siblings of children with cancer in Australia.

Chapter Three – Methodology

Chapter overview

This chapter will describe the theoretical orientation of the current study, the survey design, and the procedures used to advertise the survey, recruit participants, and collect data.

3.1 Theoretical orientation

3.1.1 Positivist and post-positivist paradigms

Research is a methodological process that investigates a phenomenom, addresses an issue, answers a particular question, and contributes to existing knowledge (Shah & Al-Bargi, 2013). The research process has three major dimensions: ontology, epistemology, and methodology. Ontological beliefs are concerned with the nature of reality and what can be known; epistemological beliefs are concerned with the theory of knowledge; and methodological beliefs are concerned with how knowledge is discovered and analysed in a systematic way (TerreBlanche & Durrheim, 1999). A research paradigm is a system of all-encompassing practice and thinking that defines the nature of enquiry along these three dimensions (Khaldi, 2017). The term paradigm is described by Kuhn (1977), as a set of values, beliefs, and assumptions that a particular group of researchers share in regards to the nature and conduct of research. Thus, a paradigm is a comprehensive belief system, pattern, structure or framework that guides research in a given field (Willis, 2007).

The positivist paradigm is considered the ‘scentific method’ and is related to schools of thought such as naturalism, behaviouralism, empiricism, deductionism, and scientism. It reflects the philosophy that cause determines effects or outcomes (Creswell, 2003). Positivism maintains that knowledge is based on sensory experience that only observation or experiment can accomplish (Cohen, Manion, & Morrison, 2007). Positivist researchers in the

social sciences apply the scientific method used in natural sciences to social phenomenom with the belief that the social world can be objectively understood and be independent of the researcher.

Post-positivism emerged as a cristicism of positivism. Similarities between the two paradigms include an emphasis on logical reasoning, precision, and attention to evidence; however there are key differences. Post-positivists do not limit science to what can be directly perceived and they do not attempt to gain a definitive knowledge of reality in the form of universal truths. While positivists view the researcher as value free and neutral, post-positivists believe the researchers' experience, culture, knowledge, and values can influence observations (Hakansson, 2013; Schumacher & Gortner, 1992). This is reflected in the post-positivists acceptance that all observation is fallible, and has error, and all theory is revisable (Trochim, 2006). While post-positivists reject the idea that any individual can see the world objectively due to bias, they believe we can approach obectivity through triangulation, which involves multiple research approaches, and through critiquing each others work (Trochim, 2006). The current study is underpinned by the post-positivist paradigm, and uses triangulation through the collection of both quantitative and qualitative data.

3.1.2 Research methodology

Quantitative and qualitative research

While quantitative methods have traditionally been underpinned by positivist principles, they can also be valuable in post-positivist research depending on the questions that are being asked. The values of quantitative research include the ability to examine patterns across many cases, being used as a starting point for a qualitative study, showing that a problem is statistically significant, and providing broad familiarity with cases (Ryan, 2006). Quantitative research assumes data can be collected through measurement, analysed using

numerical comparisons, and reported through statistical analyses. It is concerned with discovering facts about social phenomena (Hakansson, 2013).

In contrast, qualitative data is concerned with understanding the participant's perspective. Data is collected through participant observation and interviews, is analysed by themes in the data, and is reported in the language of the participant. Using an inductive approach, qualitative researchers aim to develop indepth understandings of how people perceive their social realities (Hakansson, 2013).

Descriptive research

The descriptive research method is a type of non-experimental research which can use either qualitative or quantitative methods. Non-experimental research is systematic empirical inquiry in which the researcher does not control the independent variables either because their manifestations have already occurred or they are not able to be manipulated (Kerlinger, 1986). Descriptive research studies a phenomenon and aims to describe characteristics, meanings, and/or relationships in data, but not the causes. It often uses surveys or case studies to produce representations of persons, events, or situations (Hakansson, 2013). The descriptive survey method is interested in the characteristics of both individuals and whole samples. It employs the scientific method through the initial data collection (in language or numerical form), analysing and interpreting the data, and arriving at generalisations and/or predictions (Salaria, 2012).

The current study used quantitative and qualitative data collection methods within a descriptive research methodology to answer the research questions. Non-experimental descriptive research was dictated by the nature of the research question, as the aim was not to establish a causal relationship between variables; rather it was to investigate an experience.

Survey research

Survey research is used to assess needs, and set goals to determine whether objectives have been met, establish baselines, and describe what exists (Isaac & Michael, 1995). Online survey research has grown in popularity with the increase in the use of the internet and social media. It is an effective research method for a number of reasons, including the ability to reach a large sample of the population, and the relative ease in obtaining demographic data that describe the composition of the sample. Other benefits of internet-based research is the capability of complete anonymity, reduced bias in response to sensitive topics, minimal costs; and rapid convenient input for respondents who can either be sampled or self-selected (Lazar & Preece, 1999; Rhodes, Bowie, & Hergenrather, 2003).

Cross-sectional survey research is the most appropriate type of descriptive research for this research project as it can describe specific aspects of a given population, and the data collected from a sample of the population can be generalized back to that population. However, it should be noted that generalisations from survey research provide estimates, rather than true measurements, of the given population (Salant & Dillman, 1994).

3.1.3 Research questions

The current study aimed to identify and compare the unmet needs of siblings of children with cancer, and serious chronic health conditions in an Aōtearoa/New Zealand sample. Informed by a thorough review of the literature, the three serious chronic health conditions that were selected for this study were cancer, Type 1 diabetes, and cystic fibrosis. The questions being asked in this research were:

- Do siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa have unmet needs, and if so, what are they?

- What are the similarities and differences in unmet needs between siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa?
- Are there differences in the unmet needs of female siblings and male siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa?
- Are there differences in the unmet needs of older siblings (>12 years old) and younger siblings (≤12 years old) of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa?
- Are there differences in the unmet needs of Māori and non-Māori siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa?
- Are there differences in the unmet needs of siblings of children with cancer in New Zealand/Aōtearoa and siblings of children with cancer in Australia?

3.2 Method

3.2.1 Participants

Criteria

To determine eligibility for the current study - the Sibling Needs Survey - siblings were asked to confirm they met the following criteria: be age 16 years or over; have a sibling, or someone who was like a sibling to them (cousin, whāngai) who was diagnosed with cancer, cystic fibrosis, or Type 1 diabetes one year ago or longer; and that they were living with their sibling/whānau member when they were diagnosed.

The minimum age of sixteen years was aimed at firstly, protecting the younger and more vulnerable members of the sibling population (who may not fully understand the process of consent), while allowing older siblings the autonomy to complete the survey without the need for parental consent. Requiring the diagnosis to have been made twelve months ago or longer reduced the risk of siblings being in the initial stage of acute grief

which could have increased their vulnerability and the risk of harm from completing the survey. Furthermore, in line with the research findings above, siblings were able to reflect (with the passage of time) on their experiences. The requirement that the respondent lived with their family/whānau when their sibling was diagnosed was necessary because this research was investigating the unmet needs of siblings who were living with their affected brother or sister.

Recruitment

The researcher approached the following organisations by email to invite them to take part in this research; CanTeen NZ; Child Cancer Foundation; Cystic Fibrosis NZ; and Diabetes NZ (Appendix A). All organisations agreed to advertise the Sibling Needs Survey on their social media pages (Appendix B). Facebook has previously been found to be a useful mechanism for recruiting young adult participants and the use of online social media is convenient and flexible. In addition, CanTeen NZ and Cystic Fibrosis NZ agreed to advertise the survey and provided a link to the Sibling Needs Survey on their websites; and Cystic Fibrosis NZ also included the survey link in their monthly eletter 'Panui". All organisations independently emailed their own employees introducing the research and asking them for support.

During the recruitment phase, an invitation to speak about the current study on the Nine to Noon programme (Radio New Zealand) gave the researcher and supervisor an opportunity to discuss this research on air and reach a broader audience. Following the interview, the interview link became available on the Radio New Zealand website, and it was posted to all of the supporting organisations' Facebook pages. The researcher then contacted field workers from Cystic Fibrosis NZ and Diabetes NZ via email asking them to forward an

email advertising the survey to families with siblings. Rare Disorders NZ also posted the Sibling Needs advert on their Facebook page.

The Sibling Needs Survey advertisement was accompanied by a link, which when selected, opened a new window with the Information Sheet (Appendix C). The Information Sheet introduced the research and described: the criteria; research procedures; possible risks and supports; data management; participants' rights; and who to contact for more information about the study. The information sheet was followed by a respondent consent page which required respondents to select 'Yes' before beginning the survey.

3.2.2 Measure

Permission was given by CanTeen Australia for the current study to adapt the Sibling Cancer Needs Instrument (SCNI) to an online survey design for use in Aōtearoa/New Zealand, and to broaden it to include serious chronic health conditions.

Sibling Cancer Needs Instrument (SCNI)

The SCNI was developed to measure the psychosocial unmet needs of young people who have a brother or sister 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 previously been adapted for young people impacted by parental cancer called the Offspring Cancer Needs Instrument (OCNI; Patterson et al., 2014a). Like the SCNI, the OCNI has sound psychometric properties and is beneficial in identifying the unmet needs in this population to assist with targeted support services (Patterson et al., 2014a). Both the SCNI and the OCNI have been successfully translated for a Persian-speaking population (Masoudifar et al., 2018). This is significant because the culture and health provision similarities between New Zealand and Australia are much stronger than

those between Iran and Australia which suggests the items would retain their validity in an Aōtearoa/New Zealand population.

Psychometric properties of the SCNI

CanTeen Australia own the copyright for this measure. The developers of the SCNI recruited participants using three approaches: posters at three hospitals around Sydney directing people to the online survey; paper copies of the survey were sent from CanTeen; and siblings of patient members of CanTeen Australia were invited to participate via their brothers and sisters. During the first phase of development the instrument consisted of 80 items across 10 domains; this was reduced to 73 items after an exploratory factor analysis (Patterson et al., 2011).

In 2014, the psychometric properties of the instrument were re-evaluated in a study of 106 adolescent and young adult participants; following validity measures and factor analysis, the instrument was reduced to 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 dichotomized. 'No need' and 'low need' are categorized as 'met' needs, and 'moderate need' and 'high need' are categorized as 'unmet' needs.

Content validity was established for the SCNI through a focus group, interviews, a literature review, pilot work, a survey with professionals working with this population, as well as asking siblings whether they had any additional unmet needs on completion of the

survey. Construct validity was assessed through a positive correlation between the number of unmet needs and psychological distress as measured using the Kessler 10 (Kessler et al., 2003). All correlations were moderate to large and statistically significant. Internal consistency was good to excellent with a Cronbach's alpha for each domain ranging from 0.78 – 0.94 and 0.98 for the total instrument. Good test-retest reliability was found with a retest coefficient of 0.88 (Patterson et al., 2014b).

The Persian version of the SCNI applied confirmatory factor analysis which approved construct validity. Cronbach's alpha ranged from 0.80 to 0.92 for each domain and 0.97 for the total instrument. The authors approved the applicability of the Persian version of the SCNI for measuring the unmet needs of adolescents in Iran (Masoudifar et al., 2018).

Adaptation of the SCNI to the Sibling Needs Survey

The adaptation of the SCNI to the Sibling Needs Survey involved the following changes:

1. The replacement of the word 'sibling' with the words 'sibling/whānau member'. A key consideration in the development of the Sibling Needs Survey was to ensure the principles of the Treaty of Waitangi were applied to this research. Dr Simon Bennett, Consultant Clinical Psychologist/Kaimatai Hinengaro Matua: Māori, was consulted for advice (Appendix C). Indepth consideration was given to the advertisement and the survey to ensure the language used would not marginalise NZ Māori participation due to cultural nuances in the way that sibling relationships are defined in Te Ao Māori. Because Māori families are less likely to live within a nuclear family structure (and more likely to live in a home with multiple generations, cousins, and whāngai), this has also been reflected in the language used in both the advertisement and the survey (Edwards, McCreanor &

Moewaka-Barnes, 2007). For example, the first domain of the SCNI reads "Information about my sibling's cancer...", and the adapted Sibling Needs Survey reads "Information about my sibling/whānau member's illness...". Every domain heading and question was adapted in a similar style.

2. The question: "Which illness was your sibling/whānau member diagnosed with?" was included at the beginning of the survey. This was followed by a dropdown menu with the options of cystic fibrosis, cancer, and Type 1 diabetes which enabled survey responses to be analysed within the appropriate health condition. Additionally, the word 'cancer' was replaced throughout the survey with the word 'illness';
3. Because the SCNI was developed to be administered *at the time immediately following* a siblings diagnosis, the language in the Sibling Needs Survey was altered to reflect the retrospective nature of the Sibling Needs Survey (sibling/whānau members needed to be one year post diagnosis);
4. The inclusion of an open-ended question at the end of the survey allowed siblings to describe how their needs would have best been met (in their own words), providing the researchers with additional insights into siblings' experiences. Additionally, this question provided valuable feedback to contributing organisations as to how siblings of children with serious health conditions can be better supported.

Sibling Needs Survey

The survey consisted of seven demographic questions including: What is your gender? (options included: male, female, or other); Do you identify as Māori? (options included yes or no); What illness was your sibling/whānau member diagnosed with? (options

included: cancer; cystic fibrosis, and Type 1 diabetes); What is your current age?; What age was your sibling/whānau member at the time they were diagnosed?; What age were you at the time of your sibling/whānau members diagnosis?; and What region did you live in at the time of your sibling/whānau member's diagnosis? (options included: Northland - Te Tai Tokerau; Auckland – Tāmaki makau rau; Waikato, Bay of Plenty - Te Moana a Toi; Gisborne - Te Tai Rāwhiti; Hawkes Bay - Te Matau a Māui; Taranaki, Manawatū – Whanganui; Wellington – Te Whanga nui a Tara; Tasman – Te Tai o Aorere, Nelson – Whakatū; Marlborough – Te Tauihu o te waka; West Coast – Te Tai Poutini, Canterbury – Waitaha; Otago – Otākou; and Southland – Murihiku).

Following the demographic questions, 45 items were adapted from the SCNI across the same seven domains. These included: Information about my sibling/whānau member's illness (8 items); 'Time out' and recreation (6 items); Practical assistance (3 items); Support from friends and other young people (8 items); Dealing with feelings about my sibling/whānau member's illness (8 items); Understanding from family (5 items); and My relationship with my ill sibling/whānau member (7 items). This section of the survey measured the number, and type, of unmet needs siblings experienced at the time of their brother or sister's cancer diagnosis. Under the heading of each of the seven domains was the statement "I needed" followed by each question in that domain for which participants selected one of the following options on a likert-type scale: 1 (no need); 2 (low need); 3 (moderate need); or 4 (strong need).

These items were followed by the final question in the survey which was the open-ended question.

On completion of the survey respondents selected the 'submit' button and the survey was electronically collected by Qualtrics software. Qualtrics online survey software was used for the development and data collection of the online survey (Qualtrics, 2014). Qualtrics was

identified as the premium survey software due to it's options for question structure, mobile device compatibility, easy integration with social media platforms, and high security.

3.2.3 Data Analysis

Survey data was was exported from Qualtrics and analysed using Statistical Package for the Social Sciences software (SPSS V25). Descriptive statistics were presented for the mean percentage of unmet needs for each domain, the mean percentage of unmet needs for each item in the survey, and the mean percentage of unmet needs for each health condition. A Posthoc comparison of the three health conditions was presented (with Bonferroni correction for multiple comparisons). Mean percentages of unmet needs and independent groups t-tests were presented for comparisons between the unmet needs between Māori and non-Māori, females and males, and children >12 years old and ≤ 12 years old (without Bonferroni correction for multiple comparisons). A comparison was also made between siblings of children with cancer in Aōtearoa/New Zealand and Australia.

3.3 Ethical considerations

Full ethical approval was obtained from the Massey University Human Ethics Committee prior to participant recruitment.

Support

Considerable thought was given as to whether a low risk ethics application or a full ethics application should be submitted for the current study. While it was unlikely participants would be harmed by the online survey, there was the possibility of discomfort being caused due to a participant's close connection with their affected sibling. To ameliorate this risk, participant criteria required the unwell sibling be a minimum of twelve months post

diagnosis. However, to ensure the safety of our young participants and approach this research in a way that was sensitive and respectful of their experiences, a full ethics application was sought and approved. When the survey was submitted a 'thank you' page was displayed. This page gave options of support services should they be needed. Participants were informed in the information sheet they were welcome to miss out a particular question or stop participating at any time (see Appendix C).

Data storage, consent and confidentiality

Following the Information page, a Respondent Consent page was displayed. Participants had to agree to the statement 'I have read and understood the information sheet for this study and consent to the collection of my responses' before beginning the survey.

Data responses were collected via the online survey using an existing Massey University School of Psychology Qualtrics licence. Data was stored in the Qualtrics cloud-based system under a secure user/password system. All downloaded data files were stored on a local password protected computer.

The survey was anonymised and no IP address, names, or email addresses were stored with the data responses. The data collected was used solely for research purposes. The survey company, Qualtrics, published a security statement that states they protect customer data using the best industry standards.

Chapter Four – Results

Chapter overview

This chapter describes the results of this research. The specific aims of this survey were to identify the unmet needs of siblings of children with cancer, cystic fibrosis, and Type 1 diabetes in an Aōtearoa/New Zealand sample. Comparisons were made between the three health conditions, genders, age groups, Māori and non-Māori, and Australian and New Zealand samples. Descriptive statistics are presented for each domain of unmet needs and inferential statistics are applied to the data. The Statistical Package for the Social Sciences software (SPSS V25) was utilized for the analysis of data.

Throughout this chapter, the seven domains in the Sibling Needs Survey, will be referred to in an abbreviated form as outlined below in Table 2.

Table 2

Abbreviated domain names of the Sibling Needs Survey

Domain	**No. of items**	**Abbreviation**	**Concerns the Need:**
Information about my sibling/whānau member's health condition	8	INFO	For information about their sibling's treatment and side effects presented in an easily understood, age appropriate format
"Time out" and recreation	6	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
Practical assistance	3	PRAC	For support with daily living/practical issues including household chores, work/education-related support and connection with relevant support services
Dealing with feelings	8	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	8	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	5	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/whanau member	7	RSIB	For help with issues involving their relationship with their ill sibling and navigating changes in that relationship

4.1 Quantitative Results

4.1.1 Sample overview

Data screening

Data was checked for missing values prior to analysis. For the purpose of analysing results, when a domain was missing responses for over half of the items, that domain was discounted for that respondent. When a domain was missing less than half of the items, the domain total was recorded as the mean score of the completed questions in that domain. This means the sample size varied depending on the particular analysis used.

Sample characteristics

In total, the final sample included 204 respondents which consisted of 84 siblings of children with cancer, 47 siblings of children with cystic fibrosis, and 73 siblings of children with Type 1 diabetes. Of the total sample, 26 respondents identified as Māori and 177 identified as non-Māori. One quarter of the respondents were male (n=50), three quarters

female (*n*=150), and one respondent selected 'other' for gender (three respondents did not specify gender). The average age of respondents was 10.9 years (*SD*=6.34).

A subset of the final sample consisted of respondents who provided enough item level responses to have valid data for *every* domain. This sample included 174 respondents. Of these, 68 were siblings of children with cancer, 40 were siblings of children with cystic fibrosis, and 66 were siblings of children with Type 1 diabetes. This subset was used for the analysis of the domains and is referred to as the Domain sample.

A further subset of the final sample consisted of respondents who answered *all* questions in the survey (*n*=153). This sample included 59 siblings of children with cancer, 35 siblings of children with cystic fibrosis, and 59 siblings of children with Type 1 diabetes. This data set was used to analyse numbers and proportions of siblings unmet needs.

For each analysis, the largest possible sample was used.

4.1.2 Regional response

All regions were represented in this study (see Fig 1). Twenty one percent of respondents (*n*=42) lived in the South Island at the time of their sibling/whānau member's diagnosis, compared to seventy nine percent of respondents who lived in the North Island (*n*=154). This is roughly proportional with the populations of the North and South Islands. The Auckland region had the highest number of respondents (*n*=39), followed by the Wellington region (*n*=30), then the Waikato (*n*=23), and Canterbury (*n*=17). The West Coast, Gisborne, Northland, and Marlborough regions had the lowest number of respondents (*n*=1,2, 3 & 4 respectively).

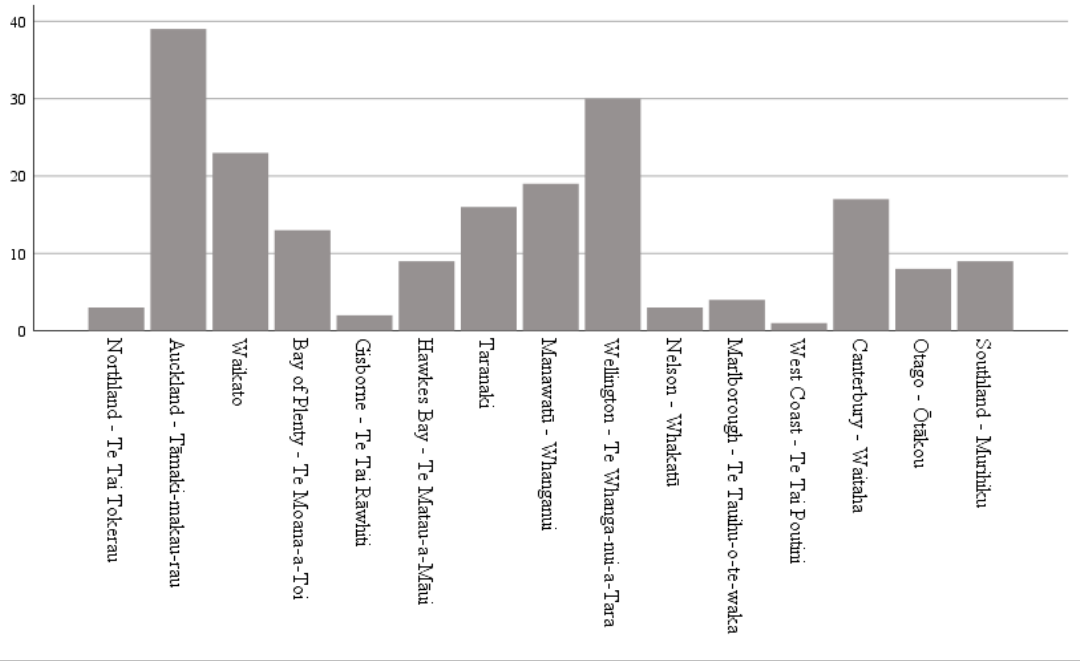

Figure 1. Number of responses from each region.

4.1.3 Health conditions

The highest number of respondents were siblings of children with cancer (*n*=84), followed by siblings of children with Type 1 Diabetes (*n*=73), and siblings of children with cystic fibrosis (*n* =47). To increase the number of respondents for the cystic fibrosis health condition, and because cystic fibrosis is commonly diagnosed at birth, siblings who were unborn at the time of their brother or sisters diagnosis were also included in this study. The effect of this adjustment was that siblings of children with cystic fibrosis were younger (on average) when their affected sibling was diagnosed (*M* = 4.2, *SD*=4.1) than siblings of children with cancer (*M* = 13.4, *SD*=6.0) or Type 1 diabetes (*M* = 12.0, *SD*=5.1).

4.2 Psychometric properties of the Sibling Needs Survey

Face and content validity

While the language was altered to reflect biculturalism in Aōtearoa/New Zealand, the Sibling Needs Survey used identical items to the SCNI. Face and content validity were established for the SCNI using quantitative findings which included previous literature, consultation with siblings, and staff who worked in the field. Feedback indicated all items were comprehensive and acceptable (Patterson, Miller & Visser, 2011). Furthermore, all items in the Sibling Needs Survey were endorsed by some of the respondents, indicating that all items were relevant for identifying the unmet needs of siblings of children with cancer, Type 1 diabetes, and cystic fibrosis.

Construct Validity

The following exploratory factor analysis is a rotated solution using the Varimax criterion carried out on the data collected from the Sibling Needs Survey. While the original SCNI used each domain as a separate factor, the decision to use three factors in the current study was based on a Parallel Analysis which indicated that three factors was what the collected data could support. The items in each domain in the current study, congregated together in the same area of the three factor solution as the original seven factor solution used in the SCNI (Patterson et al., 2014b). This indicates that the links intended by the developers of the SCNI were reflected in the way siblings in an Aōtearoa/New Zealand population reported the items. This supports the construct validity of the Sibling Needs Survey (see Figure 2).

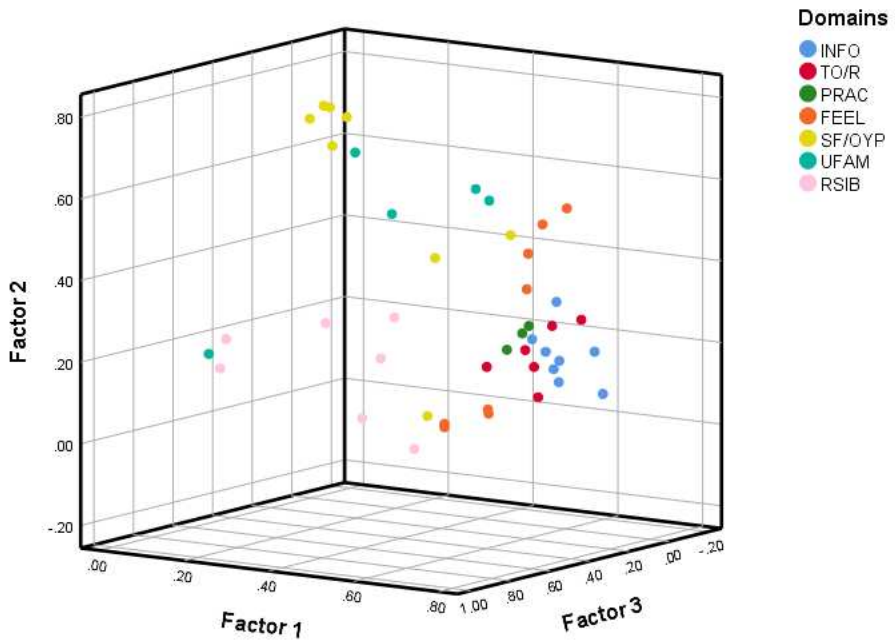

Figure 2. Exploratory factor analysis of Sibling Needs Survey results with three rotated factors. Items located by factor loadings and colour-coded according to domain.

Internal consistency

Cronbach's Alpha was measured for each domain and overall. Results showed good to excellent internal consistency for all of the domains: INFO (α = .86); TO/R (α =.88); SF/OYP (α =.86); PRAC (α =.92); FEEL (α = .94); RSIB (α = .92); and UFAM (α = .91). The overall Cronbachs Alpha showed the Sibling Needs survey had excellent internal consistency (α = .97).

4.3 Unmet needs in a New Zealand population

For this analysis on the numbers and proportions of unmet needs, the sample of siblings who answered all questions in the survey was analysed (n = 153). The average number of unmet needs was 26.01 (SD = 12.27, range 0-45). Almost all survey respondents endorsed at least one unmet need (98%), 86.3% of respondents endorsed ten or more unmet

needs, and 50% of respondents endorsed thirty two or more unmet needs. The average percentage of unmet needs was 57.8%.

For the analysis of unmet needs for each domain, the sample of respondents who provided enough answers to give a valid score for *any* domain was used. Results showed INFO had the highest mean percentage of unmet needs (65.3%), followed by FEEL (58.5%) and RSIB (58.1%). The PRAC domain was reported as having the lowest average percentage of unmet needs (38.0%). Table 3 shows the mean percentage of unmet needs for each domain.

Table 3

Mean percentage of unmet needs for each domain

Domain	Items	*n*	Mean	*SD*
INFO	8	182	0.653	0.295
FEEL	8	175	0.585	0.367
RSIB	7	174	0.581	0.364
SF/OYP	8	176	0.567	0.365
TO/R	6	177	0.529	0.358
UFAM	5	174	0.521	0.404
PRAC	3	177	0.380	0.347

An analysis of the mean percentage of unmet needs for each individual item in the survey shows the top four unmet needs were from the INFO domain (see Table 4). The most commonly endorsed unmet need (reported by 84.4% of siblings) was the need for 'Information about the impact the illness and it's treatment might have on my sibling/whānau member's life in the future'. The second most commonly endorsed unmet need (reported by 80% of siblings) was the need 'To be informed about my sibling/whānau member's condition – good or bad'. The third and fourth most commonly endorsed unmet needs (reported by

72.5% of siblings) were ‘To get information about the illness and its treatment in a way that I understood’ and ‘Information about what would happen when my sibling/whānau member came home following treatment’.

The least commonly endorsed unmet need (reported by 18.6% siblings) was item number 15 ‘Assistance with managing daily tasks’. This is less than half of the next least commonly endorsed unmet needs which were ‘To have 'time-out' from the extra duties that I had taken on at home’, and ‘To be linked in with a social support network with others who shared a similar experience’ (both reported by 42.9% of siblings).

Table 4

Mean percentage of unmet needs for each item (ranked from the most commonly endorsed unmet need to the least commonly endorsed unmet need).

Item ranking	Domain	Item Wording: I needed:	% Respondents Reporting Unmet Need
1	INFO	Information about the impact the illness and it's treatment might have on my sibling/whānau member's life in the future	84.4
2	INFO	To be informed about my sibling/whānau member's condition – good or bad	80.0
3	INFO	To get information about the illness and its treatment in a way that I understood	72.5
4	INFO	Information about what would happen when my sibling/whānau member came home following treatment	72.5
5	RSIB	To know ways of giving practical support to my sibling/whānau member	69.4
6	SF/OYP	To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty	68.8
7	RSIB	To know ways of giving emotional support to my sibling/whānau member	68.4

8	SF/OYP	To have someone close to discuss my feelings about my sibling/whānau member's illness	68.0
9	TO/R	To be able to have fun	67.4
10	FEEL	Help dealing with feelings about the possibility that my ill sibling/whānau member might die	67.4
11	SF/OYP	Support from my friends	66.5
12	RSIB	Help with understanding how my sibling/whānau member was feeling	64.9
13	FEEL	To have learnt ways of coping with the added stress placed on my family	64.3
14	FEEL	To be able to express how I felt about the illness without worrying about upsetting people	64.0
15	SF/OYP	To know how to talk to my friends about my experience with my sibling/whānau member's illness	60.2
16	INFO	Information about the side-effects of the treatment	59.9
17	SF/OYP	My friends to understand what I was going through	58.5
18	FEEL	Help dealing with sadness related to the illness	58.0
19	RSIB	To have 'time-out' with my sibling/whānau member away from 'the illness'	57.8
20	INFO	My teachers to have understood my situation and been more flexible	56.6
21	UFAM	To feel that I could openly talk with my family about the illness	55.7
22	FEEL	Help dealing with feelings of anxiety and feeling scared about the illness	54.9
23	UFAM	My family to acknowledge that this was happening to me too	54.6
24	INFO	To be spoken to by health professionals in a way that I understood	54.4
25	FEEL	Help dealing with feelings of frustration and anger about the illness	54.3
26	FEEL	Help dealing with feelings of guilt related to the illness	54.3
27	UFAM	To feel that I was as important and valued as my ill sibling/whānau member	54.0
28	TO/R	To have time to look after myself and focus on my own needs	53.7

29	TO/R	Somewhere to go when it got too hard to deal with my sibling/whānau member's illness	52.8
30	TO/R	To feel like a 'normal' young person, which it seemed I'd lost as a result of my sibling/whānau member's illness	52.4
31	FEEL	To have talked with a counsellor/psychologist/social worker	50.6
32	UFAM	To know my parent/s hadn't forgotten about me	50.6
33	TO/R	Help concentrating on tasks at school, university or work	49.7
34	RSIB	To feel included in my sibling/whānau member's illness experience	49.4
35	RSIB	To know how to talk to my sibling/whānau member about how I was feeling	48.9
36	RSIB	Help dealing with changes in my relationship with my sibling/whānau member	48.3
37	PRAC	Access to information about support services that were available to me	48.0
38	PRAC	People around me who helped out by taking over some of the things that my parent/s didn't have time to do anymore	47.2
39	UFAM	To be able to spend time with my parent/s - just me and them	46.6
40	SF/OYP	To feel supported by other young people who'd had a similar experience to my own	44.6
41	SF/OYP	The opportunity to spend time with other young people affected by their own sibling/whanau member's illness	44.3
42	INFO	To feel health care professionals included me in discussions about the illness	43.1
43	TO/R	To have 'time-out' from the extra duties that I had taken on at home	42.9
44	SF/OYP	To be linked in with a social support network with others who shared a similar experience	42.9
45	PRAC	Assistance with managing daily tasks	18.6

4.4 Unmet needs for each health condition

The health condition with the greatest average percentage of unmet needs was cancer, followed by cystic fibrosis, then Type 1 diabetes (see Figure 3).

Cancer

The mean number of unmet needs for siblings of children with cancer who completed every question in the survey (n =59) was 31.7 (SD = 10.0, range 0-45). Almost all survey respondents (98.3%) endorsed at least one unmet need and 98% respondents endorsed ten or more unmet needs (only one respondent reported fewer than 10 unmet needs).

An analysis of the domains for siblings in the cancer health condition (using the domain sample) show FEEL had the highest average percentage of unmet needs (74.4%), followed by INFO (70.3%), then TO/R (67.6%). The domain with the lowest average percentage of unmet needs was PRAC (49.0%).

Cystic Fibrosis

The mean number of unmet needs for siblings of children with CF who completed every question in the survey (n =35) was 24.8 (SD = 12.3, range 0-43). Almost all survey respondents (97.1%) endorsed at least one unmet need and 80% of respondents endorsed ten or more unmet needs.

An analysis of the domains for siblings in the CF health condition (using the domain sample) show RSIB had the highest average percentage of unmet needs (58.2%), followed by FEEL (58.1%), then INFO (57.6%). The domain with the lowest average percentage of unmet needs was PRAC (32.5%).

Type 1 Diabetes Mellitus

The mean number of unmet needs for siblings of children with Type 1 diabetes who completed every question in the survey (n =59) was 21.5 (SD = 12.5, range 0-45). Almost all survey respondents (98.3%) endorsed at least one unmet need and 78% of survey respondents endorsed ten or more unmet needs.

An analysis of the domains for siblings in the Type 1 diabetes health condition (using the domain sample) show INFO had the highest average percentage of unmet needs (64.4%), followed by RSIB (50.1%), then UFAM (49.4%). The domain with the lowest average percentage of unmet needs was PRAC (29.6%).

4.5 Comparison of health conditions for each domain

An analysis of the mean percentage of unmet needs for each domain using the Domain sample, showed cancer (n=68) had the highest average percentage of unmet needs in every domain with a total average of 66.3%, CF (n=40) had the second highest total average percentage of unmet needs (53.0%), and Type 1 diabetes (n=66) had a total average percentage of unmet needs of 48.6% (see Table 5).

The domains in which siblings of children with CF had a higher mean percentage of unmet needs than siblings of children with Type 1 diabetes were SF/OYP, PRAC, FEEL, and RSIB. Siblings of children with Type 1 diabetes reported higher average percentages of unmet needs than siblings of children with cystic fibrosis in INFO, TO/R, and UFAM (see Figure 3).

Overall, the domain with greatest difference in unmet needs between the three health conditions was FEEL (Cancer: 74.4%; CF: 58.1%; and diabetes: 43.2%). Cancer had significantly higher numbers of unmet needs than both CF and Type 1 diabetes in the TO/R and PRAC domains. The domains INFO, UFAM, RSIB and SF/OYP showed while cancer

had the highest level of unmet needs in each of these domains, there were strong similarities across the three health conditions.

Table 5

Mean percentage of unmet needs for each domain for each health condition

Domain	**Abbreviation**	**Concerns the Need:**	**Average % Needs Unmet**		
			Cancer (*n*=68)	**CF (*n*=40)**	**Diabetes (*n*=66)**
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	70.3	57.6	64.4
"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	67.6	42.2	44.2
Practical assistance	PRAC	For support with daily living/practical issues including household chores, work/education-related support and connection with relevant support services	49.0	32.5	29.6
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	74.4	58.1	43.2
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	66.5	57.4	46.0
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	57.1	48.0	49.4
Relationship with my ill sibling	RSIB	For help with issues involving their relationship with their ill sibling and navigating changes in that relationship	65.1	58.2	50.1
TOTAL			**66.3**	**53.0**	**48.6**

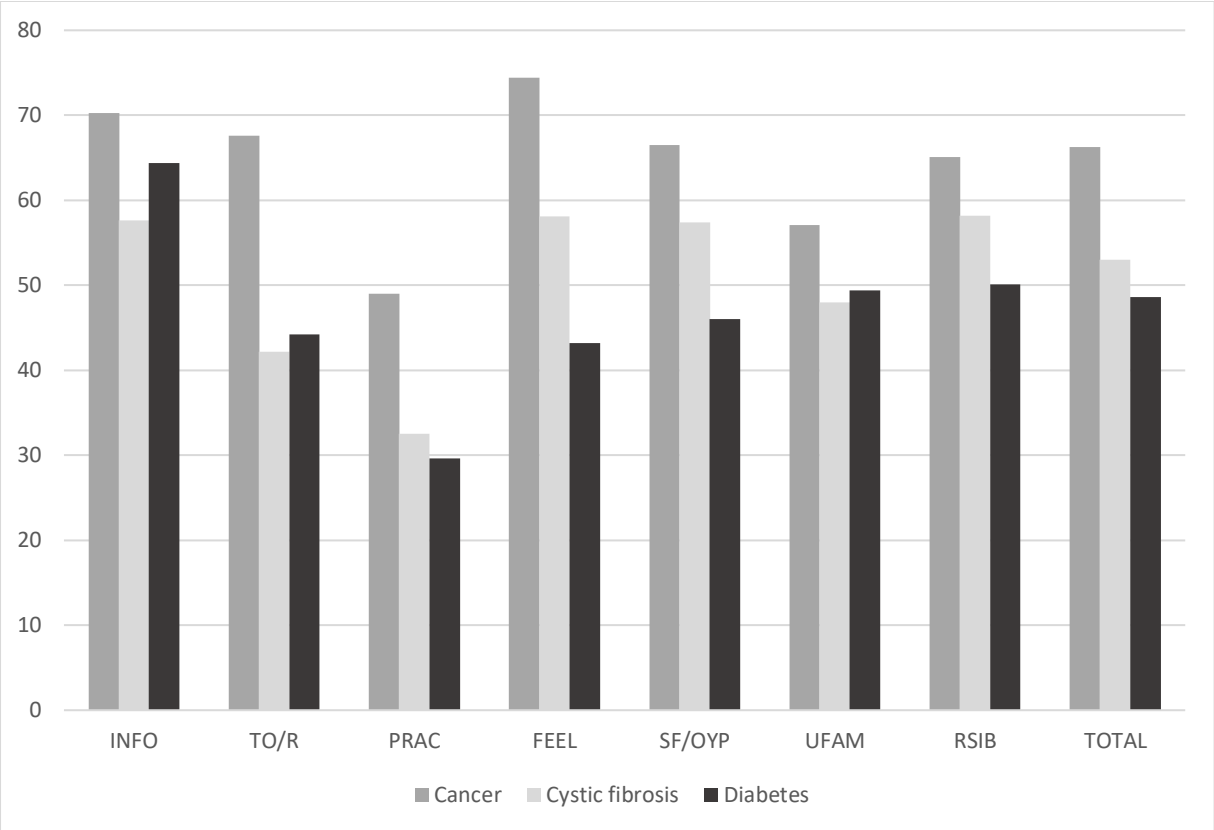

Figure 3. Mean percentage of unmet needs for each health condition

To compare the mean number of unmet needs between all seven domains for each health condition, the sample included any respondent who provided enough responses for a score within that domain. A one way ANOVA analysis was applied to the data using SPSS software (see Table 6). The hypothesis of equal means was disproven as results showed a significant difference in all domains except INFO, UFAM and RSIB which all had p values of >.05. A Posthoc comparison of health conditions (using Bonferroni correction for multiple comparisons to make the test more stringent) found a statistically significant difference between cancer and Type 1 diabetes in the PRAC, SF/OYP, and FEEL domains. A statistically significant difference also existed between cancer and both CF and Type 1 diabetes for the TO/R and the Total scores.

A MANOVA for all of the domains together (plus the total) with the health condition as the independent variable, gave very similar results to ANOVA, which looks at each domain in isolation.

Table 6

Multiple comparisons between health conditions (Bonferroni)

Domain	Health condition	Health condition	Mean Difference	Std. Error	Sig.	*95% CI of the diff.*	
						Lower	Upper
INFO	Cancer	Cystic Fibrosis	0.111	0.057	0.165	-0.028	0.249
		Diabetes	0.044	0.049	1.000	-0.076	0.163
	Cystic Fibrosis	Cancer	-0.111	0.057	0.165	-0.249	0.028
		Diabetes	-0.067	0.058	0.753	-0.207	0.073
	Diabetes	Cancer	-0.044	0.049	1.000	-0.163	0.076
		Cystic Fibrosis	0.067	0.058	0.753	-0.073	0.207
TO/R	Cancer	Cystic Fibrosis	.25119*	0.067	0.001	0.088	0.414
		Diabetes	.23007*	0.058	0.000	0.090	0.371
	Cystic Fibrosis	Cancer	-.25119*	0.067	0.001	-0.414	-0.088
		Diabetes	-0.021	0.068	1.000	-0.185	0.143
	Diabetes	Cancer	-.23007*	0.058	0.000	-0.371	-0.090
		Cystic Fibrosis	0.021	0.068	1.000	-0.143	0.185
PRAC	Cancer	Cystic Fibrosis	0.161	0.067	0.053	-0.001	0.323
		Diabetes	.18472*	0.058	0.005	0.045	0.324
	Cystic Fibrosis	Cancer	-0.161	0.067	0.053	-0.323	0.001
		Diabetes	0.024	0.068	1.000	-0.139	0.187
	Diabetes	Cancer	-.18472*	0.058	0.005	-0.324	-0.045
		Cystic Fibrosis	-0.024	0.068	1.000	-0.187	0.139
SF/OYP	Cancer	Cystic Fibrosis	0.095	0.071	0.543	-0.076	0.265
		Diabetes	.21139*	0.061	0.002	0.064	0.359
	Cystic Fibrosis	Cancer	-0.095	0.071	0.543	-0.265	0.076
		Diabetes	0.117	0.071	0.307	-0.055	0.288
	Diabetes	Cancer	-.21139*	0.061	0.002	-0.359	-0.064
		Cystic Fibrosis	-0.117	0.071	0.307	-0.288	0.055
FEEL	Cancer	Cystic Fibrosis	0.162	0.068	0.054	-0.002	0.327
		Diabetes	.31646*	0.059	0.000	0.175	0.458
	Cystic Fibrosis	Cancer	-0.162	0.068	0.054	-0.327	0.002
		Diabetes	0.154	0.068	0.075	-0.011	0.319
	Diabetes	Cancer	-.31646*	0.059	0.000	-0.458	-0.175

		Cystic Fibrosis	-0.154	0.068	0.075	-0.319	0.011
UFAM	Cancer	Cystic Fibrosis	0.091	0.081	0.787	-0.104	0.285
		Diabetes	0.077	0.070	0.822	-0.092	0.246
	Cystic Fibrosis	Cancer	-0.091	0.081	0.787	-0.285	0.104
		Diabetes	-0.014	0.081	1.000	-0.210	0.182
	Diabetes	Cancer	-0.077	0.070	0.822	-0.246	0.092
		Cystic Fibrosis	0.014	0.081	1.000	-0.182	0.210
RSIB	Cancer	Cystic Fibrosis	0.069	0.072	1.000	-0.105	0.243
		Diabetes	0.143	0.062	0.070	-0.008	0.293
	Cystic Fibrosis	Cancer	-0.069	0.072	1.000	-0.243	0.105
		Diabetes	0.073	0.072	0.931	-0.101	0.248
	Diabetes	Cancer	-0.143	0.062	0.070	-0.293	0.008
		Cystic Fibrosis	-0.073	0.072	0.931	-0.248	0.101
TOTAL	Cancer	Cystic Fibrosis	.13287*	0.053	0.042	0.004	0.262
		Diabetes	.17739*	0.046	0.001	0.065	0.290
	Cystic Fibrosis	Cancer	-.13287*	0.053	0.042	-0.262	-0.004
		Diabetes	0.045	0.054	1.000	-0.086	0.175
	Diabetes	Cancer	-.17739*	0.046	0.001	-0.290	-0.065
		Cystic Fibrosis	-0.045	0.054	1.000	-0.175	0.086

* The mean difference is significant at the 0.05 level.

4.6 Comparison of unmet needs between age categories

Of the 174 respondents who provided their own age when their sibling was diagnosed and sufficient data in at least one domain, 98 respondents were over the age of twelve when their sibling was diagnosed and 76 respondents were age twelve or under (M = 10.9, SD = 6.3). Considering the age distribution and developmental stage of respondents in this sample, twelve years old was a reasonable cut-off point to use, resulting in approximately equal division between the two age categories.

Results for each domain showed the mean percentage of unmet needs were higher for the older age group (>12) in all seven domains as well as the Total score (see Table 7). While an independent groups t-test detected no significant difference between the two age

categories, there was a clear pattern of responses. The greatest differences found were in the FEEL domain followed by the UFAM domain (see Table 8).

Table 7

Mean percentage of unmet needs for age categories

Domain	Age	N	Mean	*SD*	Std. Error Mean
INFO	>12	103	0.668	0.275	0.027
	≤12	71	0.654	0.325	0.039
TO/R	>12	101	0.570	0.334	0.033
	≤12	68	0.502	0.383	0.046
PRAC	>12	101	0.391	0.350	0.035
	≤12	68	0.373	0.348	0.042
SF/OYP	>12	100	0.598	0.341	0.034
	≤12	68	0.542	0.390	0.047
FEEL	>12	99	0.634	0.358	0.036
	≤12	68	0.549	0.372	0.045
UFAM	>12	98	0.553	0.420	0.042
	≤12	68	0.482	0.385	0.047
RSIB	>12	98	0.596	0.360	0.036
	≤12	68	0.563	0.373	0.045
TOTAL	>12	98	0.596	0.272	0.027
	≤12	68	0.541	0.286	0.035

Table 8

Equality of Means between age categories (t-test)

Domain	t	df	Sig. (2-tailed)	M	Std. Error	*95% CI of the diff.*	
						Lower	*Upper*
INFO	0.302	172	0.763	0.014	0.046	-0.076	0.104
TO/R	1.226	167	0.222	0.068	0.056	-0.042	0.178
PRAC	0.338	167	0.735	0.019	0.055	-0.090	0.127
SF/OYP	0.983	166	0.327	0.056	0.057	-0.056	0.168
FEEL	1.475	165	0.142	0.085	0.057	-0.029	0.198
UFAM	1.103	164	0.272	0.071	0.064	-0.056	0.197
RSIB	0.576	164	0.566	0.033	0.058	-0.081	0.147
TOTAL	1.243	164	0.216	0.054	0.044	-0.032	0.141

4.7 Comparison of unmet needs between males and females

The mean percentage of unmet needs for males (*n*=43) was 44.0% (*SD* =.26). In comparison to this, the mean percentage of unmet needs for females (*n*=128) was 60.1% (*SD*= .27). An analysis of the results show the mean percentage of unmet needs for females is higher than males for each of the seven domains (see Table 9). The domain which shows the greatest difference between means was FEEL, and the domain with the least difference between means was RSIB. An independent groups t-test shows evidence there is a significant difference between means in the following domains: TO/R (p=.001), FEEL (p<.001), SF/OYP (p=.002), and UFAM (p=.028; see Table 10). The t-test also showed a significant difference between the Total mean percentage scores between males and females (p=.001) with females reporting a higher percentage of unmet needs.

Table 9

Mean percentage of unmet needs for gender categories

Domain	Gender	N	Mean	*SD*	Std. Error Mean

INFO	Male	44	0.579	0.283	0.043
	Female	135	0.676	0.297	0.026
TO/R	Male	43	0.372	0.352	0.054
	Female	131	0.572	0.347	0.030
PRAC	Male	43	0.302	0.324	0.049
	Female	131	0.401	0.352	0.031
SF/OYP	Male	43	0.409	0.348	0.053
	Female	130	0.610	0.357	0.031
FEEL	Male	43	0.381	0.341	0.052
	Female	129	0.644	0.351	0.031
UFAM	Male	43	0.400	0.373	0.057
	Female	128	0.556	0.407	0.036
RSIB	Male	43	0.535	0.364	0.055
	Female	128	0.588	0.364	0.032
TOTAL	Male	43	0.440	0.257	0.039
	Female	128	0.601	0.274	0.024

Table 10

Equality of Means between females and males (t-test)

Domain	t	df	Sig. (2-tailed)	M	Std. Error	*95% CI of the dif.*	
						Lower	*Upper*
INFO	-1.895	177	.060	-0.097	0.051	-0.197	0.004
TO/R	-3.272	172	.001	-0.200	0.061	-0.321	-0.079
PRAC	-1.622	172	.107	-0.098	0.061	-0.218	0.021
SF/OYP	-3.218	171	.002	-0.201	0.062	-0.324	-0.078
FEEL	-4.291	170	.000	-0.263	0.061	-0.384	-0.142
UFAM	-2.223	169	.028	-0.156	0.070	-0.295	-0.017

RSIB	-.831	169	.407	-0.053	0.064	-0.180	0.073
TOTAL	-3.384	169	.001	-0.161	0.048	-0.255	-0.067

4.8 Comparison of unmet needs between Māori and non-Māori

An analysis of the difference in the mean percentage of unmet needs between Māori respondents (n = 20) and non-Māori respondents (n = 154) did not show any evidence of statistically significant differences in the total percentage of unmet needs, although non-Māori had a slightly higher total mean percentage of unmet needs than Māori. Table 11 shows the domains in which Māori reported a higher mean percentage of unmet needs were TO/R, PRAC, and FEEL, and non-Māori reported a higher percentage of unmet needs in the INFO, SF/OYP, UFAM, and RSIB domains. Table 12 shows the only statistically significant difference found in this sample was in the SF/OYP domain where non-Maori reported having a higher percentage of unmet needs than Māori (p=.03).

Table 11

Mean percentage of unmet needs for respondents who identify as Māori

Domain	Māori	N	Mean	*SD*	Std. Error Mean
INFO	Yes	24	0.645	0.398	0.081
	No	158	0.654	0.278	0.022
TO/R	Yes	21	0.595	0.380	0.083
	No	156	0.520	0.355	0.028
PRAC	Yes	21	0.460	0.324	0.071
	No	156	0.369	0.350	0.028
SF/OYP	Yes	21	0.405	0.413	0.090
	No	155	0.588	0.354	0.028

FEEL	Yes	21	0.608	0.381	0.083
	No	154	0.582	0.366	0.029
UFAM	Yes	20	0.420	0.394	0.088
	No	154	0.534	0.405	0.033
RSIB	Yes	20	0.529	0.394	0.088
	No	154	0.588	0.360	0.029
TOTAL	Yes	20	0.543	0.317	0.071
	No	154	0.568	0.274	0.022

Table 12

Equality of Means between Māori and non-Māori (t-test)

Domain	t	df	Sig. (2-tailed)	M	Std. Error	*95% CI of the dif.*	
						Lower	*Upper*
INFO	-0.140	180	0.889	-0.009	0.065	-0.137	0.119
TO/R	0.903	175	0.368	0.075	0.083	-0.089	0.239
PRAC	1.138	175	0.257	0.092	0.081	-0.067	0.251
SF/OYP	-2.185	174	0.030	-0.184	0.084	-0.349	-0.018
FEEL	0.300	173	0.764	0.026	0.085	-0.143	0.194
UFAM	-1.186	172	0.237	-0.114	0.096	-0.303	0.076
RSIB	-0.688	172	0.492	-0.060	0.087	-0.230	0.111
TOTAL	-0.385	172	0.701	-0.026	0.066	-0.157	0.105

4.9 Comparison of unmet needs between siblings of children with cancer living in Aōtearoa/New Zealand and Australia

A comparison of the results between an Australian sibling sample (*n*=106) and an Aōtearoa/New Zealand (*n*=68) sibling sample was carried out. The Australian data was taken

from a recent investigation into the unmet needs of siblings of adolescents and young adults using the SCNI (Patterson et al., 2017). This allowed the current study to make direct comparisons between the seven domains of unmet needs. Results showed strong similarities across all domains except FEEL and RSIB however the Aōtearoa/New Zealand sample was systematically higher across all domains (approximately 20%; see Table 13 & Figure 4).

Table 13

The average percentage of unmet needs between Australian and New Zealand samples.

Domain	Australia	New Zealand
INFO	46.7	70.3
TO/R	46.1	67.6
PRAC	24.2	49.0
SF/OYP	44.9	66.5
FEEL	43.4	74.4
UFAM	31.6	57.1
RSIB	46.8	65.1

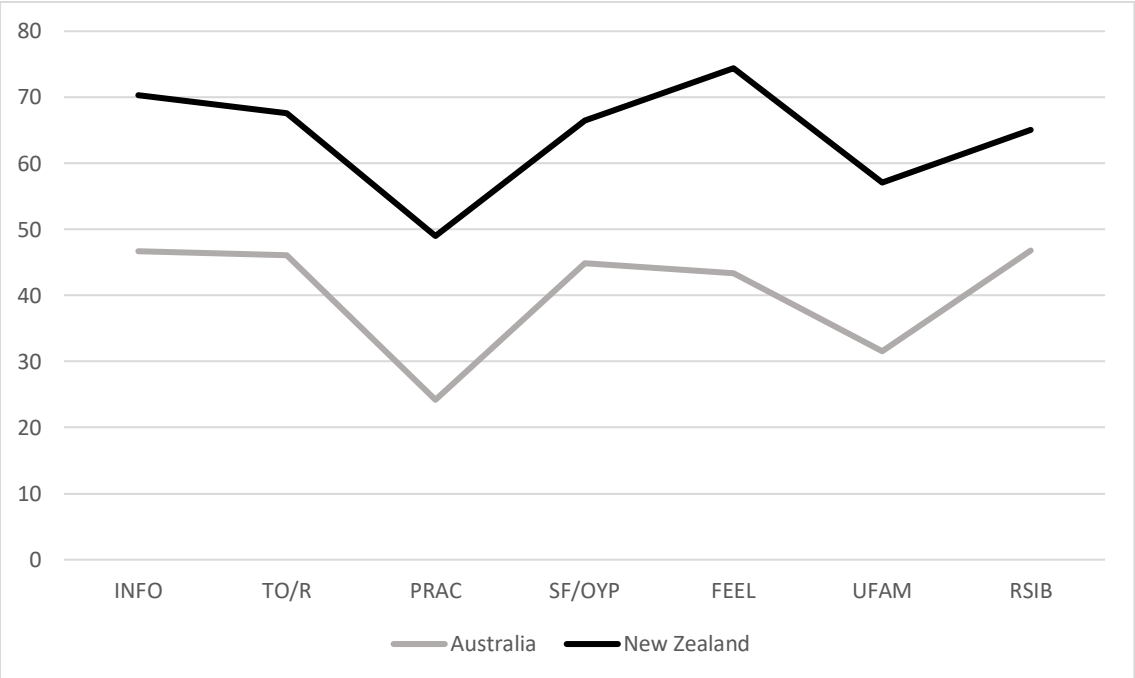

Figure 4. Comparison of domains of unmet needs of siblings of children with cancer between Australian and New Zealand samples.

4.10 Qualitative Results

The aim of the present study was to identify the unmet needs of siblings of children with cancer, Type 1 diabetes, and cystic fibrosis from the viewpoint of siblings; thus a qualitative component was included in this study. The final item in the survey was an open-ended question which aimed to extend the knowledge of the needs of this population through inviting respondents to reflect on, and express, their own personal experiences. The question in the survey was 'Considering the needs that have been identified, how do you feel your needs would have best been met?'. Responses were collected (*n*=118) and the main themes and subthemes were analysed and categorised (see Table 14). The four main themes were: Siblings need support; Sibling roles; Impact on the whole family; and When things go well. These themes and the subthemes will be described in the following section.

Table 14

Abbreviated domain names

Theme	**Subtheme**
Siblings need support	• Support from friends, family and school • Support from peers • Support from professionals • Support needs to be offered • Long term support needs
Sibling roles	• Being included and given information • Taking care of others
	• Disruption to the family

Impact on the whole family	• Extended family • Financial burden
When things go well	• Time, understanding and routines • Individual time

Theme 1: Siblings need support

This was the most frequently reported theme across all three health conditions and was divided into five subthemes: Support from friends, family and school; Support from peers; Support from professionals; Support needs to be offered; and Long term support needs. Around three quarters of siblings of children with cancer identified this theme in their responses, and approximately two thirds of siblings of children with cystic fibrosis and Type 1 diabetes.

Support from professionals

Of the five 'support' subthemes, the need for professional support was the most frequently mentioned by siblings of children with cancer and cystic fibrosis. For siblings of children with Type 1 diabetes, it was the most common theme, equal with 'Support from friends, family and school'. Responses reflected the strong need for siblings to receive professional advice:

> *The opportunity to talk to a psychologist or counsellor with understanding on the matter would have been incredibly helpful for me to feel heard during this time*
>
> Sibling of a child with Type 1 Diabetes Mellitus (T1DM)

Psychological support would have been an excellent thing as a child but mainly as a teenager Sibling of a child with Cystic Fibrosis (CF)

a free counselling support would have been very helpful (CF)

Option to see a psychologist Sibling of a child with Cancer (CA)

Siblings also commented specifically on the importance of needing professional advice around how to support their affected brother or sister:

I would have valued speaking to a psychologist to understand better ways to communicate with my sick sister during different stages in her treatment (CA)

guidance and support around speaking to my sibling about her illness and guidance about what I could do to support her would have been great for both of us (CF)

The need for professional advice on how to support their affected sibling links with the theme of 'sibling roles' (discussed below). Having a supportive role to play helped siblings feel included, which was important for their wellbeing:

Supporting me to support her would have made a significant difference to both of our experiences of her diagnosis and subsequent 'back to normal' period - she would have felt appropriately supported and I would have felt that I had done all I could to be there for her at a seriously difficult time in her life (T1DM)

... knowing how to support my sibling emmotionally [sic] too (T1DM)

Siblings also pointed to the importance of (and having a strong need for) support from outside the family. Siblings described wanting to protect family members' by not speaking

about their own needs which they perceived could add to the burden their parents were carrying:

> *I needed someone I could have talked to about this growing up, somebody who could help me bring this subject up without causing pain to anybody else* (CF)

> *A safe space to ask someone questions without upsetting my parents or sick sibling* (CA)

> *Counseling [sic] was very important to talk to someone how I was feeling and helped deal with my stress and anxiety outside of my family* (CA)

Support from friends, family and school

This subtheme was mentioned by around one third of siblings of children with Type 1 diabetes, cancer, and CF. These siblings articulated the need for the significant people in their lives to provide understanding and support around their circumstances. Support from family members' was frequently commented on: *"The best that could've been done in my situation would b [sic] more understanding from family"* (T1DM). Having good communication with family members was also identified as important: *"Communicating with my family more about it all"* (T1DM).

Support particularly focussed on communication and being able to share information, between family members and with other potential supports. When families tried to keep the illness hidden or secret, participants said it had a negative impact on them:

> *By my parents not hiding my sisters Illness and letting me tell people so that I could talk about it. The anxiety and depression that I have gone through, partially because of her illness could have been alleviated I fit [sic] wasn't considered a secret* (CF)

We were not included or open about the illness in my family and I felt guilty and sad when I thought about it (CF)

The following comment by a sibling (reflecting on when they were a twelve year old child) describes how they were able to get the family support they needed through clear communication with their parents:

when I was about 12, I told my parents I felt neglected, and that I was always pushed aside b/c of my sister, and after that it was way better, i needed them to realise this sooner and pay more equal attention to me and my siblings [sic] (CF)

Siblings' comments about the importance of family support often interlinked with other key themes. For example: *"Support from family members and being talked to and not forgotten by them"* (T1DM) speaks to the importance of family support – this involved the need to feel included, be given information, and the need not to feel forgotten. When families didn't provide siblings with the support they needed, they often felt invisible or forgotten within their family:

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 (T1DM)

to have been given the chance by someone to prepare for never feeling like the important child. Every family member or friend only ever asked how my sister was, it felt as if they never cared for me or my needs (T1DM)

Better support/understanding of the feelings of guilt and feeling selfish (why don't my parents ask me how I am?) (T1DM)

The ability of parents to understand and meet the needs of their non-affected children was identified as important. A number of responses referred to the need for support services that helped parents understand how to talk to siblings and how to support them:

> *Helping out my parents first so that they could see the issues affecting me and not just my sibling…* (CF)

> *Probably better support for my parents and more information for them on how to talk with the non ill members of the family* (CF)

In addition to family support and understanding, support from teachers was also spoken about as being important. While some siblings reported good support from teachers: *"My teachers and family throughout her illness were amazing and so supportive…"* (CA), other siblings felt very unsupported in their school environment: *"My school was not very understanding, not heeding my parents warning about what was happening – I should have been checked up on, and booked in with the councellor [sic] there*" (CA). This emphasizes the importance of educating both schools and families on how to support siblings: *"My experience of this was a long time ago but the memories of how devastating it was for my whole family are still very strong. Education for whanau and schools in particular are vital"* (T1DM).

Finally, siblings talked about the need to feel understood by their friends who were often unable to provide them with adequate support due to not fully understanding the impact of the health condition:

> *My friends were as good as they could be (but I didn't feel so at the time), but they had never experienced anything like that, so had no idea what to do. Whenever I brought up my mental health, or feeling alone or sad… I was aggressively, if not violently, shut down, I wasn't important, and my feelings didn't matter* (CA)

…to feel like I could tell my friends without upsetting my sibling (CF)

I needed better support from my friends… (CA)

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 (CA)

Support from other siblings/peers

The need for peer support from other siblings was mentioned by approximately twenty percent of siblings of children with cancer and ten percent of siblings of children with cystic fibrosis and Type 1 diabetes:

Having a support group or forum to talk to other siblings in (CA)

It would have been cool to have a group of "the siblings (T1DM)

By having sibling rooms at the hospital (CA)

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 (CA)

A group to go to bimonthly or the likes where siblings or siblings + affected family member got together to chat about our feelings and have a fun activity (T1DM).

One participant described the experience of meeting another sibling of a child with cystic fibrosis for the first time and the positive sense of connection this engendered: *"I never met anyone who had a family member with CF until I was 25. It was actually special to be*

able to talk to them so being connected earlier to other CF siblings would have potentially been helpful" (CF).

Other siblings had experienced 'sibling camps' and enjoyed spending time with peers who had lived through similar experiences*: "I loved the diabetes camp we went to as it was a great experience with lots of others in the same position"* (T1DM).

Support needs to be offered – not asked for

Although this theme was mentioned by siblings of children from all three health conditions, it was most frequently reported by siblings of children with cancer (around twenty percent of respondents). Comments reflected the importance of siblings being offered help rather than needing to ask for it:

> *For more help to be available and that it was Okay to have that help* (T1DM)

> *I wish someone had offered me someone professional to talk to about it. I was 17 so they thought I could handle everything but I was alone for a lot of the time and left to do things for myself in my final year of high school. I truly think a lot of my abandonment issues stem from this (along with other things)* (CA)

Siblings needed to know that it was okay to accept help and be encouraged to engage in these services. Feelings of guilt and selfishness for expressing their own needs, when their sibling was so unwell, could make it difficult to ask for help:

> *To stand up and say you need help when your sibling is ill, feels very selfish* (CA)

> *Greater support services for siblings and encouragement to use those services i.e. encouragement that it is not'selfish to use them* (CA)

We did have the option of joining Canteen but I never felt like I deserved it (CA)

A sibling of a child with cystic fibrosis described the underlying process that can lead to difficulty accepting support, despite having significant needs around their mental health: *"I have always felt extremely guilty that I was the 'lucky' twin, but have also felt guilty that I have a mental illness when I really don't have anything to complain about in comparison…"* (CF).

CanTeen

Siblings of children with cancer referred to the recent transition from 'face-to-face' to online support services at CanTeen NZ as a huge loss:

More stuff with Canteen. Only saw them once then was told no more visit just online but don't really like that. Would rather hang out with someone that's chill (CA)

CanTeen provided what I needed in every aspect. It's upsetting their services have ceased and no longer support young people in a similar situation (CA).

These comments suggested the organisation's recent change in structure and reduction in staff numbers may have had a negative impact on sibling support services, from the perspective of those who have used their services previously.

Long-term support needs

Approximately five percent of siblings across all three health conditions commented on their ongoing distress when they lacked opportunities for support following their affected siblings diagnosis:

Mum and I struggled with the impact this had on our lives massively. While at the time I just coped - it has taken time as an adult to deal with anger and some distance I felt in my family because I missed some attention (T1DM)

Sometimes the impact of a sibling's diagnosis wasn't fully recognised until much later, which made it hard to ask for support during that time:

It had serious impact - I was always noticing and wondering if things were okay. I wish that I had been able to share how I was feeling with people but I don't think I realised at the time how much it impacted me (T1DM)

Some siblings described how the impact of unmet needs following the diagnosis led to long-term anxiety, depression and post-traumatic stress symptoms (PTSS):

It has absolutely impacted my life path negatively - causing severe distress, social issues, severe anxiety, and destroyed my place in my immediate family as I was left alone at such a young age and got used to being alone. It negatively impacted my schooling, and my career path (CA)

The anxiety and depression that I have gone through, partially because of her illness could have been alleviated if it wasn't considered a "secret". Now that I am a mother I understand it would have been very scary for them but the way that they dealt with me and my feelings was not the best. Whenever my boys have a cough, I suffer panic attacks and anxiety due to the suffering I heard from my sister (CF)

...I was eventually diagnosed with GAD, OCD, and mild SAD, and attended treatment at the Anxiety Disorders Unit for this. People going through these sorts of things need to have a streamlined process to the necessary services and diagnosticians in order to

get on top of things early. They need to have round the clock contacts and supports. Access to transport and events. They need to be made to feel like they matter too (CA)

I felt as though I was carrying all the emotional weight of the entire family, and it was overwhelming, and resulted in me having emotional issues as an adult that I'm still processing (CA)

Some siblings who felt their needs were met during the illness nevertheless reported needing support later in life, speaking to the potential for long-term effects from their experiences, and delayed responses (discussed below): *Personally, my needs were met during the time of the illness. However a few years later was when it all started to catch up with me and that was when I needed more support* (CA). Other siblings reported the long-term impact of unmet needs affected not only their emotional wellbeing, but also their view of themselves in relation to others:

I needed someone I could have talked to about this growing up, somebody who could help me bring this subject up without causing pain to anybody else. I always felt invisible growing up and that has caused me to shy away even as an adult and caused [sic] my confidence to be lowered, letting me know I was just as important may have prevented this. Because my siblings always came first due to their health, I have always put my own needs last (CF)

Another sibling spoke of feeling *"less than"* their affected sibling, and simultaneously significantly affected and guilty for being so:

It all came to a nasty head in my adult years and even in receiving therapy for my healing, I still feel less than my sister. As if my problems will never be bigger than

hers. And I feel so guilty, I sound like the jealous little child that never got her way (T1DM)

Siblings also described an underlying sense of guilt for having needs of their own (both in the short-term and the long-term), which impacted on their ability to seek or accept support. They also commented on feeling guilty for being the 'healthy sibling' suggesting feelings of guilt were pervasive and difficult to overcome: *"I do remember feeling not as important but the guilt that I was healthy got the better of me so never spoke up"* (CA).

Theme 2: Sibling roles

This was the second most frequently mentioned theme that was spoken about by approximately forty percent of siblings (equally distributed across health conditions). Siblings' comments reflected the importance of feeling included, having access to age appropriate information, and of not being given care-giving roles that felt overwhelming.

Being included and given information

This was the most commonly reported subtheme within the 'Siblings roles' theme. Siblings indicated their parents and health professionals tried to protect them by minimising the information they were given; however, siblings frequently described the importance of being given age appropriate information and feeling included:

I needed my family to be more transparent with me with what was going on instead of "trying to protect me" from difficult information (CA)

Because I was so young I felt that I was out of the loop and no one informed me of what was truly going on (CA)

I was confused and didn't know what was happening, no one told me, no one thought it necessary thst [sic] I knew or understood (T1DM)

Siblings also commented on the need for health professionals to provide them with information they could understand:

It would also be great to have a meeting with a doctor to advise in layman terms what our sisters are dealing with, what they will go through and how we can support them (CF)

During this time as a young person, I don't think I really realised the scope of what was going on. Getting the information about the illness and treatment in a way I could understand was an issue. That could definitely have been improved, looking back in retrospect (CA)

Better access to the information and in a way that i [sic]was able to understand as a child (T1DM)

Siblings reported on how being excluded from being involved with the illness could lead to feelings of jealousy toward their affected sibling - closely followed by feelings of guilt:

We were not included or open about the illness in my family and I felt guilty and sad when I thought about it and often jealous of my sister when I was a child which brought more guilt I would have liked more family openness and support (CF).

Some siblings described how being involved in daily caregiving routines helped them feel included:

being able to sit next to my sister in the hospital bed and being able to eat her leftovers always made me feel included (CA)

growing up i felt occasionally overlooked or less important so my parents would give me raspberry viatmins [sic] to take when he took his enzymes (CF).

Taking care of others

This was a subtheme which was commented on more frequently by siblings of children with cancer and Type 1 diabetes than siblings of children with cystic fibrosis. Siblings expressed the personal toll of taking on the caregiving duties to family members:

It felt like I often cared more for her than myself. The toll it has taken on my mental and physical health is huge (T1DM)

I was then neglected and had to go through my teenage years basically raising myself and my two younger siblings (T1DM)

I needed my parents to remember I was a teenager, already going through a lot, and not a substitute mother to my now two younger siblings (CA)

Siblings also commented on how their new responsibilities at times felt overwhelming but the feelings of not wanting to be a 'burden' meant they were unable to ask for the support they needed:

I felt that i took care of my family more than they took care of me, i took up jobs around the house and supported my mother and siblings, i feel as though someone should've been there to help me but i didn't want to be a burden as they were dealing with so much [sic] (CA)

Sometimes these responsibilities led to them growing up quickly and 'missing out' on being a child. These responsibilities encompassed both practical jobs, caregiving for younger family members, and emotional responsibilities:

> *I'm the eldest child, and my younger sibling was the ill one. Because I was older I was expected to take on an enormous amount of practical and emotional responsibility. Far more than any typical 7 -11 year old would be expected to do. I needed to be "allowed" to be a child, and to be reassured that I did not need to carry so much responsibility. Especially emotional responsibility* (CA)

> *… it was quite a traumatic experience at my age of 13 where I played the role of a mother as I was the oldest* (T1DM)

Theme 3: Impact on the whole family

Disruption to the family

Disruption to the family was reported by around twenty percent of siblings, although there were slightly fewer comments from siblings of children with Type 1 diabetes. Siblings of children with cancer commented on the difficulties of family separation during periods of treatment, and the lack of predictability as to routines and when the family would be together again:

> *The biggest disruption was not having Mum and my sister there for weeks then when they came back it would be disrupted again* (CA)

> *The first time I was left completely alone as one parent had to work, the other was up at the hospital, and my younger sibling was put into full time nannying. I was not*

> *included at all, I never knew when someone was going to be home, when food was coming, what was happening* (CA)

Siblings also described the negative impact of a child's diagnosis on a family: *"My experience of this was a long time ago but the memories of how devastating it was for my whole family are still very strong"* (T1DM), as well as strategies that were or were not helpful for meeting their needs:

> *I think a lot of it comes down to the way your family itself deals with the illness - my parents wanted everything to be as normal as possible for my sibling, and as such I think I possibly wasn't made aware of services that could be available. I also needed to talk about it & have the fact that the illness affected me too, validated* (CF)

Extended Family

Some siblings reported that while the support of extended family was helpful (grandparents, aunties and uncles), parental separation was still difficult:

> *Having grandparents really helped as me and my younger sister spent our days with them Over the time my sister was going through treatment And having aunties and uncles toe help look after us to We were lucky to have enough support around us at the time, just was hard being away from mum and dad and having to also look after my other younger sister [sic]* (CA)

Other siblings described the difficulties of being placed in the care of extended family members who were not well equipped to support them during this time, leaving them feeling alone, distressed and 'abandoned':

> *My parents both went with my brother to Christchurch for treatment leaving me with grandparents who had vastly different parenting styles from my parents. I struggled with anxiety and panic attacks that were not appropriately dealt with at the time due to a lack of understanding on everyone's behalf* (CA)

> *My needs would have been met if I was not cast aside. My parents sent me to live weeks and weeks at a time with my strict grandparents, so I was very left out of my brother's cancer experience. The worst part was the loneliness* (CA)

Financial Burden

In addition to emotional support, practical needs were identified that had an impact on the coping of the family as a whole, and consequently siblings' experiences. One sibling commented that *"Funding for help at home"* (T1DM) would have supported their needs. A couple of siblings mentioned the negative impact of financial burden and the stress it added to their family's journey:

> *The biggest things that caused issues was the financial burden it created within my family. The stress on my parents was immense as they were essentially running two households, this burden impacted greatly* (CA)

> *A specialist service involving sibling wellbeing, especially for those having to stay behind due to financial and educational needs, would have greatly benefited me* (CA)

Theme 4: When things go well – time, understanding and routine.

Approximately ten percent of siblings described having some of their needs met - this often related to support and understanding from family members:

Support and good communication from family – which I felt like I had the whole time (CF)

Family support is always the best support and I had so much of it (CF)

By feeling supported by my family, and not feeling judged when I asked questions about the illness (CF)

Another sibling described the strategy for having their needs met was through clear communication with friends and family: *"In most cases my needs were met. A few times they weren't but I was able to work around with family and friends to express what it is I needed"* (CA). Siblings expressed that individual time with family members was important for having their needs met:

one on one time with family… makes the process easier (CF),

One on one time with parents (CF)

My parents always find time for all of us. They spend one on one time with my brother and me. My sister understands that we need the attention to (CA)

Better support for parents/extended family so they were less stressed and could spend time with me (T1DM).

In one case, a strong belief system was reported as helping a family cope with having a child with cystic fibrosis: *" i can only be so so grateful that our family had strong christian beliefs that has kept us together [sic]"* (CF).

Chapter Five – Discussion

Chapter overview

The previous two chapters have outlined the methodology and results of the current research – the Sibling Needs Survey study, which was completed by siblings of children with cancer, cystic fibrosis and Type 1 diabetes, age sixteen years or over, in Aōtearoa/New Zealand. This chapter will: identify and discuss the key findings of the study; interpret the results in the context of the existing literature; and discuss the strengths and limitations of this research, along with recommendations for research in the future.

5.1 Key findings

5.1.1 The unmet needs of siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa

The overall number of unmet needs reported by siblings in Aōtearoa/New Zealand was very high in this sample. On average, 26.01 (*SD* = 12.27, range 0-45) items from a total of 45 items in the Sibling Needs Survey were reported as unmet needs. The average percentage of unmet needs of siblings was 57.8%. 32 out of a total 45 items were endorsed as unmet needs by over 50% of respondents. The high level of unmet needs found in the current study echoes the findings of previous studies on siblings of children with cancer in Aōtearoa/New Zealand which suggest siblings' experience relatively high levels of adjustment difficulties (Lamb, 2015; Porteous, 2019; Riddick, 2013).

The following section will discuss the top ten most commonly endorsed unmet needs found in the quantitative results of the Sibling Needs Survey and describe how they overlap with the key themes in the qualitative findings and existing literature.

Sibling Needs Survey – the most commonly endorsed unmet needs

The following four unmet needs were the most commonly endorsed unmet needs in the Sibling Needs Survey and all belonged to the domain 'Information about my sibling/whānau member's health condition':

1) 'Information about the impact the illness and it's treatment might have on my sibling/whānau member's life in the future' (endorsed by 84.4% of siblings)

2) 'To be informed about my sibling/whānau member's condition – good or bad' (endorsed by 80.0% of siblings)

3) 'To get information about the illness and its treatment in a way that I understood' (endorsed by 72.5% of siblings)

4) 'Information about what would happen when my sibling/whānau member came home following treatment' (endorsed by 72.5% of siblings)

These results are supported by the findings of the qualitative data in the current study, in which the need for information was a strong theme. Siblings talked about needing *"transparency"* around their siblings illness rather being "*protected"* from difficult information and described needing access to information that they could understand: *"Better access to the information and in a way that i was able to understand as a child*" (T1DM), and *"Getting the information about the illness and treatment in a way I could understand was an issue*" (CA).

These findings are well documented in existing literature which repeatedly identifies the need for siblings to have access to age-appropriate information about the affected child's health condition (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). A recent meta-synthesis suggested that providing siblings with information about the illness close to the time of diagnosis might help

them build understanding and assist with accepting the situation. Findings also showed a lack of information could lead to fear and effect siblings negatively (Deavin et al., 2018).

It is important siblings receive age-appropriate information about their sibling's health condition instead of being 'protected' from difficult information. Being excluded from being involved with the illness can lead to feelings of jealousy toward their affected sibling - followed by feelings of guilt. In contrast, access to information helps siblings feel included, valued, important, and less fearful than when information is withheld.

The fifth and seventh most commonly endorsed unmet needs both belonged to the 'Relationship with my ill sibling/whānau member' domain:

5) 'To know ways of giving practical support to my sibling/whānau member' (endorsed by 69.4% of siblings)

7) 'To know ways of giving emotional support to my sibling/whānau member' (endorsed by 68.4% of siblings)

The need for guidance on how to support their affected sibling was reflected in the qualitative findings in the current study. Siblings talked about needing *"help with supporting siblings during treatment"* (CA), and the need for *"... knowing how to support my sibling emmotionally [sic]"* (T1DM).

At a practical level, quantitative findings showed siblings were sometimes placed in positions of responsibility for their affected siblings medical care (such as on sports days and at camps) without adequate knowledge of how to support them. This could be stressful and difficult:

> *My biggest issue is the fact that we play the same sport and go away on trips together and i have the responsibility to make sure she is okay. for example on a trip she had a low and i had to leave my group of friends to support her. which is hard because this*

is my sport trip too and its hard having to worry and stress about her to when your trying to have your own life and exsperinces [sic] (T1DM)

Findings in international literature show siblings often help care for the affected child, taking on a supportive role within the family which can lead to siblings feeling included and give them a clear role. Literature also suggests siblings alter their behaviour by taking on caring goals to meet both their own needs and the needs of the family which can lead to post traumatic growth (Deavin et al., 2018. Havill et al., 2019). These findings point towards the importance of siblings receiving guidance in this area.

The sixth most commonly endorsed unmet need belonged to the 'Support from friends and other young people' domain:

6) 'To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty' (endorsed by 69.4% of siblings)

This need echoed the qualitative results in the current study where siblings commented on the need to feel "validated" and to be able to speak openly without worrying about upsetting anyone: *"I also needed to talk about it & have the fact that the illness affected me too, validated"* (CF), and *"I needed someone I could have talked to about this growing up, somebody who could help me bring this subject up without causing pain to anybody else"* (CF). Other comments described the difficulty siblings had when family's kept the chronic health condition a secret which prevented siblings from talking about their experiences and accessing support: *"The anxiety and depression that I have gone through, partially because of her illness could have been alleviated if it wasn't considered a "secret"* (CF).

The need for support services which allow siblings to openly express their feelings is also a strong theme in the existing literature. Vermae et al. (2012) suggested their findings of

siblings being at increased risk of internalising problems may be because siblings suppress their emotions and feelings, rather than ask for attention from their overburdened parents. This emphasizes the importance that siblings have a safe space where they can speak freely and have their feelings heard and prioritised.

Also in relation to the fifth most common unmet need, was feelings of guilt which was also a significant theme in the qualitative data. Siblings talked about feeling 'guilty' and 'selfish' for needing to express their own feelings which led to them concealing their needs, impacting on their ability to access the support they needed:

> *I do remember feeling not as important but the guilt that I was healthy got the better of me so never spoke up* (CA)

> *We were not included or open about the illness in my family and I felt guilty and sad when I thought about it and often jealous of my sister when I was a child which brought more guilt* (CF)

> *Better support/understanding of the feelings of guilt and feeling selfish* (T1DM)

> *To stand up and say you need help when your sibling is ill, feels very selfish* (CA)

Guilt is a strong negative emotion that has been repeatedly reported by siblings and well documented in existing literature for siblings of children with cancer and chronic health conditions (Deavin et al., 2018; Long et al., 2018; Patterson, 2014; Weiner & Woodley; 2018; Williams et al., 2009). Siblings need support dealing with feelings of guilt for being the 'healthy' sibling, and for feelings of jealousy toward their affected sibling for the extra parental attention they receive.

The eighth most commonly endorsed unmet need also belonged to the 'Support from friends and other young people' domain:

8) 'To have someone close to discuss my feelings about my sibling/whānau member's illness' (endorsed by 68.0% of siblings)

This reflects the need for siblings to be able to access understanding and support from friends and family members which was another key theme in the qualitative results: *"The best that could've been done in my situation would b [sic] more understanding from family"* (T1DM), and *"I needed better support from my friends…"* (CA).

The importance of peer support for siblings (either understanding friends or siblings who have shared experiences) has also been well documented in existing literature (Barrera, Flemming & Khan, 2004; Deavin et al., 2018; Murray, 2001). During adolescence, social connection and peer relationships are of primary importance – these relationships are often where adolescents can safely express themselves and feel understood. Peers can offer valuable emotional support and a chance for adolescent siblings to 'relax' (Read, Kinali, Muntoni, Weaver, & Garralda, 2011).

A large systematic review identified an association between lower perceived social support and unmet friendship needs with: behaviour and attention problems; greater alienation; and lower quality of life (Long et al., 2017). A meta-synthesis by Deavin et al. (2018) found strong negative emotions including loneliness as a result of familial and peer isolation could impact siblings social and emotional wellbeing. These findings show familial and peer support is a strong need for siblings, particularly for adolescents.

The ninth most commonly endorsed unmet need belonged to the domain 'Time out and recreation':

9) 'To be able to have fun' (endorsed by 67.4% of siblings)

While only a few siblings specifically mentioned the need for the ability to have fun in the qualitative results of the current study, these comments were made in the context of needing time away from the illness in the form of fun, recreation, and maintaining a sense of normality. This is reflected in comments such as: *"[I needed a] fun/safe space outside of the hospital. This space having things like movie nights, hangouts and a drop in centre was so important to feel like things were okay"* (CA) and *"to chat about our feelings and have a fun activity"* (T1DM). Siblings also talked about the need for personal time with their family members: *"family time without worrying about diabetes"* (T1DM); *"one on one time with family"* (CF) and; *"My parents always find time for all of us. They spend one on one time with my brother and me. My sister understands that we needs attention to [sic]"* (CA). These comments show how important a sense of normality through 'time out' from the illness, and individual time with parents, is for siblings.

Existing literature strongly supports the need for fun and recreation for siblings, somewhere they can feel normal again and forget the stress of their affected sibling's diagnosis (Oberoi, 2019). The concept of 'sibling camps' stems from the recognition of the importance that siblings get to enjoy some 'time out' and have fun with sibling peers who have been through similar experiences (Sidhu, Passmore, & Baker, 2006). Literature also suggests disruptions in schooling can negatively impact siblings in the areas of fun and recreation, access to peer support, and a sense of normality through daily routines (Long et al., 2018).

The tenth most commonly endorsed unmet need was from the 'Dealing with feelings' domain:

10) 'Help dealing with feelings about the possibility that my ill sibling/whānau member might die' (endorsed by 67.4% of siblings)

The qualitative findings in the current study showed siblings had difficulty dealing with strong negative emotions around the fear of losing their affected sibling: *"…counciling [sic] sessions to get the fear out and open early on…"* (CF); *"…at the beginning of her diagnosis I was scared of losing her…"* (T1DM); and *"I struggled with anxiety and panic attacks that were not appropriately dealt with at the time"* (CA).

Existing literature identifies fear as a dominant emotion experienced by siblings following a child's diagnosis with a chronic illness, underpinned by pervasive worry about their sibling's health and wellbeing (Derouin & Jessee, 1996; Herman, 2010; Velleman, Collin, Beasant & Crawley, 2016). This worry can interfere with other areas of a sibling's life, including their ability to concentrate at school (Deavin, 2018). A recent review found siblings experience fear following a sibling's diagnosis; this was sometimes accompanied by anticipatory grief, even when the prognosis was good (Weiner & Woodley, 2018).

It is important siblings receive support to deal with the strong negative feelings they experience following their affected sibling's diagnosis, particularly because reduced familial communication at this time can lead to siblings suppressing their complex emotions.

Overview of qualitative themes and existing literature

The qualitative themes identified in the current 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 the current study with the recent meta-synthesis by Deavin et al., (2018) include: 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 the current study 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 the current study 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. This was also found in the literature with some siblings reporting they experienced positive emotions with the support of friends and family (Havill et al., 2019; Weiner and Woodley, 2018).

5.1.2 The differences in unmet needs between siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa

An analysis of the mean percentage of unmet needs for each health condition showed siblings of children with cancer had the highest number of unmet needs in total (66.3%), followed by cystic fibrosis (53.0%), and diabetes (48.6%). These are all extremely high levels. The domains with the greatest differences were 'Time out and recreation' and 'Practical assistance' where siblings of children with cancer reported higher unmet needs than siblings of children with cystic fibrosis or diabetes. The domain 'Dealing with feelings'

showed the largest difference in unmet needs between the three health conditions, and the following four domains showed strong similarities between the three health conditions: Information about my sibling/whānau member's health condition; Understanding from my family; Relationship with my ill sibling/whānau member; and Support from friends and other young people.

An analysis of the qualitative results of this study showed the themes of unmet needs were very similar across all three health conditions. The main theme 'Siblings need support' was endorsed by approximately three quarters of siblings of children with cancer compared to two thirds by siblings of children with cystic fibrosis and diabetes. The subthemes that were more frequently mentioned by siblings of children with cancer than siblings in the cystic fibrosis or diabetes health conditions were: Support needs to be offered – not asked for; and 'Support from other siblings/peers'. The other three subthemes: Support from professionals; Support from friends, family and school; and Long-term support needs were endorsed approximately equally by siblings from all three health conditions.

The main theme 'Siblings roles' showed a strong need for feeling included and being given age-appropriate information about the health condition. This was mentioned by approximately forty percent of siblings (equally distributed across health conditions). The subtheme 'Taking care of others' was mentioned less frequently by siblings of children with cystic fibrosis than siblings of children with diabetes and cancer.

'Disruption to the family' was commented on by approximately twenty percent of siblings, with slightly fewer comments from siblings of children with diabetes. Siblings of children with cancer commented more frequently on the difficulties of family separation during periods of treatment and 'financial burden'. This response was unsurprising given there are only two paediatric oncology treatment centres in Aōtearoa/New Zealand and

because initial treatment is often immediate and prolonged, familial separation is somewhat unique to the families who have a child with cancer.

In summary, 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 and diabetes. However, when considered with the qualitative results, the *types* of unmet needs between the three health conditions have multiple similarities particularly in the areas of information, support, sibling relationships, and familial understanding. These findings support the argument for taking a non-categorical approach in the development of targeted support services for siblings of children with a range of serious chronic health conditions.

5.1.3 The effects of gender, age and culture on the unmet needs of siblings of children with cancer, cystic fibrosis and diabetes in New Zealand/Aōtearoa

A statistically significant difference was found between the mean percentages of unmet needs between males and females. Females reported a greater average percentage of unmet needs than males in total and in the following four domains: 'Time out' and recreation; Support from my friends and other young people; Understanding from my family; and Dealing with feelings. Existing literature on the moderating effects of gender are inconclusive; however, the results in the current study suggested females have a greater number of unmet needs than males.

Siblings who were over the age of twelve showed higher mean percentages of unmet needs in all seven domains, as well as the total score; however, no statistically significant differences were found between the two age categories. This is similar to existing literature that has investigated the effect of age on sibling adjustment, and showed varied results.

Finally, no effect was found for culture; the only domain where a statistically significant difference was found was 'Support from friends and other young people' where non-Maori reported having a higher percentage of unmet needs than Māori (p=.03).

5.1.4 Similarities and differences between the unmet needs of siblings of children with cancer in New Zealand/Aōtearoa and Australia.

A comparison of the seven domains of unmet needs for siblings of children with cancer between an Australian sample (n=106) and a New Zealand sample (n=67) were strongly correlated across five domains. The two domains with differences were 'Relationship with my ill sibling' and 'Dealing with feelings'. The most striking finding when comparing these results were that every domain in the New Zealand sample was systematically higher than the Australian sample. On average, the unmet needs reported in the Aōtearoa/New Zealand sample were over twenty percent higher than the unmet needs reported in the Australian sample.

The similarity in the pattern of unmet needs across the seven domains between these two samples adds credibility to the findings of the current study. When this is considered alongside the strong psychometric properties of the Siblings Needs Instrument (discussed in the Results section), this forms a strong argument for the use of this measure in Aōtearoa/New Zealand including the potential to expand it to other health conditions.

5.2 Public response to this research

The identification of the gap in needs-based support services available to siblings of children with serious chronic health conditions in Aōtearoa/New Zealand was reinforced by the response to this research project during the recruitment phase. All four of the organisations invited to support the current study expressed their encouragement and the need for research in this area. When the Sibling Needs Survey advert was posted on each of the

organisations' social media pages there were approximately thirty comments thanking us for doing this research and/or including personal stories about siblings. In the 'comments section' on the Cystic Fibrosis NZ Facebook page, a parent wrote:

> *I'm really thankful that someone is doing some research in this area in order to help support families. It's not easy to help look after healthy siblings let alone figuring out how to look after everyone's needs when one is unwell. Thank you Katie*

Another parent wrote:

> *...they have missed out on valuable time with their parents with all the hospital admissions, treatments and surgeries etc.. would love to see these studies done on kids from a very young age because it has made life even harder for our family and have no idea what to do about them as the siblings constantly miss out on so much*

An email to the siblingneeds@gmail.com website from a mother of a child with cancer wrote: *"Siblings are forgotten way to much in the cancer journey, however feel our older child was his younger brothers best medicine [sic]"* (Personal communication, 2019). In addition to comments of support from parents of siblings, we were also contacted by multiple health care professionals thanking us for doing this necessary research and asking for a summary of the results. Advocates of siblings, and siblings of children with other serious chronic illnesses also contacted us to ask if they could take part in this study. For example, the following email was sent to the siblingneeds@gmail.com email address:

> *Hi Katie Armstrong, I am a Family Support Worker for HeartKids. I was wondering if our families could be included in the study or are you only looking at cancer, CF and diabetes siblings. Some of our Heartkids live a daily battle with chronic illness hospital appointments and admissions* (personal communication, September 9, 2019)

A comment on the Cystic Fibrosis NZ Facebook page read:

> *Oh wow this is such a great idea around importance of sibling wellbeing and services. Can't relate to cf but my daughter does have bf and a rare lung disease and having 4 older siblings it took it's toll on them all* (Facebook post, 2019)

Another example was an email sent to the supervisor of this research by a woman in Australia who had a son living with autism. After hearing the interview on RNZ, she had a talk with her older daughter who has been having some issues, and the daughter opened up for the first time and expressed that she felt her issues were not as important as her brothers, and that she was not loved as much because they spent so much time with him. This led to them communicating for the first time over these feelings and the impact of the illness on her, and the family as a whole.

These examples demonstrate the recognition (by families and health workers) of siblings needs across a range of serious chronic health conditions, and the importance of offering siblings support.

5.3 Conclusion

The current study focused on identifying the unmet needs of siblings of children with cancer and serious chronic health conditions. The qualitative results supported the quantitative results adding valuable depth and detail, and providing a platform for siblings to have their voices heard. The comparison of the three health conditions in the quantitative results showed cancer had higher levels of unmet needs than both diabetes and CF, however, both sets of results show strong similarities in the types of needs identified across all three health conditions.

Findings from both the quantitative and qualitative data showed siblings have the highest number of needs in the following areas; information about their affected sibling's

health condition in a way they can understand; being included and having a clear role; guidance on how to support their affected sibling both practically and emotionally; being able to talk openly about their feelings in a safe environment without feeling guilty for expressing their own needs or worried about upsetting people; being offered professional support; support and understanding from parents, friends, peers and teachers; the opportunity for 'time out' and to feel 'normal'; and to feel validated, important and valued.

The review of existing literature combined with the findings in the current study suggest how these needs, if left unmet, can result in psychosocial and adjustment difficulties (see Figure 5). Following a child's diagnosis with a serious chronic health condition siblings 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. Existing literature suggests that the impacts of these needs (if left unmet) may lead to depression, anxiety, post-traumatic stress symptoms and affect beliefs around self-worth (sometimes long-term).

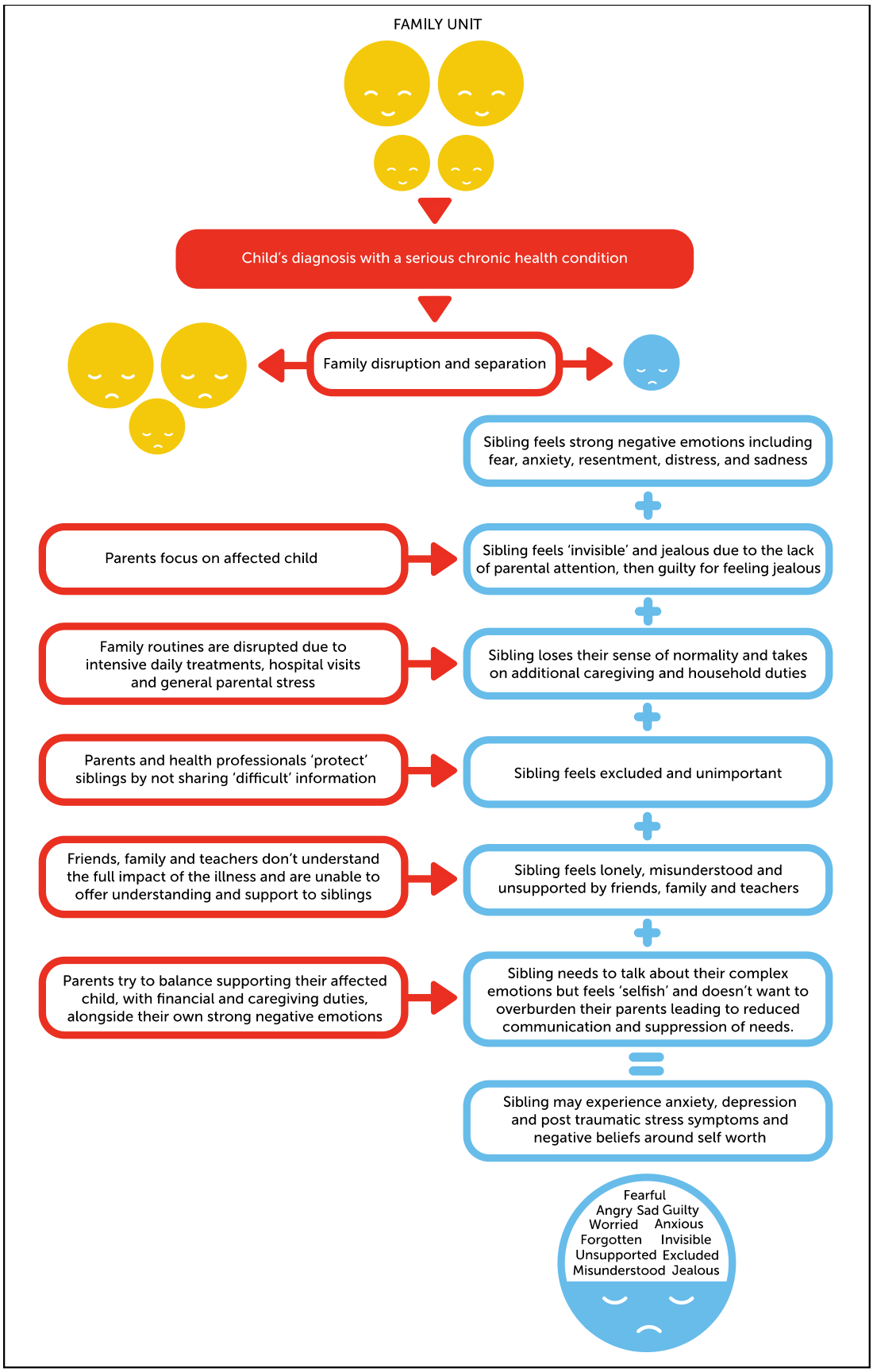

Figure 5. A typical pattern of a sibling's experiences following a child's diagnosis with a serious chronic health condition.

An investigation into the targeted support services currently available to siblings of children with serious chronic health conditions in Aōtearoa/New Zealand found this is an under-serviced area. A non-categorical approach to the development of support services for siblings of children with serious chronic health conditions was supported by the findings which revealed strong similarities in the experiences of siblings across the three health conditions. Quantitative findings provided important evidence that siblings of children with cancer, cystic fibrosis, and diabetes experience very high levels and numbers of unmet needs in Aōtearoa/New Zealand which (when considered with findings that show the unmet needs identified in the SCNI are strongly correlated with a range of psychosocial adjustment problems), is extremely concerning (Patterson (2014).

In conclusion, the findings of this research emphasise the urgent need to develop targeted support services for siblings – which are age appropriate, culturally sensitive, and supported by both professional and peer involvement - that aim to protect the health and wellbeing of this underserved population.

5.4 Recommendations

Having identified a gap in support services for siblings of children with cancer and serious chronic health conditions in Aōtearoa/New Zealand, future research should aim to ameliorate this by building on these findings to develop targeted intervention programmes. Because findings suggest that siblings find it very difficult to request help, due to the complex array of emotions they feel around their sibling's health condition, support services need to be offered to siblings so they do not need to ask for help.

Recommendations arising from these findings point to the need for effective support for siblings including:

- age-appropriate information about their sibling's health condition

- guidance on how to support their sibling practically and emotionally
- professional support offered to them close to the time of diagnosis
- support and understanding from peers, family and teachers
- time with parents to feel included and valued
- a safe space where they feel validated and can speak freely
- recreation and 'time out' with other siblings who understand them.

Further research is required to identify the unmet needs of siblings of children with other serious chronic health conditions, and if the similarities are strong enough, these siblings will also benefit from a targeted intervention programme.

5.5 Strengths and Limitations

The primary limitation of the current study is potential sampling bias due to some members of the sibling population having lower sampling probability than others, this could impact the study's external validity. For example, siblings who are regular social media users and follow the supporting organisation's Facebook pages are more likely to have responded than siblings who do not use social media. Caution is also needed when interpreting the results of research that use a self-selection recruitment procedure. The recruitment techniques used (an anonymous internet survey and radio interview on a National Radio station) mean this study may incur some voluntary response bias (Rosenthal & Rosnow, 2009).

Survey research can also incur nonresponse bias. This occurs when some respondents in a sample do not respond; either through respondents declining to participate, or the researcher's inability to reach some respondents. The researcher has aimed minimised nonresponse bias by using the following techniques: pretesting the survey medium to ensure the it runs smoothly for all respondents; avoiding short data collection periods; posting

reminder advertisements; and ensuring confidentiality (How to avoid nonresponse errors, n.d.).

The number of reported unmet needs could also be influenced to some degree by measurement error due to potential inaccuracies in the recollection of retrospective data. However, to collect the data prospectively was not an option for this study, due to ethical and practical reasons. A review of the literature on recall-induced bias suggests concurrent mental health factors may influence the impact of traumatic childhood experiences and this study did not investigate the current mental health of respondents (Colman et al., 2016). However a recently published longitudinal study (which investigated the accuracy of retrospective reports of family environments as experienced by adolescents) found that retrospective and prospective self-reports agreed well in the domain of emotional dimensions in family life (Bell & Bell, 2018).

Finally, the comparison between the unmet needs of Māori and non-Māori siblings had a relatively small sample size of Māori respondents which reduced the power to detect effects that may have been present.

Despite these limitations, this study also had a number of strengths. While previous research on siblings has largely relied on measures of wellbeing and psychosocial adjustment, this study used a needs-based instrument. This means the findings can be utilized in the development of specific needs-based targeted support services. Furthermore, psychometric testing showed the strong psychometric properties of the original SCNI (Patterson et al., 2014b) were retained in the adapted Sibling Needs Survey which supports the argument for the use of this measure in Aōtearoa/New Zealand.

Another strength was the use of sibling self-report. Siblings themselves are the only ones who can give an accurate account of their needs and experiences, and it is empowering for siblings to have an opportunity to express themselves and have their voices heard.

Finally, while the recruitment techniques mean the representativeness of the sample cannot be determined, it should be noted the demographic questions show the numbers of regional responses are roughly proportional to regional populations which indicates a geographically representative sample.

The overarching finding of this research is that siblings have unmet needs and they *need* to be offered support. This is reinforced by: siblings themselves who reported concerningly high levels of unmet needs; the response to this research (from siblings, their families, and health workers) which emphasised the need for, and the importance of, better support services for siblings; and the identification that there is currently a gap in targeted sibling support services in Aōtearoa/New Zealand. These factors converge to form a strong argument for the development and provision of needs-based support services for siblings nationwide that protect the health and wellbeing of this vulnerable population.

> *I'm the eldest child, and my younger sibling was the ill one. Because I was older I was expected to take on an enormous amount of practical and emotional responsibility. Far more than any typical 7 -11 year old would be expected to do. I needed to be "allowed" to be a child, and to be reassured that I did not need to carry so much responsibility. Especially emotional responsibility. I felt as though I was carrying all the emotional weight of the entire family, and it was overwhelming, and resulted in me having emotional issues as an adult that I'm still processing* (CA)

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Appendices

Appendix A

Invitation of support

Kia ora,

my name is Katie Armstrong. I am a post-graduate student at Massey University currently working on my Masters research thesis.

My supervisor, Dr Kirsty Ross is a clinical psychologist who is involved in a nationwide child cancer project through which she identified a gap in needs-based services available to healthy siblings of children with serious health conditions in New Zealand.

We are looking to conduct some research around the unmet needs of siblings of young people with cancer, diabetes and cystic fibrosis. We have permission from Pandora Patterson to adapt an existing measure designed by CanTeen Australia (Sibling Cancer Needs Instrument) and will put together a simple survey. We would love the survey to be advertised through CCF, Canteen, Diabetes NZ and Cystic Fibrosis NZ.

We would like to invite you to take part in this research. I have attached a research proposal and a sample of the online survey to help you decide whether you are happy to support this research by placing some information and a link to the survey on the CanTeen Facebook page and the website.

Please don't hesitate to contact me or my supervisor, Dr Kirsty Ross, with any questions,

I look forward to hearing from you,

Kind regards,
Katie Armstrong

Appendix A (cont.)

Brief Research Proposal (attached as a pdf to the invitation of support)

The Unmet Needs of Siblings of Children with Cancer or Chronic Illness

Research Proposal by Katie Armstrong

Research Aim

A childhood diagnosis of cancer or chronic illness has a significant impact on the lives of healthy siblings who must adapt to major disruptions in their family's daily routines, considerable emotional stress, reduced time with their parents, and increased responsibilities at home. Existing research shows healthy siblings of children with serious health conditions have a range of unmet psychosocial needs which can lead to adjustment difficulties and the development of mental health problems. This research project aims to identify the unmet needs of healthy siblings in New Zealand. It is needs-based research which will contribute to the development of targeted, evidence-based services which will protect the health and wellbeing of siblings.

Research Design

Data will be collected through a nation-wide online survey. Permission will be sought from CanTeen New Zealand, Child Cancer Foundation, Diabetes Youth New Zealand and Cystic Fibrosis New Zealand to conduct research with their sibling members by providing a link to the online survey through their websites and social media pages.

Survey

The survey will be adapted from the Sibling Cancer Needs Instrument (SCNI) which was developed by CanTeen Australia. It is a well validated measure of siblings unmet needs and has been previously adapted for research.
The SCNI has been designed to minimise inconvenience to participants. It takes approximately ten minutes to complete and includes 45 items across seven domains including: information; practical assistance; "time out" and recreation; feelings; support (friends and other young people); understanding from my family; and sibling relationship. Each question is answered using a 4-point Likert-type scale where 1 = "no need" to 4 = "strong need".
To adapt the SCNI to this research study the survey will begin with some demographic questions and will conclude with an open ended question which will be of value to the organisations and the study (please see sample survey attached).

Data Analysis

The Statistical Package for the Social Sciences software (SPSS) will be utilized for the analysis of data. The SCNI response format allows for calculation of unmet needs as total scores and mean scores. Descriptive statistics will be presented for each domain of unmet needs and inferential statistics will be applied to the data. This research aims to:

1. Identify and compare the domains of needs reported as unmet by siblings of children with cystic fibrosis, Type 1 diabetes and cancer.
2. Compare the overall proportions of each domain of unmet needs for siblings who were 13 years or over and 12 years or younger at the time of diagnosis.
3. Compare the overall proportions of each domain of unmet needs between male siblings and female siblings.

Participants

Participants will be age 16 years or over. They will have a sibling who has been diagnosed with cancer, Type 1 diabetes or cystic fibrosis one year ago or longer.

Siblings will be assured they are under no obligation to take part in this research; they will be informed their questionnaire will remain anonymous; they will be assured they can decline to answer any question; they can withdraw from the study at any time; and they can have access to research results once completed should they choose.

Research contacts

If you have any further questions about this research, please don't hesitate to contact either Myself, or my supervisor, Dr Kirsty Ross (K.J.Ross@massey.ac.nz).

Appendix B

Sibling Needs Survey Advert

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

SIBLING RESEARCH

We would love to hear your voice

We want to offer better support services to siblings of children with serious chronic illness in New Zealand, but to do this we need to hear from you.

- Are you 16 years old or over?
- Do you have a sibling or someone who was like a sibling to you (cousin, whāngai) who was diagnosed with cancer, Type 1 diabetes, or cystic fibrosis, one year ago or longer?
- Were you living at home with your family/whānau when they were diagnosed?

If you said 'yes', we'd like to invite you to do a 10 - 15 minute online survey. Please click on the link or email siblingneedsresearch@gmail.com to have it sent to you.

Appendix C

Information sheet

Researcher introduction

Kia ora, my name is Katie Armstrong. I am a postgraduate student at Massey University studying towards a Master of Arts (Psychology). I would like to invite you to take part in my research project which is to identify the unmet needs of siblings of children with cancer, cystic fibrosis, or Type 1 diabetes. Existing research shows siblings of children with chronic health conditions have a range of unmet psychosocial needs which can lead to adjustment difficulties and mental health problems. This research will contribute to the development of targeted services that will promote health and wellbeing in siblings.

Participant recruitment

To participate in the survey you will need to meet the following criteria:

• . Be 16 years old or over
• Have a sibling or someone who was like a sibling to you (brother, sister, cousin, whāngai) who was diagnosed with cancer, cystic fibrosis or Type 1 diabetes one year ago or longer
• Have been living with your family/whānau when your sibling was diagnosed.

Your participation will help the researcher identify the unmet needs of healthy siblings of children with chronic health conditions. Results of this survey will be analysed and the number and type of unmet needs will be identified. Differences and similarities between the unmet needs of siblings of children with cancer, cystic fibrosis and Type 1 diabetes will be compared. The researcher will also compare the needs of males versus females, and younger children versus teenagers.

Research procedures

Research data will be collected through an online survey which is estimated to take ten to fifteen minutes to complete. You will be asked to select whether you had 'no need', 'low need', 'moderate need', or 'strong need' across seven domains. These domains include: information about your sibling's illness; "time out" and recreation; practical assistance; support from friends and other young people; dealing with feelings; understanding from your family; and your relationship with your ill sibling. You will also be asked a question about how you feel your needs would have best been met.

Support

It is possible you may experience some level of discomfort from reflecting on a difficult time while completing the survey. You are welcome to skip a particular question or stop participating at any time. If your sibling/whānau member has cancer in the advanced stages, or if it has not been responsive to treatment, please consider carefully if participating in this survey is right for you at this time; thinking about your needs may cause you distress. On completion of the survey we will suggest some avenues of support should you need them. These avenues include linking in with your social supports/family/whānau, visiting your GP, or contacting one of the following organisations:

- Youthline 0800 376 633 - 24 hours a day, 7 days a week.
- Free call or text 1737 to speak to a trained counsellor - 24 hours a day, 7 days a week.
- Depression Helpline 0800 111 757 or free text 4202 - 24 hours a day, 7 days a week.

- Lifeline 0800 LIFELINE (0800 543 453) - 24 hours a day, 7 days a week.

Data management

Data collected will be used solely for research purposes. Survey answers will be anonymous. We will not record your name and should the results of this study be presented or published no identifiable information will be used. If you wish to receive a summary of findings for this research you will need to provide your email address but this information will be stored separately to your survey data. The data collected in this research will be stored securely on a password protected computer. De-identified data will be shared with other researchers for future research projects on request. Any identifiable data you provide, such as your email address, will be deleted as soon as the research is complete.

Participant's rights

Your participation in this research is completely voluntary. You are under no obligation to accept this invitation. If you decide to participate, you have the right to decline to answer any particular question or stop at any time. Completion and return of the questionnaire implies consent and indicates you are happy for your survey data to be used in this research.

Contacts

If you have any questions about this research, please feel welcome to contact me at siblingneedsresearch@gmail.com. Alternatively, you can contact my supervisor at k.j.ross@massey.ac.nz.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/21. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix D

Cultural Consultation

11th June 2019

Human Ethics Committee
Massey University

Tēnā koutou,

Re: Cultural Consultation – Katie Armstrong
Project Title: The Unmet Needs of Siblings of Children
with Cancer or Chronic Illness

I am writing to confirm that Katie has sought my cultural advice in preparing her ethics application and developing her research project. We have also had a phone conversation and I've had an opportunity to review her research proposal, her sibling needs survey, and a flyer advertising her study.

Katie's study aims to identify the unmet needs of healthy siblings in New Zealand and in doing so she hopes that her findings contribute to the development of targeted, evidence-based services to support siblings of children with cancer or chronic illness. Katie's proposed methodology is quantitative and she is using a survey and whilst her project does not specifically focus on Māori she has given a very impressive depth of consideration to the implications that her study could have for Māori. In particular she has spent considerable time and effort crafting her questionnaire to ensure that the wording does not marginalize Māori participation due to cultural nuances in the way that sibling relationships are defined in Te Ao Māori.

Based on my phone conversation with Katie and reviewing her materials I have every confidence that she is well prepared to ably and sensitively facilitate positive Māori participation in this study. Independent of this project, but still of considerable relevance, I am aware that Katie is undertaking further study in Te Reo Māori which will certainly enrich her capacity to undertake research involving the Māori community.

Finally, I have a close working relationship with Katie's first supervisor Dr Kirsty Ross and have indicated my availability to have an ongoing consultative role in this project should issues arise pertaining to Māori.

Noho ora mai rā,

Simon Bennett, PhD

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