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School Support for Siblings of Patients with Cancer

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Abstract

This research project investigated the importance of providing support structures within school communities for siblings of patients diagnosed and treated for cancer. A cancer diagnosis is traumatic and devastating for the child or young person with cancer but what sometimes gets lost is the impact such a medical event can have on siblings whose need for a range of emotional, social, academic, and physical support tend to be overshadowed by the focus on the patient and how the parents/caregivers cope. Sibling members of CanTeen New Zealand (an organisation which supports young people living with cancer and their siblings) were invited to participate in a nation-wide online survey or a focus group session in Auckland, both exploring siblings' perceptions of school based support. Both methods of data collection were created with the support of CanTeen staff and were informed by the literature surrounding support for siblings living in families affected by cancer. Participants responded to questions regarding who supported them at school, how they were supported, what they wanted members of the school community to understand, and what supports they wish had been available while they were on their cancer journey. Highlighted in the research findings were that different school communities fulfil different sibling needs, siblings' everyday lives are disrupted by their brothers' or sisters' cancer diagnoses, every cancer journey is different (shaped by a sibling's unique familial and community circumstances), and there is a need for home-school partnerships to ensure the best outcomes for siblings. By having siblings express their thoughts and feelings regarding the cancer journey in their own words, this research can provide valuable insight for schools who have students living in families affected by cancer and can act as a guide for how to best support the needs of this population.

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Hei whāngai i te harakeke

To nurture the harakeke/flax

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Table of contents

Abstract	i
Acknowledgements	ii
Table of contents	iii
Chapter 1 – Introduction	1
Chapter 2 – Literature Review	4
The impact on family systems	4
Post-traumatic stress and negative effects	6
Post-traumatic growth and positive effects	9
School counselling in New Zealand	12
Teacher support	15
Peer support	17
Home-school partnerships	19
Community and national support	22
Study rationale	23
Chapter 3 – Methodology	24
An ecological approach	24
Research design and rationale	25
Survey methodology	25
Focus group methodology	26

Participants	27
Criteria	27
Recruitment	28
Consent	29
Ethical considerations	30
Data collection	30
Online survey	30
Focus group	31
Data Analysis	32
Chapter 4 – Results and Discussion	34
Different school community members fulfil different sibling needs	35
The role of school peers	35
The role of teachers	37
The role of school counsellors	39
Disruption of everyday life	42
Change in routine	42
Change in family systems	44
Every journey is different	46
Length of treatment and other demographic variables	46
Address individual needs	48
An ongoing journey	49
Need for home-school partnerships	50

Importance of parental involvement	50
Need for supportive school climates	52
Chapter 5 – Conclusion	54
Limitations	54
Conclusion of findings	56
Recommendations for future research	57
Implications for practice	59
References	60
Appendices	69

Chapter 1 – Introduction

“Cancer is a word, not a sentence.”

– John Diamond

Having a sibling diagnosed with cancer can turn a child’s world upside-down. Many people would likely agree with the statement from cancer survivor Chris Reason (as cited in Collings, 2009) that “there are few more terrifying words in the English language than ‘cancer’” (pp.3-4). Every year in New Zealand, an average of 196 children are diagnosed with cancer (Ministry of Health, 2010). The National Plan for Child Cancer Services, released by the Ministry of Health (2010) stated that the incidence of cancer among children and adolescents aged 0 to 19 did not vary significantly in the seven years prior to the plan being published, calculating a mean of 15 per 100,000 children aged 0-19 years. Cancer has been described by some researchers as a ‘family disease’ (Chesler & Barbarin, 1987). Having cancer does not only impact upon the child with the diagnosis, but dramatically changes the normal everyday routines of their family, who must try to incorporate the demands of such a disease into their daily lives. While childhood cancer is no longer classified as a purely fatal disease due to advances in multiple treatments combined with earlier parental awareness of cancer symptoms, the experience for children can still be harrowing, involving repeated hospitalisations, long periods of chemotherapy, painful procedures, exhaustion, changes in appearance, and absences from their regular schooling (Hamama, Ronen, & Feigin, 2000; Rollins, 1990).

Siblings are able to significantly influence each other, therefore when one child is affected by a chronic illness, such as cancer, it is bound to affect their healthy siblings in some way or other (McKeever, 1983). When someone is faced with the threat of death involving a loved one, grief is an individualised experience with no predetermined course or time-frame, regardless of age or cultural background (Nolbris, Enskär, & Hellström, 2014). A number of school-aged siblings of patients with cancer have reported experiencing physical pain (Nolbris & Ahlström, 2014; Walker, 1988), struggles with emotional regulation (Houtzager, Grootenhuis, & Last, 1999; Nolbris & Ahlström, 2014), and problems at school relating to academic performance and behaviour (Fife, Norton, & Groom, 1987). When children are diagnosed with cancer, they usually become the focus of family, friends, and professionals (Rollins, 1990). While the parents are also widely included in this focus, siblings are frequently overlooked

during childhood illnesses, and have been labelled by some researchers as “the forgotten children” due to their isolation from support systems inside and outside the family (Rollins, 1990; Van Dongen-Melman, De Groot, Hahlen, & Verhulst, 1995). It is, therefore, important to explore what support systems can be accessed by siblings of patients with cancer, such as those which exist in a school environment, how those systems are currently meeting the needs of the sibling population, and what improvements can be made.

The environments that children and adolescents are immersed in can either encourage or discourage emotional expression and discussion of their issues (Kilmer, 2006). One of the environments where children and adolescents can form supportive relationships in is the school environment. School staff and students are in a position to help ease the burden siblings may experience in relation to their brother’s or sister’s cancer. Schools should be aiming to promote their pupils’ self-knowledge and emotional acceptance, while also encouraging positive student development so they can reach their potential and become content and productive individuals (Hornby, 2003b). By helping young people talk about their problems and providing them with validation and appropriate support, members of the school community can help siblings perceive some beneficial personal growth and view their cancer journey in some positive light (Kilmer, 2006).

While there is research in New Zealand that looks at the mental health of parents of children with cancer (Dockerty, Williams, McGee, & Skegg, 2000), research looking at the wellbeing of siblings of children with cancer in the New Zealand context is needed. Although international studies can give us an insight into what the experience of childhood cancer is like for siblings, exploring perceptions of support for siblings of children with cancer in the New Zealand context would be valuable for families here, as well as schools and organisations, who are dedicated to improving the lives of young people affected by the childhood cancer experience. Due to the lack of research in New Zealand, generally, and on school-based support for siblings of patients with cancer, specifically, within and outside New Zealand, there needs to be an exploration of the types of resources and services that are available in New Zealand to help this population, what support systems are most effective, and ways to best support these students.

Thus, the purpose of the current study was to explore siblings' perceptions of support in school. The study aimed to answer the following four questions:

- Who/what are supports for siblings at school;
- How were they supported during their cancer journey;
- What do siblings wish people understood about the impact of a cancer diagnosis on their lives; and
- What supports do siblings wish had been available?

This thesis is presented in five chapters. Following the introduction chapter, the second chapter explores the literature surrounding siblings' cancer experiences, including the negative and positive impact a cancer diagnosis has on the whole family. Chapter two also takes a look at how school communities function in the context of Aotearoa New Zealand and explores the roles that school counsellors, teachers, and school peers can play in providing siblings with support throughout their journey. Chapter three describes and justifies the methodology employed to answer the research questions. Chapter four provides an overview of the results and themes that emerged from the research in relation to the research questions and literature review. The fifth chapter discusses the limitations of the research, recommendations for future research, implications for practice and a conclusion of the study.

Chapter 2 - Literature Review

“Call it a clan, call it a network, call it a tribe, call it a family. Whatever you call it, whoever you are, you need one.”

– Jane Howard

The impact on family systems

To better understand the cancer journey through the eyes of a sibling, there needs to be an exploration of the young person's life, what they may be watching their sibling with cancer go through and how their parents are coping with the illness of a child. Being diagnosed with cancer is bound to greatly affect the individual with the diagnosis and bring about stressful life changes. Through interviews with parents, nurses, and patients, Hedström, Haglund, Skolin, and Von Essen (2003) investigated distressing events that occur for children and adolescents with cancer, ranging in age from infancy to 19 years old. Patients most often discussed the physical repercussions related to the disease, with the most common events experienced being feelings of nausea, pain from diagnostic procedures and treatment, and fatigue (Hedström et al., 2003). Participants also noted emotionally distressing cancer-related events, including feelings of alienation and isolation, and anxiety before medical procedures (Hedström et al., 2003). Collins and colleagues (2000) investigated symptom prevalence, characteristics, and distress in young cancer patients and collated the following list of the most common symptoms experienced by participants: “lack of energy, pain, drowsiness, nausea, cough, lack of appetite, and psychological symptoms (feeling sad, feeling nervous, worrying, feeling irritable)” (p.363). Of course, these symptoms are just a small selection of the possible side effects associated with cancer and treatment. Children and adolescents with cancer have also reported experiencing insomnia, diarrhoea, constipation, hair loss, weight loss, fever, and lack of concentration, among other symptoms (Collins et al., 2000; Hedström et al., 2003). While going through these emotionally and physically distressing events must be harrowing for patients, it is likely that it would take a toll on loved ones watching them suffer, as well.

A child's cancer diagnosis has the ability to affect multiple areas of a parent's life, and this either directly or indirectly affects the wellbeing and experiences of their other children. Kobayashi, Hayakawa, and Hohasi (2015) explored the interrelations between siblings and their

parents when living with a child with cancer. Their study revealed three stages that a family face following a child's diagnosis: "(a) role changes and relocation of family members and subsystems, (b) managing to maintain stability of the family unit, and (c) reuniting of family members and subsystems into a unit" (Kobayashi et al., 2015, p. 133). In the first stage, the siblings' experiences are largely influenced by the parents' experiences, as decisions about where to live, who takes care of them, and how much knowledge the sibling has about their brother's or sister's illness all lies in the hands of the parents (Kobayashi et al., 2015). Families experience a lot of stress and exhaustion during the second stage, faced with dividing their time between home, work, and the hospital, and trying to keep the family connected (Kobayashi et al., 2015). In the second stage, siblings appear to be aware of the challenges their family members face and repress their own feelings so they do not burden their parents (Kobayashi et al., 2015). Once the family is reunited and the threat of cancer has faded, the members re-evaluate their relationships within the family unit and recognise the importance of sticking together (Kobayashi et al., 2015). At this point, parents also realise they may need to repair relationships with their other children and show them more care (Kobayashi et al., 2015).

Research regarding the effects of a cancer diagnosis on the family system typically focuses on parents; a central concern of this project was to expand this focus to include the wellbeing of siblings. Alongside dealing with their own feelings related to having a sibling with cancer and witnessing the cancer-related struggles their brother or sister may face, siblings may also have to face their parents' struggling to come to terms with having a child diagnosed with such a disease. A number of children will have to deal with their parents' stress-related health problems (McKeever, 1983). A study in the Netherlands by Hoekstra-Weebers, Jaspers, Kamps, and Klip (2001) revealed that parents report high levels of psychological distress around the time their child was first diagnosed with cancer. For a parent, witnessing their own child suffer as a result of disease and treatment can lead to feelings of powerlessness and other intense emotions (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997). Parents of children with cancer commonly report feelings of shock, denial, anxiety, guilt, sadness, despair, uncertainty, chaos, loneliness, and fear during their child's sickness (Björk, Wiebe, & Hallström, 2005; Enskär et al., 1997; Patistea, Makrodimitri, & Panteli, 2000). Björk and colleagues (2005) describe this as a "broken life world", where the lives the family had previously known completely fall apart.

Parents of children with cancer often find themselves pre-occupied by the needs of their ill child, and have reported the difficulties associated with having to organise life around treatment and periods of hospitalisation, which places limits on their time, energy, and ability to meet all family members' needs (Sidhu, Passmore, & Baker, 2005; Sloper, 2000). Enskär and colleagues' (1997) research noted the extent to which a child's cancer dictated the family's everyday life. One interviewed parent stated that "Of course you just live from one day to the next... You can set up a goal for when you will do something, but then it has to be changed since the child has to go to the hospital" (Enskär et al., 1997, p. 159). A child's illness can negatively impact upon parents' ability to work and this seems to especially affect fathers (Enskär et al., 1997; Hoekstra-Weebers et al., 2001). Although both parents tend to stay in hospital for part or all of their child's treatment and accompany their child to appointments, fathers were more likely than mothers to be in full-time employment, leading to regular absences from work, and criticism and annoyance from colleagues (Hoekstra-Weebers et al., 2001). Having a child with cancer can also place financial strain on the family, especially when the family has to travel out of town for treatment (Enskär et al., 1997). Families vary in their ability to cope with such strains on their work and finances, depending on factors such as whether or not they are a single parent household, the kind of support they have from extended family/whanau, and their financial stability.

Post-traumatic stress and negative effects

Although negative outcomes for siblings of cancer patients are not assured, they are certainly a population at risk for anxiety, confusion, and personal suffering (Bendor, 1990). Daily stressors would likely affect their everyday functioning, at home and in school life. There are a number of studies that look at post-traumatic stress disorder (PTSD) and associated symptoms (PTSS) in parents of children and adolescents with cancer (Brown, Madan-Swain, & Lambert, 2003; Kazak, Alderfer, Rourke, et al., 2004; Kazak, Alderfer, Streisand, et al., 2004) but there has been very little research exploring how other family members go through the same ordeal. Yehuda (2002) described the conditions needed in order to be diagnosed with PTSD:

A person has to have been exposed to an extreme stressor or traumatic event to which he or she responded with fear, helplessness, or horror and to have three distinct types of

symptoms consisting of reexperiencing of the event, avoidance of reminders of the event, and hyperarousal for at least one month. (p.108)

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013) expanded their previous definition of PTSD to acknowledge that PTS not only occurs for individuals who have been exposed to actual or threatened death or serious injury, but symptoms of the disorder can also be exhibited by witnesses to traumatic events and by people who learn that a close family member or friend has been involved in a traumatic event, or events.

Repeated exposure to details of the traumatic events can also contribute to the development of PTSS (American Psychiatric Association, 2013). For siblings of cancer patients, their brother's or sister's cancer diagnosis would be considered a traumatic event, which is usually followed by repeated hospitalisation and dealing with the side effects of the illness and/or cancer treatment. Symptoms of PTS can include recurrent and intrusive memories and dreams of the traumatic event(s), sleeping problems, feeling detached from others, detachment from self (depersonalisation), exaggerated negative beliefs, concentration problems, verbally or physically aggressive behaviour, and intense psychological distress (American Psychiatric Association, 2013). Alderfer, Labay, and Kazak (2003) looked at the prevalence of PTS in siblings of childhood cancer survivors, and found 49% of the sample reported mild PTS while 32% indicated moderate to severe levels of PTS. Over half of the sample population considered the cancer experience scary and difficult (Alderfer et al., 2003). Alderfer and colleagues (2003) found that siblings who were older than six at the time of diagnosis indicated more PTS symptoms than those children aged six or younger. It is possible that the older children's more vivid memories of events in their cancer journey and their greater understanding of the realities of cancer contributed to their higher levels of PTSS (Alderfer et al., 2003). Similar results were found by (Alderfer & Hodges, 2010) who reported in their sibling research that 54% of their sample population reported moderate to severe PTSS related to their cancer journey.

Studies looking at the responses of siblings to their brother's or sister's illness have also revealed that siblings can exhibit physical reactions throughout their cancer journey (Houtzager et al., 1999; Nolbris & Ahlström, 2014; Walker, 1988). A number of siblings who participated in a study by Nolbris and Ahlström (2014) reportedly experienced physical pain in relation to

their cancer experience. More specifically, Walker (1988) noted headaches, and stomach aches among some of the physiological responses of healthy siblings identified by parents since the diagnosis of their ill child. More than half of the 21 sibling sample who participated in a study by Heffernan and Zanelli (1997) reported experiencing headaches at school, specifically. Sleep disturbances have been noted in a number of studies looking at the physical reactions of children to their sibling's cancer diagnosis and related experiences (Heffernan & Zanelli, 1997; Nolbris & Ahlström, 2014; Walker, 1988). Nolbris and Ahlström (2014) specifically attributed poor sleep quality to thinking for hours and having nightmares. Such research suggests that school staff have a role to play in helping families when symptoms such as inattention, fatigue, and other physical symptoms are apparent and affect performance in the school environment.

Siblings also display externalised social responses (including concerns about their social competence and school related problems), and internalised emotional responses related to the siblings' feelings of distress regarding their brother's or sister's illness (Houtzager et al., 1999). Some siblings have reported having issues controlling their emotions and would easily get angry at home with their parents and healthy siblings, as well as in school and with their school friends (Nolbris & Ahlström, 2014). Fife and colleagues (1987) explored the effects of the stress of childhood leukaemia on family life and looked at the impact on individual family members. As part of the study, data were collected from patients' and siblings' school teachers. A decline in academic performance was noted in 38.7% of the siblings, while incidences of behaviour problems (including hostility, being uncooperative, attention seeking, and withdrawal) were exhibited by 54.8% of the sibling sample (Fife et al., 1987). Siblings' academic functioning can be affected by many factors: fatigue, demands of increased household responsibilities, and the decline of parental supervision and involvement in their healthy children's school life (Barbarin et al., 1995). Siblings may experience stigmatisation by peers, which can lead to shyness and social isolation at school (Barbarin et al., 1995). Interestingly, Cairns, Clark, Smith, and Lansky (1979, as cited in Bendor, 1990) compared the results of psychometric tests conducted with school aged cancer patients and their healthy siblings and found that siblings reported higher levels of distress than the patients in terms of "perceived social isolation, perception of their parents as over indulgent and over protective of the sick child, fear of expressing negative feelings, and concern with school failure" (p.19). Some sibling responses to the cancer journey

can be more obvious to outside observers than others, but families and communities need to be aware of all the possible risks to sibling wellbeing and behaviour.

There is debate in the field of paediatric oncology as to the role age and gender play in predicting a sibling's frequency of problem behaviours in response to the cancer experience. According to Barbarin and colleagues' (1995) research, sibling age, sibling gender, birth order and severity of cancer diagnoses were all found to be unrelated to the frequency of problems experienced by siblings after their brother or sister was diagnosed. In opposition to Barbarin and colleagues' (1995) findings, two significant findings emerged in Sahler and colleagues (1994) research that related to gender/age differences among siblings of children with cancer. Firstly, problem behaviour was most commonly reported in boys aged 11 or younger (Sahler et al., 1994). Secondly, older girls in the sample (which ranged from siblings aged four to 18 years) appeared to experience a greater increase in distress compared to boys or younger girls (Sahler et al., 1994). It was suggested that in accordance with social norms, older girls may be expected to adopt more responsibilities around the house and take on a caregiving role to help out their parents, which could negatively impact upon their normal social routines (Sahler et al., 1994). No matter the age of the sibling, measures need to be in place to cater for any potential issues they may face.

Post-traumatic growth and positive effects

Data focusing solely on dysfunctional behaviours of siblings rather than adaptation or resiliency related to the cancer experience may not be helpful when exploring what resources would be useful to help siblings adapt and promote resilience (Sahler et al., 1994). Attention also needs to be drawn to the positive outcomes for families faced with childhood cancer. While it is possible for siblings of cancer patients to experience PTS and other negative effects, siblings can also experience post-traumatic growth (PTG) from their cancer journey. Tedeschi and Calhoun (2004) defined PTG as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (p.1). PTG goes beyond effective coping and adjustment when faced with a crisis, but rather profoundly affects the individual which results in transformation (Kilmer, 2006). In their review on the literature surrounding PTG, Calhoun and Tedeschi (2006) found that the greatest amounts of growth have been reported to occur in people who experience high levels of stress related to the crisis, and also suggested that

in order for PTG to occur, “the set of circumstances the individual faces must present a significant degree of threat to the preexisting assumptive world” (p.9). The cancer experience can provide siblings with opportunities to demonstrate their maturity, supportiveness, and independence in the face of adversity (Barbarin et al., 1995). Trauma can also lead people to experience a greater sense of compassion with others who struggle with life difficulties (Kilmer, 2006). The demands of an illness such as cancer can provide siblings with the opportunity to display acts of self-sacrifice and generosity in responding to the needs of others (Barbarin et al., 1995). Barbarin and colleagues (1995) found that these positive effects from the cancer experience were more likely to occur among adolescent and first-born siblings, and also when the patient's prognosis was poorer.

It is important to note that there are different influences in children's lives compared to adults' which means different models of understanding PTG are needed. As illustrated in Kilmer's (2006) hypothesised model of PTG in children below (Figure 1), children's adaptability in the face of trauma can be influenced by their parents' reactions, severity and duration of trauma, and their ability to cognitively process events, to name a few factors. Pynoos, Steinberg, and Wraith (1995, as cited in Kilmer, 2006) also suggested that factors such as a child's developmental level, including their ability to make cognitive discriminations, self-esteem, and history of prior trauma can all impact upon the likelihood of a child achieving PTG.

Also illustrated in Figure 1, trauma can act as a catalyst for change and encourage survivors to take a new perspective on relationships, such as discovering who they can discuss intimate details of their life with and who they can depend upon in times of need (Kilmer, 2006). Björk and colleagues (2005) identified a theme of “striving to survive”. Many families made an effort to take back control in their lives and strengthen their bonds with others (Björk et al., 2005). Eighteen months after a cancer diagnosis, half of the siblings who participated in a study by Sloper (2000) reported gaining stronger family relationships, due to an increase in communication within the family and the common need to cope with the threat to the family's wellbeing. The same proportion of siblings also noted an increase in independence and maturity, due to an increase in responsibilities at home, and gained greater understanding and compassion due to contact with ill children and the knowledge of illness (Sloper, 2000). Almost a third of mothers who participated in a study by Heffernan and Zanelli (1997) indicated that their healthy

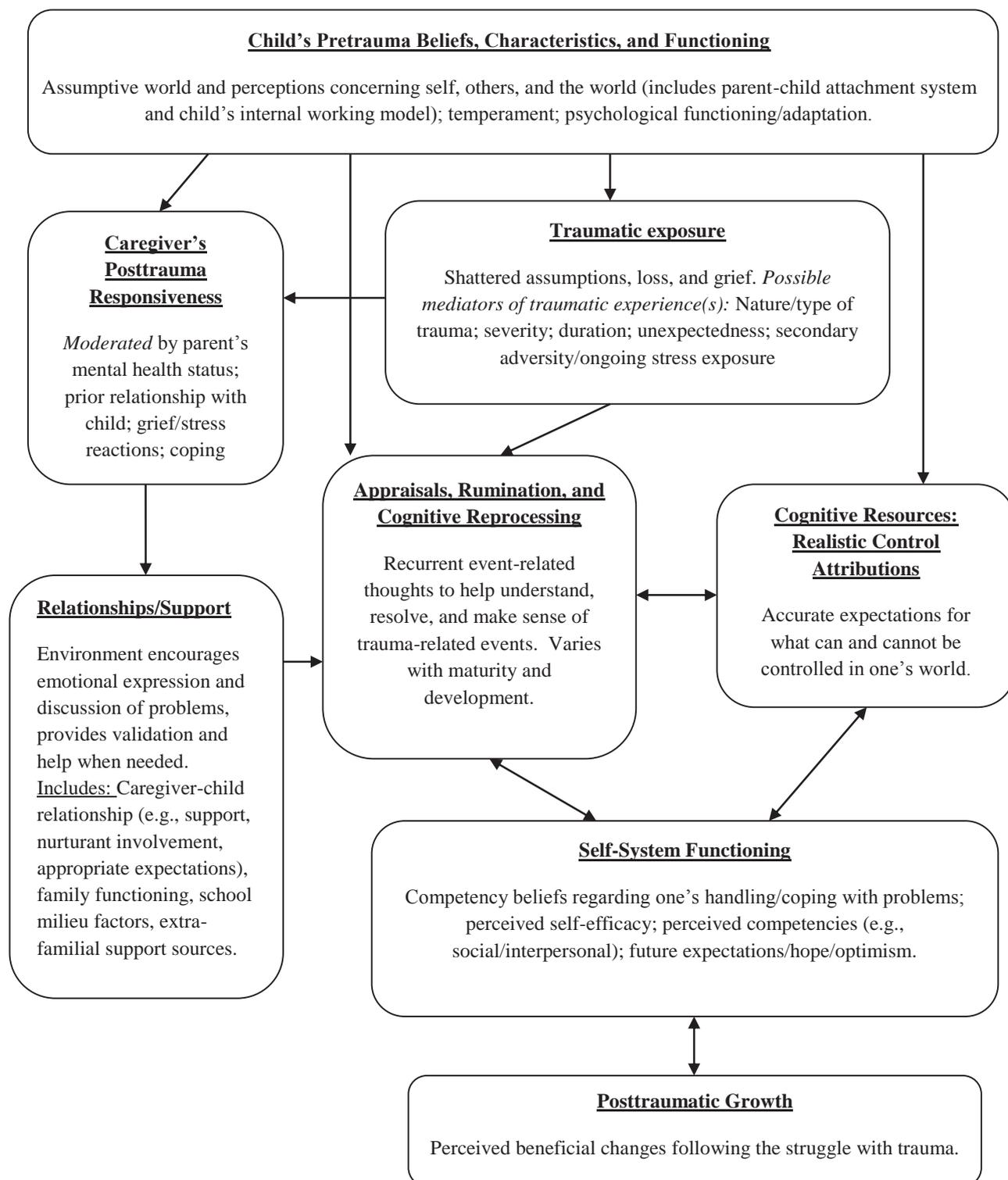


Figure 1: A hypothesised model of PTG in children (Kilmer, 2006, p.271)

children were more thoughtful in light of their sibling's cancer diagnosis, while 57.1% of mothers reported their healthy children as being more sensitive to the needs of others. Living in a world where the media so often focuses on the tragic discourse of cancer (Breaden, 2003), studies which focus on PTG and other positive effects showcase the strength families can exhibit when faced with adversity.

Balanced perspectives on the possible effects are especially critical in the school setting, where siblings of patients with cancer could be supported by school staff, such as school counsellors and teachers, and also school peers. The following sections detail some of the sites and potential support systems in the New Zealand education environment.

School counselling in New Zealand

The New Zealand Association of Counsellors (2012) Code of Ethics described the nature of counselling as the following: "Counsellors seek to assist clients to increase their understanding of themselves and their relationships with others, to develop more resourceful ways of living, and to bring about change in their lives" (p.3). On-site counsellors are able to actively help students improve on their educational outcomes and attend to their wellbeing, by, for example, building resilience and self-esteem, assisting with family/whānau communication, and connecting students with information and resources relevant to their situation (New Zealand Association of Counsellors, 2015a). During the 1960s, guidance and counselling positions in secondary schools were formally established in New Zealand, resulting in at least one counsellor being employed at each state secondary school by the late 1970s (Education Review Office, 2013a; Hermansson & Webb, 1993). Since then, a shift towards a free market ethos and the introduction of policies such as the Picot Report (Picot, 1988) and Tomorrow's Schools (Ministry of Education, 1988) has resulted in schools being self-governed and self-responsible, and the employment of counsellors has become optional (Hermansson & Webb, 1993; Payne & Lang, 2009). As stated in section 77 of the 1989 Education Act (Ministry of Education, 1989) "the principal of a State school shall take all reasonable steps to ensure that students get good guidance and counselling." While the Boards of Trustees have a legal obligation to provide a school environment which is both physically and emotionally safe, the Ministry of Education does not provide any national guidelines and standards about how guidance support should be provided (Education Review Office, 2013a; Payne & Lang, 2009).

In documenting the history of guidance and counselling in New Zealand, Hermansson and Webb (1993) expressed concern that in their movement towards local management in education, some schools may not take advantage of employing counsellors. Schools in New Zealand with small rolls (100 to 400 students) are less likely to have guidance counsellors than those with a greater number of students (Education Review Office, 2013a). Hermansson and Webb (1993) also believed that an expansion of services beyond secondary schools would be unlikely in their near future. In 1987, eight intermediate schools introduced new staff members who would take the role of ‘guidance resource teachers’ (Tuck, Adair, & Manthei, 1990). The work of guidance resource teachers involved supporting teachers in dealing effectively and positively with their students, developing and coordinating effective guidance networks in the school, and liaising with other agencies to provide support services to the school. One of the ‘innovations’ which emerged was counselling of students and staff to a greater extent, which involved crisis counselling, developmental counselling, the provision of ‘quiet rooms’, and mediating both pupil-teacher and pupil-pupil conferences to resolve conflict (Tuck et al., 1990). After two years, the teachers in schools with guidance resource teachers perceived a significant increase in the quality of the support for students with personal crises and special needs and were encouraging greater parental involvement (Tuck et al., 1990). As the guidance resource teacher was an integral part of the school and involved in staff development, they were ideally positioned to support teachers, refer to outside agencies and help monitor individuals (Tuck et al., 1990). Tuck and colleagues (1990) concluded that the new position had a positive impact on the schools and fulfilled an obvious need as intermediate schools are under-resourced when it comes to trained guidance personnel.

Although such research supports the validity of placing guidance and counselling staff in pre-secondary schools in New Zealand, there has been little movement in the direction of making this a reality. Twenty-five years on from Tuck and colleagues’ (1990) research, the New Zealand Association of Counsellors (2015b) is still pushing for counselling services to be available at primary and secondary schools, stating in a press release “by introducing counsellors at a primary and intermediate level, you are providing these young students with regular access to someone in whom they can establish trust and from whom they can get much-needed support if they have problems at home” (no page given). In order for trust to be built between young people and counsellors, the provision of quality counselling services should be available early on

in their schooling and allow for frequent access (New Zealand Association of Counsellors, 2015b). The press release also stressed the importance of early intervention, being ‘the fence at the top of the cliff’, and being able to work with whole families to help them resolve problems and connect them with appropriate professionals or agencies, if required (New Zealand Association of Counsellors, 2015b).

In their review on guidance and counselling in New Zealand, the Education Review Office (2013b) found that just under two-thirds of schools were doing ‘well’ or ‘very well’ in providing students with guidance and counselling, while over one-third of schools had room for improvement. The schools that were assessed as providing good care to their students had a strong ethos of care with “a commitment to the holistic wellbeing of students, and an understanding that student wellbeing is critical to learning and achievement” (Education Review Office, 2013b, p. 15). The majority of the schools providing good care also provided guidance and counselling staff with appropriate, comfortable spaces where students could seek help and communicate freely (Education Review Office, 2013b). The Education Review Office (2013b) also noted that in addition to preventative programmes, these schools also had sound procedures in responding to critical incidents and good practices regarding seeking help from external sources.

In some of the schools that were classified as needing to improve their guidance and counselling practices, Education Review Office (2013b) found that guidance and counselling staff were dealing with high caseloads (especially in schools with large or very large rolls) and were in need of reviewing their strategic resourcing. Underpinning philosophies of care informing guidance and counselling also appeared to need clarifying in strategic planning (Education Review Office, 2013b). The Education Review Office (2013a) reported that of the students who participated in a survey on guidance and counselling in schools, 65% said it was socially acceptable to seek support at school for guidance and counselling, while the remaining third of students believed it was unacceptable. The stigma attached to seeking guidance counselling is a challenge for some schools and work needs to be done to break down this and other barriers to students’ seeking help.

Teacher support

In their review on how to improve guidance and counselling in secondary schools, the Education Review Office (2013b) adapted a 'circle of care' approach used in Manitoba, Canada (Manitoba Education & Citizenship and Youth, 2007) for New Zealand schools with the student situated in the centre of several layers of care, guidance and counselling being just one of those layers, and the guidance counsellor as one of many sources of support in an in-school guidance and counselling team (as shown in Figure 2). In Manitoba, guidance and counselling is viewed as a shared responsibility of all staff, where each member has a specified role (Manitoba Education & Citizenship and Youth, 2007). As students choose to discuss their issues with multiple individuals and/or groups throughout the school community, there is a need for a clear and systematic approach to guidance and counselling which is understood and applied by everyone (Education Review Office, 2013a). The Education Review Office (2013a) asked students who they would talk to about a variety of issues, including learning issues, health issues, family problems, and issues with friends. While students were more likely to confide in guidance counsellors regarding mental health issues, issues with friends, grief, and family problems, students were more likely to turn to a form teacher or dean to discuss issues with learning over other school staff (Education Review Office, 2013a). It appears that different school staff have different roles to play in providing care and support to students, though all play vital roles in shaping student wellbeing. However, many schools in New Zealand are not maximising this 'circle of care' ethos. While teachers should be seen as a source of support for young learners, one-third of the students surveyed by Education Review Office (2013a) reported that no one, other than the guidance counsellor, provided guidance and counselling at school.

During the adolescence stage of development, more time is spent at school, on school work, and on school-related activities, which can strengthen the bond between students and their teachers, and strengthens the bond they share with their school mates (Garnefski, 2000). Due to the daily school routine, teachers find themselves in regular contact with students and in an ideal position to be able to identify changes in children's behaviour (M. Biddulph, 2003; Hornby, 2003a). However, some researchers have argued that for students in intermediate and high school, the shift from having one primary teacher to multiple classroom environments (and likely larger class sizes) may result in fewer opportunities to develop close relationships with teachers

(Lynch & Cicchetti, 1997; Reddy, Rhodes, & Mulhall, 2003). The impact of the change in classroom environment has been supported by research by Lynch and Cicchetti (1997) which reported that while only 23% of primary school children perceived their pattern of relatedness with their teacher to be disengaged, over 60% of secondary school students reported disengagement with their teachers. Older children have also been found to be less likely than younger children to consider the quality of their relationships with teachers to be secure (Lynch & Cicchetti, 1997). Students are likely to vary in how they approach the challenges faced in adolescence and some will experience differing degrees of success in forming close relationships with their teachers (Reddy et al., 2003).

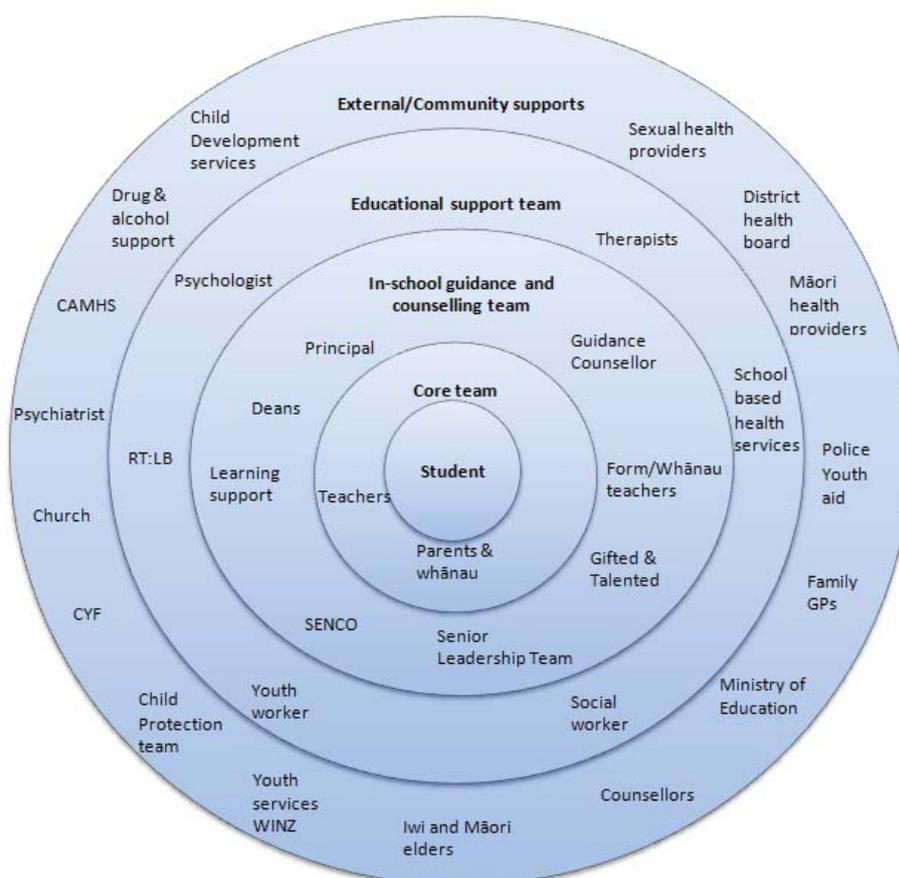


Figure 2: Circle of care (Education Review Office, 2013b, p. 10)

Teacher-student relationships also have an impact on student wellbeing. In their research looking at the influence of teacher support on student adjustment in American middle schools, Reddy and colleagues (2003) found that students who perceived increases in levels of teacher support over their time at middle school experienced decreases in depression and increases in self-esteem, while conversely, students who perceived decreases in the level of teacher support experienced increases in depression and decreases in level of self-esteem. In early adolescence, students are often facing changes in their self-identity, as well as attempting to negotiate changes in their relationships with family and friends (Reddy et al., 2003). Separate from these struggles, teachers have the ability to act as a third party and provide support and guidance to students which comes with adult advice from an adult perspective (Reddy et al., 2003).

Considering the increased time spent at school and the influence teacher-student relationships can have on school performance and wellbeing, teachers and other school staff could be important sources of support for siblings of patients with cancer. Siblings interviewed in research by Björk and colleagues (2005) indicated that they turned to friends and teachers in school as sources of hope and support. Teachers were also noted by Sloper (2000) as important sources of support and information, providing siblings with comfort and a focus outside of the illness. Alderfer and Hodges (2010) found that greater levels of teacher social support perceived by siblings in their study were significantly related to better school performance. Support from teachers was rated as equally important to siblings as support from parents, and the amount of support received from both groups was also rated as equal (Alderfer & Hodges, 2010). Despite the role of school support being mentioned briefly in many studies relating to the wellbeing of siblings of cancer patients, there is a need for research looking more in-depth at what schools do (or could do) to support this sibling population, and what teachers could specifically do to help siblings.

Peer support

Child development plays a major role in the impact of childhood cancer experiences on siblings in terms of their understanding of the disease and the support they may require. One of the aims of the current study was to find out how school peers and friends could be better educated on the experiences of siblings of patients with cancer and how they can provide support to those siblings. For younger children, the major source of social support appears to be received from

parents and family members (Barrera, Fleming, & Khan, 2004). When children reach school age, they experience a transition from family relationships to identifying strongly with their school peers (Murray, 2000b). Peers can widely influence other children's self-esteem, and anything that may identify a child as being different can negatively affect their sense of belonging in a peer group (Murray, 2000b). During adolescence, relationships with peers typically grow in importance and in closeness, and peers also become the models against which adolescents measure acceptability (Garnefski, 2000; Murray, 2000b).

Having a sibling with cancer is an experience that the majority of school children and adolescents are unfamiliar with. Consequently, it may be a topic that many children and young people are uncomfortable discussing. In a study by Sidhu and colleagues (2005), parents discussed in focus groups that siblings were often isolated in school and felt unsupported by their school peers. Siblings aged eight to 13 who participated in focus group discussions in a study by Bendor (1990) reported that they made periodic attempts to share their feelings of frustration and loneliness with friends, but the attempts were made in vain. The situation siblings find themselves in was made more difficult and lonely due to the lack of social interaction outside of school (Bendor, 1990). A child's sense of belonging can be negatively affected when they are not able to participate in after-school activities, such as sports events, as a result of their altered family care-taking responsibilities after their sibling was diagnosed with cancer (Murray, 2000b). Siblings have also reported changes in their own social activities due to restrictions being placed on their friends visiting to reduce the risk of infection (Sloper, 2000). Anxieties around peer support can be an issue for older siblings as well, with siblings in a focus group for young people aged 14 to 19, reporting that peers responses' varied from 'supportive' to 'disinterested', and the siblings feared that teachers and friends would gossip about them (Bendor, 1990).

Patterson, Millar, and Visser (2011) reported that most of the top unmet needs of siblings of patients with cancer related to peer support, which included receiving support from friends, spending time with friends, and spending time with peers who had gone through similar experiences. Research by Murray (2002) also emphasised how important it was for siblings to spend time with same-aged peers and to feel like they are a 'normal' child. The school environment is one place where siblings can be surrounded by friends and be provided with a sense of normality. In contrast to studies which emphasise the struggles siblings face in terms of peer support, a recent American study by Alderfer and colleagues (2015) suggests that siblings'

peer relationships do not differ significantly to those of their classmates, and siblings were similar in comparison to their peers in terms of social behaviours, number of reciprocated friendships, and level of peer acceptance. The researchers, however, noted that the sample was made up of children who were primarily white, well-educated, and high in socio-economic status, indicating that the results may not be able to be generalised to a broader population of families affected by cancer (Alderfer et al., 2015).

Secondary students reported that they were most likely to seek help and support from parents/caregivers, or friends and other students, before turning to any school staff (Education Review Office, 2013a). Support from peers can play a vital role in siblings' academic success at school and also impact upon their wellbeing in general. Peer groups, at secondary school in particular, can influence children's school achievement to a great extent, both positively and negatively, and can override parental expectations (F. Biddulph, Biddulph, & Biddulph, 2003). For siblings of children with cancer, greater support from friends and others in the school has been connected to better school functioning and was linked to better performance in reading skills, maths skills, critical thinking skills, as well as increased motivation (Alderfer and Hodges, 2010). Barrera and colleagues (2004) also found that siblings who had high social support had fewer behaviour problems and fewer symptoms of depression and anxiety compared to siblings who were found to have less social support. Findings such as these reinforce the importance of having peer support at school throughout one's cancer experience and add validity to the exploration of how to make sure students receive that support.

Home-school partnerships

As previously discussed when exploring the impact on family systems, siblings often perceive changes in family relationships and routines, which can include spending less time with both parents (creating a distance from their most common source of social support), and dramatic shifts in family roles, responsibilities, and dynamics (Alderfer et al., 2003; O'Shea, Shea, Robert, & Cavanaugh, 2012). Family type or family structure itself is less important than the effect of adverse outcomes (e.g. a cancer diagnosis) which changes the family structure, possibly limiting the ability of families to dedicate time and resources to their children's development (F. Biddulph et al., 2003). The demands of having a child who is sick could potentially contribute to parents' disengaging from the learning environments of their other children. With this in mind,

teachers and other school staff have a role to play in alerting families to the emotional needs of their healthy children.

It should be noted that notions of family may differ in New Zealand and between cultures. Therefore, it is important to explore home-school relationships within the New Zealand context as there are unique cultural differences that influence practices and outcomes, especially for Māori families. Rokx (1997) uses a harakeke (flax plant) analogy to illustrate the interdependency between the family unit and the wider whānau network: the core shoot of the harakeke represents the child, the other two main shoots represent the parents, while the rest of the shoots represent the family's wider whānau, enclosing the three main shoots which must remain intact in order for the plant to survive. In Māori families, parenting roles are not restricted to a child's parents. Instead, responsibilities such as reprimanding or providing a child with food and affection can be taken on by siblings, aunts, uncles, cousins, and grandparents (Richie & Richie, 1997; Rokx, 1997). There are certain challenges that may arise from different school settings (for example, rural, or low decile) or schools founded on different philosophies (such as Māori-medium) but it is important for schools and whānau to come to a shared understanding on how best to provide for students and to ensure collaboration within the school community is beneficial for all children (Mutch & Collins, 2012).

Educators are the stimulus for engaging families in their children's education, and can achieve the greatest success in engaging parents or guardians in a partnership when the school is responsive to the personal characteristics and needs of the family (Christenson, 2004). When specific circumstances (such as childhood cancer) inhibit parents' ability to get involved in their children's schooling, schools need to come up with strategies to support the family's healthy children, which could involve another individual acting as a contact between the family and the school regarding the students' needs (Christenson, 2004). Despite the importance of forming home-school partnerships, there are currently no requirements by government education policies which enforce the inclusion of comprehensive teacher training courses on working with parents in New Zealand (Hornby & Witte, 2010a), much less having difficult conversations about serious illness. A series of studies published in 2010 which looked at how schools in New Zealand address and encourage parental participation in the educational experiences of their children revealed that very few schools had a policy written specifically regarding parental

involvement, while the majority of the schools' principals reported minimal or no in-service training for their staff on parental involvement (Hornby & Witte, 2010a, 2010b, 2010c, 2010d).

Educators need to attend to the social dimension of learning, looking at social development and sense of self, and recognise the influence of family and community on a child's wellbeing and academic development (F. Biddulph et al., 2003). In a report for the Ministry of Education on the key features of successful home-partnerships, Bull, Brooking, and Campbell (2008) suggest that while each school has unique characteristics and contextual differences, successful home-school partnerships in New Zealand should generally (a) involve relationships that are both collaborative and mutually respectful; (b) be responsive to the needs of the community; (c) be embedded in schools' development plans; (d) be focused on learning; (e) encourage parental engagement at home in children's learning; and (f) facilitate two-way communication between families and school. Home-school partnerships should not be seen as optional, but rather a crucial element of teaching.

Bull and colleagues' (2008) research revealed that many teachers perceived their attitudes towards parents to be instrumental in forming successful home-school partnerships, and their beliefs were reflected in the responses from parents who felt that the positive attitudes of the teachers were influential in getting them involved in their children's learning. When teachers establish a positive two-way communication with parents/caregivers, they are able to provide guidance to families and work collaboratively to tackle the child's issues (Hornby, 2003a). In trying to nurture families burdened by stress, educators should attempt to understand the family perspective on how stressors could impact upon their lives, and work alongside families to identify ways to cope with stressful situations (Swick & Williams, 2006). Fife and colleagues (1987) noted that when problems were detected with a sibling, teachers' willingness to offer help appeared to be linked to the parents' ability to preserve a positive relationship with the school. It is essential that all children have the support of both their teachers and their whānau throughout their education so that there is trust and understanding between home and school during times that support is needed the most.

Community and national support

Alongside the valuable support from whānau, friends, hospital staff, schools, and other community networks, two organisations in New Zealand provide essential additional support to families affected by childhood cancer to help them with their emotional and physical wellbeing, and help families deal with everyday challenges associated with cancer: Child Cancer Foundation and CanTeen New Zealand. The Child Cancer Foundation supports families affected by childhood cancer at every stage of the cancer journey by providing services that reduce the impact of cancer and feelings of isolation (Child Cancer Foundation, 2010a). Families are assisted by family support coordinators who provide support across multiple settings, including in hospital and home, information and resources, financial assistance, assistance with connecting to other agency and support groups, and advocacy for the needs of children with cancer and their families (Child Cancer Foundation, 2010b). There are a number of support programmes, events, and activities that are on offer for various family members, including siblings, which aim to reduce isolation, provide information, and support the family through their cancer journey (Child Cancer Foundation, 2010b).

CanTeen aims to support, develop, and empower young people, aged 13 to 24, living with cancer and also provides support to their siblings (CanTeen, n.d.-c). CanTeen recognises that having a brother or sister living with cancer can be difficult, and losing a sibling can be even harder (CanTeen, n.d.-c). CanTeen also acknowledges that alongside complications from living with cancer, young people may also be struggling with issues surrounding relationships, education, and identity (CanTeen, n.d.-a). With this in mind, CanTeen offers recreational and educational programmes to help patients and siblings regain a sense of normality in their lives, and they also organise regular camps, workshops, and support groups which can help adolescents build confidence, leadership skills, and help deal with the stress and pain that is associated with childhood cancer (CanTeen, n.d.-c). The work of CanTeen staff rests firmly upon the belief that “young people – through meeting, talking and sharing their experiences – are better able to cope with the uncertainties of living with cancer” (CanTeen, n.d.-a). CanTeen provides individualised one-on-one support for members, such as lending a hand with studies and putting members in touch with professional counsellors (CanTeen, n.d.-b).

Study rationale

There are gaps in the research regarding the wellbeing of siblings of patients with cancer and what supports are available, specifically at schools, for this population. Research has shown that young siblings of patients with cancer are a population susceptible to PTSS and are at risk of personal suffering in relation to their brother's or sister's diagnosis (Bendor, 1990; Alderfer et al., 2003). As highlighted in the work of Kilmer (2006) and others who have explored PTG and positive outcomes of traumatic events, the relationships that children form, at home and in other environments they are embedded in have the potential to create positive change and promote resilience. Having appropriate emotional and social support are protective factors for any child or young person, regardless of whether or not they are on a cancer journey. The literature review also highlights the importance of conducting research in the New Zealand context. Ideas on how guidance and counselling are provided in schools differ between countries, and counsellors are only widely available in secondary schools in New Zealand. Concepts of family/whānau and the roles that family members take on in Aotearoa can vary as well, and may affect how families cope with a cancer diagnosis. The current research aimed to open up a discussion on the wellbeing of siblings of patients with cancer, explore how schools are currently meeting their needs, and what the future of school-based support for siblings should look like. The following chapter details the methodology chosen to achieve this aim.

Chapter 3 – Methodology

“The most basic of all human needs is the need to understand and be understood. The best way to understand people is to listen to them.”

– Ralph G. Nichols

An ecological approach

Viewing childhood chronic illness through an ecological lens, the effects of an illness such as cancer do not stay contained within the child (Kazak, 1989). Changes in one family member will influence every other member, such as parents having to attend hospital appointments and leaving the care of their other children in someone else’s hands, siblings taking on more responsibility at home due to their parents attending to their child with cancer, or siblings having to miss out on school or extracurricular activities because no one can transport them. Bronfenbrenner (1979) offered a bio-ecological perspective on understanding child development, which is made up of a number of interacting systems, and can be viewed as “a set of nested structures, each inside the next, like a set of Russian dolls” (p.22), similar to the harakeke analogy discussed by Rokx (1997). Each system has varying degrees of influence over a child’s development, though each level plays a crucial role. The child sits at the centre of the model and the “nest” or systems closest to the child represent the immediate environment, the relationships and activities they are involved in, and settings such as family, school, and neighbourhood (Kazak, 1989; Siegler, Deloache, & Eisenberg, 2006; Swick & Williams, 2006). The outer layers, or systems, further away from the child represent settings that children are not directly involved in but can still impact upon their lives, for example, their parents’ work, societal values, laws, and culture (Kazak, 1989; Siegler et al., 2006). Based on this model, the school is viewed as intimately connected to a child’s development. It is also important to keep in mind that these systems do not work in isolation. In emphasising the need for family-school partnerships, Christenson (2004) stated that “children’s level of academic, social, and behavioural competence cannot be understood or fostered by locating problems in child, family, or school in the absence of a focus on the dynamic influence of relationships among the systems” (p.95). Using an ecological approach, the current research questions were designed to explore the relationships between siblings and their school peers, teachers, and other school staff, and also to explore how the family systems and school systems interact with each other.

Research design and rationale

This study endeavoured to explore the importance of providing support structures within school communities for siblings of cancer patients in what CanTeen calls their ‘cancer journey’. CanTeen specifically refers to the cancer experience as a ‘journey’ in recognition that the effects of cancer on the self and families does not end after treatment. The choice in methodology was informed by the information that would be the most valuable to CanTeen and similar organisations. As well as providing psychosocial support as described in the literature review, CanTeen values a narrative approach and encourages storytelling to connect people. In order for appropriate support to be provided for siblings, it is important to allow the siblings of cancer patients to tell their stories and express their feelings and thoughts in their own words in order to gain a greater understanding of the cancer experience and the resources they found helpful (Sloper, 2000; Wilkins & Woodgate, 2005). For this investigation, data were collected using predominantly qualitative methods, through a nation-wide online survey, as well as through a small focus group session. The survey consisted of a series of open-ended questions, allowing participants to describe their experiences in their own words, though some questions had a quantitative component, such as the use of Likert scales to indicate quality and accessibility of counselling services. The survey questions were created by the researcher in collaboration with CanTeen staff and included questions adapted from the Nurse-Sibling Social Support Questionnaire developed by Murray (2000a) to explore support from school staff, rather than support from health professionals. The focus group was conducted by the researcher using a semi-structured approach. As well as consulting CanTeen staff on appropriate questions for the focus group, the researcher consulted with a former member of CanTeen (a bereaved sibling for 12 years) who approved the questions and allowed the researcher to practise her interviewing skills with her before working with the participants.

Survey methodology. Online surveys have the advantage of gaining access to groups and individuals who might be difficult to reach through other methods (Wright, 2005). Given that one of the aims of the research was to find out about siblings’ experiences across New Zealand, the online survey method eliminates issues of travel to interview suitable candidates or costs associated with sending out surveys by post. Conducting research online also allows the researcher to have contact with people who may be reluctant to speak face-to-face (Wright,

2005). Due to the sensitive nature of a topic such as childhood cancer, participants might prefer to share information anonymously. In collaboration with a CanTeen youth worker, great care was taken to ensure that the wording of questions was sensitive and appropriate for siblings of cancer, as well as adolescents and young people. In consideration of young people's busy lives, the number of survey questions was limited so that the survey could be completed within 15 to 20 minutes.

Focus group methodology. The focus group technique can be described as “using a semi-structured group session, moderated by a group leader, held in an informal setting, with the purpose of collecting information on a designated topic” (Carey & Smith, 1994, p. 124). The rationale behind using focus groups to gather information is that with the proper guidance, participants can share detail-rich narratives of complex experiences, and give further insight into their attitude, beliefs, and actions (Carey & Smith, 1994). The focus group method allows a researcher to understand how people view their own reality (Krueger, 1993). In the current research, focus group methods were used after a number of participants had responded to the online survey. The purpose of conducting a focus group in the later stages of the research process was to obtain information that would confirm the responses found in the survey, and, more importantly, explore some of the topics in further detail.

Focus groups are an empowering method of research for participants and gives otherwise underprivileged and vulnerable groups an opportunity to express their opinions (Ivanoff & Hultberg, 2006). Data collection methods such as focus group sessions often reveal how cancer affects families, the meanings they attach to various aspects of the journey, and allows family members of cancer patients to use their own words to characterise their experiences and responses to the illness (Barbarin et al., 1995). The focus group environment allows participants to challenge or build on other's points of view (Ivanoff & Hultberg, 2006). By only using standardised external measures and questionnaires, the information we gain is only constructed by children acting as reactors and respondents to fixed stimuli (Woodgate, 2001). The researcher can come away from the session with multiple understandings and perspectives on their topic of interest (Ivanoff & Hultberg, 2006). In terms of working with siblings of patients with cancer specifically, participants appear to respond positively to the focus group process, as was noted in a study by Nolbris and colleagues (2014) where all siblings that participated said that the

interview process gave them the opportunity to talk about their feelings, which made them feel better, and that they hoped they would be helping other siblings by sharing their story.

Participants

As the study aimed to benefit the siblings of children with cancer, it was important to include direct involvement from siblings (Ivanoff & Hultberg, 2006). As described in the literature review, CanTeen is an organisation in New Zealand which aims to support, develop, and empower young people living with cancer and also provides support to their siblings (CanTeen, n.d.-c). When approached by the researcher, CanTeen staff expressed a great interest in being involved in research that could shed some light on the importance of their work with adolescent siblings of cancer patients, and agreed to help recruit sibling members for the research project. Due to the sensitive nature of the research topic, it was also important to the researcher that participants had strong connections with an organisation such as CanTeen so that they would be provided with support if necessary.

Criteria. For participation in the online survey, the following criteria were established to guide recruitment through the population of sibling members of CanTeen New Zealand: (1) the participant must be over 16 years of age, (2) must have a survivor sibling who is two or more years post cancer treatment in their cancer journey, and (3) have attended school when their sibling was diagnosed with cancer and/or while their sibling received cancer treatment. In addition to those criteria, participants who were included in the focus group session had to be based in the Auckland region, or be able to attend a session in Auckland. CanTeen New Zealand has 507 sibling members nation-wide aged 16 years or older, however, it would have been difficult to determine the exact number of participants that would have satisfied the other required criteria to participate.

Although some studies have used parent reports to judge sibling behaviour, it must be questioned how adequately and objectively parents can do this, especially in terms of reporting siblings' internalized distress (Houtzager et al., 1999). The decision to work with young people whose siblings were two or more years post-treatment in their cancer journey was made with the knowledge that children and young people tend to have significantly higher levels of unmet needs and high distress levels when their brother or sister is undergoing cancer treatment or has

relapsed (McDonald, Patterson, White, Butow, & Bell, 2015). Van Dongen-Melman and colleagues (1995) found that childhood cancer does not result in a heightened risk of psychological disturbance for children and young people as a late effect after their sibling has successfully completed cancer treatment. While parents and survivors still felt concerned and anxious regarding the possible recurrence of the disease and dealing with long term medical consequences, the researchers hypothesised that siblings may be able to distance themselves from the cancer experience once treatment has ceased (Van Dongen-Melman et al., 1995).

In a study conducted by Sahler and colleagues (1994) looking at siblings' adaptation to childhood cancer, criteria for participation was not influenced by the type of cancer or treatment the siblings' brothers and sister received, as they believed that "for most cancer patients, cancer... is not so much appreciated as a constellation of diseases as it is perceived as a threat to the family" (p.355). A similar view was adopted in the current study and did not exclude potential participants based on their sibling's diagnosis or course of treatment.

Recruitment. Participants were recruited to participate in the online survey through the help of CanTeen New Zealand, using social media, emailing potential candidates, and meetings with sibling members. Advertisements were placed on the Facebook pages of all the CanTeen regional offices to invite CanTeen sibling members to take part in an online survey (Appendix A). Everyone who has access to the CanTeen Facebook group pages either works for CanTeen or is a member of CanTeen as a cancer patient, cancer survivor, or a sibling member. The advertisements placed on those Facebook pages would reach people that were either potential participants or people who would likely know someone who might fit the criteria and could pass on the information to potential participants. A link to the website hosting the survey was attached to the advertisements on Facebook, and was also sent to participants via email, at the discretion of CanTeen staff or upon request of a member. The survey was created by the researcher using Survey Monkey (<http://www.surveymonkey.com>), a website that enables people to create their own surveys for the purpose of research. The survey was available online for twelve weeks. Three weeks after the online survey was advertised on the CanTeen Facebook pages, the researcher sent an email to all the CanTeen offices nationwide to encourage their youth workers to discuss the survey with eligible members and to re-post the advertisement on Facebook. Another email was sent to the Auckland Regional manager after an additional three

weeks to encourage another round of advertising in all regions but the efforts yielded no more participant responses. Exhausting all efforts to recruit participants, 10 CanTeen sibling members either completed or partially completed the survey. The sample was made up of seven females, one male, and two participants did not disclose their gender. The age of the participants when their sibling was diagnosed ranged from seven to 18 years. The current age of the participants ranged from 18 to 24 years.

Youth workers employed by CanTeen Auckland, who help support and meet regularly with sibling members, invited sibling members to participate in the focus group session via email and face-to-face meetings. A poster outlining the details of the study was also displayed in the Auckland office to encourage sibling participation (Appendix B). The current research project coincided with a number of CanTeen projects which made it difficult for the CanTeen staff to devote time and attention to recruitment for the focus group sessions. Focus groups sessions were postponed or cancelled on a number of occasions due to staff illness and participant illness. As a result, only one focus group was able to be conducted with four sibling members volunteering their time. Three females, aged 16, 17 and 21, and one male, aged 18, were recruited to participate in the session. Two of the participants attended primary school when their sisters were diagnosed and the other two were high school age when their siblings were diagnosed.

Consent

A letter of request was sent to the general manager of CanTeen New Zealand requesting permission to conduct research with their sibling members (Appendix C). Once permission was granted (Appendix D), the recruitment process began. As well as being issued with information sheets (Appendix E), participants in the focus group were given informed consent forms (Appendix F) which they were required to sign before proceeding with the session. Similarly, participants in the online survey had to confirm they understood and agreed to the terms and conditions stated in the information sheet before proceeding with the survey. The CanTeen staff member that acted as a co-facilitator in the focus group session was also required to sign a confidentiality agreement form (Appendix G).

Ethical considerations

An application to the Massey University Human Ethics Committee (MUHEC) was submitted by the researcher in order to assure that all research complied with the ethical principles set out in Massey University Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants (Massey University, 2015). Due to the sensitive nature of a topic such as childhood cancer, there was a potential to expose participants to emotional distress (3.10.1 Risk of Harm to Participants). Great care was taken in creating the participant selection criteria and in the creation of the survey and focus group questions to ensure the minimisation of risk of harm. No question in the survey was compulsory to answer, and participants had the right to withdraw from the research at any point. Similarly, participants in the focus group session had the right to decline to answer any questions, withdraw from the session at any time, and also modify and/or remove any material they did not wish to have included in the research data. The project was reviewed and approved by MUHEC; Southern A Application 15/29.

Data collection

Online survey. Before responding to any of the survey questions, participants had to read a passage of information on the purpose of the research and the conditions of participation (refer to Appendix H). Participants were then required to confirm they understood the condition of participation and met the criteria to participate. The survey was divided into several sections, based around the research questions. Firstly, participants were asked to think about what support means to them, followed by questions regarding who they perceived as sources of support in school, such as teachers and peers, whose support they valued the most, and why they valued those supports.

The next section addressed the use of counselling services for emotional support. Participants who indicated that they accessed counselling services were asked to explain what they wanted to gain from counselling, and to rate the service based on accessibility, confidentiality, and quality. The researcher also wanted information on sources of social support, which was probed by asking questions on what they wanted their school peers to know

about their cancer journey and also how school staff helped siblings communicate with their peers regarding their cancer journey.

Participants were asked to describe ways that school staff can help children who have a brother or sister with cancer, and asked participants to rate the items on how helpful they were to them and how often schools actually provided the various ways of helping. Participants were also asked to describe how various school community members could help siblings. Information on academic support was gained by asking participants what forms of academic support they received and from whom.

As the priority of the research was to find out about the siblings' lived experiences and collect narratives about the cancer journey, demographic questions were placed at the end of the survey, in case participants felt any 'survey fatigue' or 'respondent burden' (Porter, Whitcomb, & Weitzer, 2004; Sharp & Frankel, 1983) and chose to exit the survey incomplete, and also to avoid issues of stereotype threat (Steele & Aronson, 1995).

Focus group. The focus group took place on a weekday evening after school and work hours, a time that was convenient for all participants, and was conducted in a quiet conference room in the CanTeen Auckland offices, an environment that was familiar to participants and a place of comfort. The choice of setting also ensured that CanTeen staff were readily available to provide support to participants if needed. As well as the four CanTeen members who volunteered to participate in the session, a CanTeen youth worker was also in attendance and acted as a co-facilitator and familiar presence. The focus group session was audio-recorded on two recording devices, in order to capture the answers made by participants in response to a series of open-ended questions from the researcher and responses to the comments of other participants.

The researcher began the session by introducing herself to the group, and reiterating the material conveyed in the information sheet given to the participants prior to the sessions start. The responsibilities as group moderator included explaining to participants the purpose of the focus group, explaining the participants' rights regarding the study, and clarifying the parameters of confidentiality (Sidhu et al., 2005). It was also made clear to the participants that the session would be recorded and the CanTeen youth worker was on hand to help, if needed.

Participants were asked to introduce themselves to the group, and tell the group a little bit about themselves, including their current age and their age at the time of their sibling's diagnosis (refer to Appendix I). The semi-structured questions that formed the foundation for the focus group session are summarised below in Figure 3. To get the group thinking about what support could mean for someone who has a sibling with cancer, the researcher read the group some of the responses from the online survey to the question 'what does the word "support" mean to you?', and then asked the participants to come up with their own definitions. The questions that followed the initial discussion of support in general then focused in on two overarching topics: the impact having a brother or sister with cancer had on their normal school life, and hopes for the future of school-based support for siblings. Participants were invited at the end of the discussion to add any comments about their cancer journey or on the topic of school-based support. The session lasted for a total of 37 minutes.

Data Analysis

Similar to the data analysis method employed by Sidhu and colleagues (2005) in their research on parents' perceptions of the needs of siblings with cancer, data in the current study, collected from both the online survey and focus group session, was "coded through a process of highlighting key words and phrases according to concepts and meaning, which formed constructs" (p.278). In order to analyse the data, the Survey Monkey website divides information into responses by questions and also responses by individual participants. By printing out the survey data, the researcher examined common ideas that emerged from each individual question, and also looked for trends that emerged from the responses of each individual. Through this process, the researcher was able to sort the content into meaningful categories and find overarching themes in the responses. As previously described, the focus group was audio-recorded and transcribed verbatim by the researcher. Once the transcripts were printed out, the researcher was able to use the same method of coding to compare the information to the themes that emerged from the survey data, and also explore new ideas. It must be noted that the names of focus group participants were changed in the write up of this research to preserve their right to confidentiality.

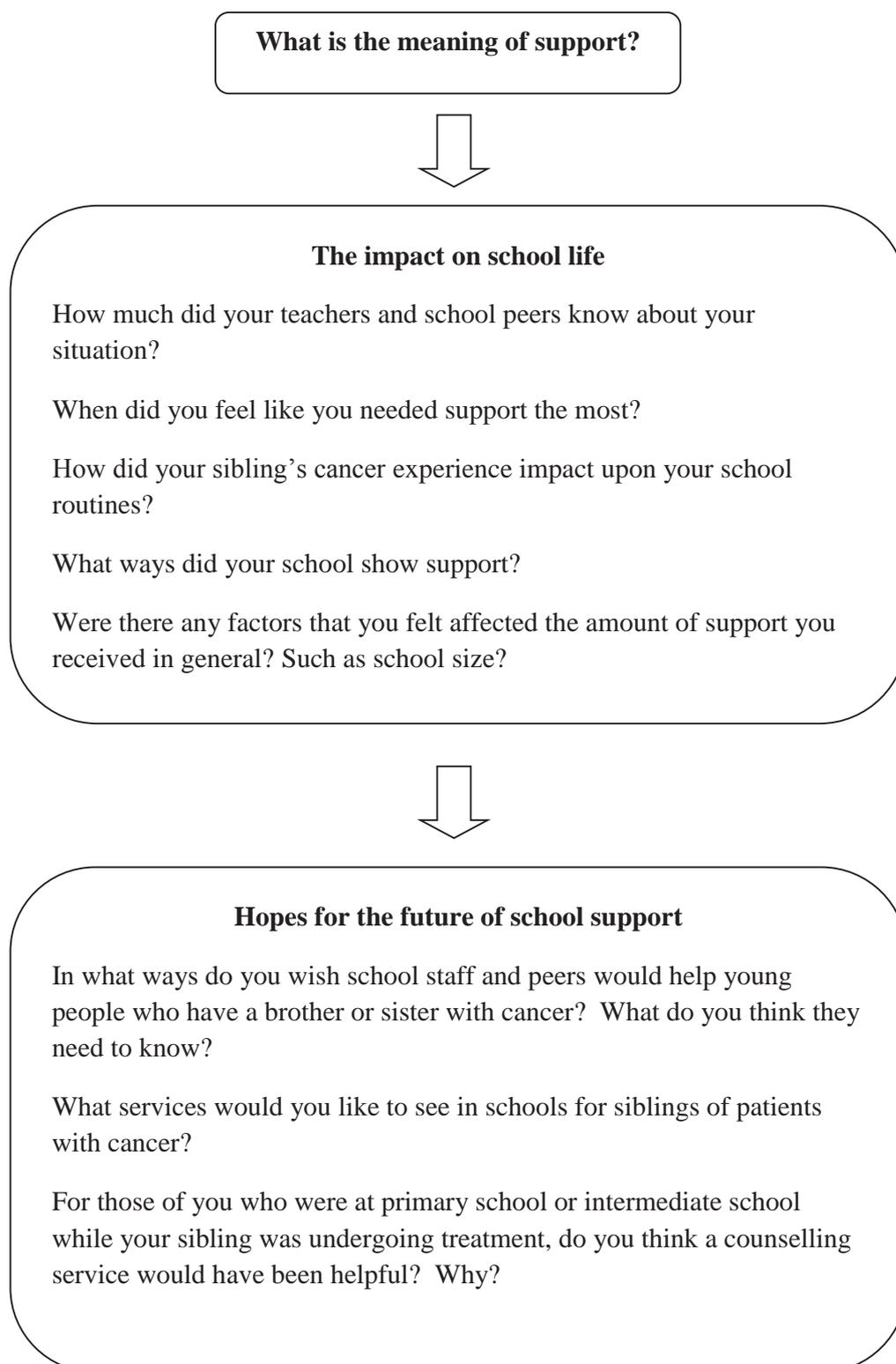


Figure 3: Summary of semi-structured focus group questions.

Chapter 4 – Results and Discussion

"One friend, one person who is truly understanding, who takes the trouble to listen to us as we consider a problem, can change our whole outlook on the world."

— *Dr. E. H. Mayo*

The themes that emerged from the current study regarding the needs of siblings of patients with cancer align with international studies, and share similarities to the findings of von Essen and Enskär (2003) who identified important aspects of assistance that siblings require: “emotional support, fair attention, family life, normal life, practical support, and school support” (p.203). As the aim of the study was to explore siblings’ perceptions of support within the school setting, it was important to gain an understanding of what support means to siblings going through a cancer journey. When asked what the word ‘support’ meant to them, seven out of the 10 survey respondents made references to emotional support: having someone ‘be there for you’, having someone to confide in, and to feel understood. Four respondents specifically mentioned support being related to having their needs attended to and met. Participants also noted that support could be informational support, which could refer to receiving advice and/or information that can help siblings deal with their brother’s or sister’s illness. One participant also noted that support could be practical, such as providing help with household chores. Support was described by three participants in these words:

“People being there for you during good and bad times. Someone to talk to, cry with, or offer advice.”

“Being provided with the tools, skills, and opportunities to acknowledge, address, and move forward from a significant period in life.”

“To me it means giving a hand when needed. Whether it be helping out with the dishes, lending an ear to someone who needs to speak, or providing a sense of positivity to someone who is not experiencing that.”

In addition to sharing their understandings of support, participants shared information regarding who supported them at school, how they were supported, the value they placed on support received at school, what they wish people understood about their cancer journey, and

what supports should be available for brothers and sisters of patients with cancer. Through data analysis of both the survey data and focus group transcripts, four main themes were identified: different school communities fulfil different sibling needs; siblings' everyday lives were disrupted; every cancer journey is different; and, the need for home-school partnerships. The following sections will discuss these themes in relation to the literature.

Different school community members fulfil different sibling needs

From the survey responses, friends were identified as the most common source of support in schools, with 75% of participants selecting friends as someone they could turn to for support. Teachers were the second most common source of support, with five survey participants identifying teachers as a group they could turn to. Three participants cited teachers or a dean as the most valuable source of support; one sibling noted their guidance counsellor, and one sibling listed their friends as the most valuable support. Four out of 10 participants said they did not particularly value any of the identified sources of support in school. One sibling, however, noted how each source of support held their own value and helped them address various needs throughout their cancer journey:

“[I] valued them all equally, they had different needs that they helped me with, teachers with extra patience and support with school work, friends for company and someone to yarn to, counsellor for talking to someone about bigger stuff.”

Participant responses throughout the survey and discussions with focus group participants support the notion that different members of the school community all have a role to play in addressing various sibling needs.

The role of school peers. Three of the survey participants indicated that their friends did not understand what they were going through and found it difficult to offer appropriate support.

“My friends didn't really understand how to help or support me so they never talked to me about it.”

“I wanted them to know it was ok to talk to me about it. I felt like I wasn't able to be sad or down around them, when I did become anti-social when I felt sad, they

brushed it off, saying I was isolating myself instead of realising I didn't have any energy to be happy-go-lucky during that time.”

The one survey participant who indicated that they valued supports from friends the most said they were a “welcome distraction from thoughts of cancer and chemo.” The same participant suggested that school peers could distract siblings by keeping them involved in activities and making sure there is time spent focusing on healthy siblings. It appeared that siblings craved a sense of normality in their lives, and that could be provided by school peers. Of the nine participants who responded to a question regarding how school peers could support siblings on their cancer journey, six survey respondents indicated that they wanted their friends to help make things as normal as possible. School peers were also seen as a potential source of emotional support for four out of nine respondents, who described the importance of school peers understanding siblings' situations, attending to their emotional needs, and asking how the siblings were coping.

“Don't disappear. It's okay to contact the sibling to see how things are going. School is often a place to escape, so it is best if things go on as normal.”

“Peers could do so much to support. Siblings at school need to be the focus, they need positivity, they need happiness, and they need people to ask about you as opposed to asking about your patient sibling.”

School peers have an important role to play in helping siblings through their cancer journey. The current study's findings support the literature that indicates that siblings of patients with cancer, both children and adolescents, often feel isolated and unsupported by their school peers, and experience feelings of frustration and loneliness (Bendor, 1990; Patterson et al., 2011; Sidhu et al., 2005). Siblings in Bendor's (1990) study indicated that they believed their friends were “either uninterested or unable to respond helpfully” (p.25). As noted in the literature review, Barrera and colleagues (2004) found that siblings with high social support exhibited fewer problem behaviours and fewer symptoms of depression and anxiety. Similar to responses found in Murray's (2002) study regarding what school-aged siblings of children with cancer perceive to be helpful in adjusting to the cancer journey, healthy siblings expressed a desire to keep their lives as normal possible, and they wanted their school peers to help them achieve this.

Siblings in the current study recognised the need for and potential value in school peer support, as expressed in their suggestions of the ways that school peers can help students on a cancer journey.

The role of teachers. Of the eight siblings that responded to questions regarding provision of academic support, four siblings received academic support from their teachers only, one respondent received help from a teacher and her dean, and another sibling cited her principal as a source of academic support. Types of support offered included extension of deadlines (43% of respondents), compassionate consideration (29%), and provision of tutorials (29%). One sibling who attended primary school at the time of her sibling's diagnosis noted that her teacher made sure she was up to date with all her work, but that it was not a big issue, given her young age. Two respondents cited that they received no academic support, however these siblings were aged eight and thirteen when their sibling was diagnosed with cancer, therefore they may not have faced the same academic pressures experienced by older siblings in the similar situations.

“If I went through this at high school it would have been an entirely different story and would've been much harder on me trying to deal with school work on top of it.”

A couple of participants in the focus group discussed receiving academic support from teachers when they couldn't make it to school. One sibling, Steven, was 15 years old when his sister was diagnosed and needed to travel from Warkworth to Auckland often to be with his family while she received treatment. Steven's mathematics teacher would send him homework via email when he was away from school, which he appreciated. Tessa received similar help when she couldn't make it to school:

“I remember we had to be off [school] for a while because of measles going around the school, and my teacher sent me a big package of work I could do at home... It was good the teachers are supporting you, knowing why you're off.”

Participants in the online survey were asked what supports teachers could provide young people who have a brother or sister with cancer. Seven out of nine respondents indicated that teachers should provide academic support to siblings, which included providing extra time or

resources to complete work, lessening the work load, help applying for compassionate consideration, and providing extra help with school work.

“It is good for teachers to take away the stress of deadlines and assignments during that time. I felt much less anxious knowing it was ok if I couldn’t get something in on time, and that I could just complete things in my own time.”

It also appeared to be important for siblings that teachers understood their situation, with four survey participants indicating that teachers need to have a level of understanding, which referred to the fact that siblings may not always be able to complete work and to acknowledge that siblings “have bad days, too”. The theme of teachers knowing and understanding the situation was prevalent throughout the focus group session, as well, with two of the participants discussing how helpful it was to have staff know why they were not at school or unable to complete work. As well as the need for teachers to try understand what they were going through, a couple of the siblings noted in the survey ways that teachers could cater to their emotional needs:

“[By] giving the sibling a safe space to go to if they feel overwhelmed in class.”

“If they are comfortable with that student... be someone to talk to.”

However, not all siblings viewed school staff as an appropriate source of emotional support in their cancer journey, with one participant expressing that while she viewed teachers as a source of academic support, she would have felt uncomfortable talking to her teachers about her feelings.

In their report on the provision of guidance and counselling at schools, the Education Review Office (2013a) found that students were more likely to turn to a teacher or dean than other school staff or peers to discuss academic issues, which was reflected in the responses from siblings in the online survey. A report compiled by the Education Review Office (2013a) also revealed that secondary students were most likely to seek help and support from friends and other students, before turning to any school staff. Lynch and Cicchetti (1997) found that older children are less likely than younger children to consider the quality of their relationships with teachers to be secure, which could provide an explanation as to why many of the survey

participants did not place a lot of value in support from teachers, as the majority of the participants attended high school while their sibling was receiving treatment. Teachers, and other school staff, such as deans and principals, are important adult figures in siblings' lives and are in a position to make a positive impact on their wellbeing. In some cases, indirect support, such as making sure students and staff were aware of the situation so that exceptions could be made, was valued more by siblings over direct emotional support.

The role of school counsellors. None of the participants in the focus group accessed school counselling services, while only two out of the ten survey respondents accessed school counselling services. Six out of those ten respondents were either attending high school or a combined intermediate and high school, and it is therefore likely that there would have been counselling services provided at their schools. When asked what they had hoped to gain from accessing counselling services, both participants who accessed counselling services cited needing someone to unload their emotions to, as they felt that they did not have anyone else in their lives that could support them to the same extent.

During the focus group session, the researcher discussed the possible value in having counsellors available to children at primary and intermediate schools. Two participants who attended primary school at the time of their sisters' diagnoses indicated that they would have found having someone to talk to at that age helpful:

“It sort of would have been helpful for us then because we were so young, you know. We didn't really understand it much either. So yeah, it might have been good to have someone.”

One of the participants in the survey also reflected on the usefulness of having a school counsellor at primary school:

“At that point in my life (because I was 8/9) school counsellors probably wouldn't have benefitted me as much as they would do now. It may, however, have helped for me to understand what I was going through, and why I was feeling so sad.”

When the researcher asked the focus group participants what they would have gained from having counselling services at primary school, one of the girls indicated that she would

want help understanding her situation, as well, and to be able to talk about her feelings. Another participant, Belinda, imagined what it would have been like if her brother had been diagnosed when she was much younger:

“Especially when you’re younger, it would be harder to approach. When you’re a teenager, it’s easier to... have the autonomy to go and ask for a counsellor but when you’re younger, you might not even know what that is or know how to, say, it probably would be easier... especially as a sibling because it would be harder to talk to your parents about that kind of stuff or family so it would be good to be able to talk to someone at school, and it would be confidential.”

Belinda’s comments acknowledge how difficult it can be for some young people to seek out help. Three of the seven siblings who provided advice in the online survey for how school counsellors could provide support to siblings used the word ‘offer’, indicating that they wanted to know that there was help readily available at school, if necessary. Many of the survey participants also wanted school counsellors to provide emotional support to siblings and be someone that siblings can talk to about their cancer experiences.

“Offer an open door if this person wants someone to talk to.”

“Offer support, advice, and [be] someone to talk to, to check in and see how the sibling is coping.”

Two of the survey respondents suggested that school counsellors should provide siblings with informational support:

“They could offer help or recommend other services such as CanTeen or Child Cancer Foundation, etc.”

“[Provide] information and resources about cancer/chemo.”

As previously mentioned, a few of the siblings who responded to the survey felt that their school friends did not understand their situation or know how to talk to them about the cancer journey. One participant suggested that school counsellors can act as a facilitator in helping siblings communicate with their peers. Survey participants were asked how their school helped

them to communicate with their peers regarding their cancer journey. All of the respondents reported that no support was given by their school to help siblings communicate with their peers.

“Facilitating an opportunity for siblings to speak with their peers often to explain how things are going for them and what could be happening/reasons for certain behaviour.”

Of all the members in the school community, the Education Review Office (2013a) identified that students were most likely to discuss grief and family problems with a guidance counsellor. As they are removed from events that occur in the home environment, school staff can act as a third party and provide support and guidance to students from an adult perspective (Reddy et al., 2003). Counsellors also have a role to play in providing siblings and other students with information regarding living in a family affected by cancer, a role which could be shared by teachers. School staff that are able to educate their students about cancer and the experiences of their affected classmate might help students, including the sibling, to understand the situation better and also spare the sibling from having to answer questions from their peers (Alderfer & Hodges, 2010). It is important for students to participate in discussions and preventative classroom programmes which aim to demystify some of the issues faced by children and young adults, including physical and mental health issues, and prepare them with suitable information in order to help and support their peers (Education Review Office, 2013a).

There could be a number of reasons why some participants did not access school counselling services. Siblings may have felt that they did not need the services, they may not have trusted the counselling system at their school, or their school may not have employed a school counsellor. As explored in the literature review, the Education Review Office (2013a, 2013b) discovered that a third of secondary school students found it socially unacceptable to see a counsellor and over a third of schools needed to improve their provision of counselling services. A greater exploration is needed to find out why some siblings chose not to access school counselling if their schools did provide such services. Hermansson and Webb (1993) predicted that an expansion of counselling services in New Zealand would unlikely extend to primary and intermediate schools in their near future. Judging from the responses gathered in the online survey and focus group discussions, counselling services are still rarely found in pre-secondary schools in New Zealand, 22 years on. What also emerged from the results was that

there is a need for school counselling at primary and intermediate schools, and steps need to be taken to ensure all students, not just the sibling population, have access to and are offered counselling in times of need.

Disruption of everyday life

One of the themes that emerged from the survey was that siblings wanted peers and teachers to understand the effect the journey has on their everyday lives. When asked to give one key message schools need to know about the cancer experiences of siblings, six out of nine survey respondents suggested that schools need to be aware that it is a really tough time for siblings and it can take a great emotional toll. Responses from the survey participants indicated that the cancer journey changed daily routines and took a toll on relationships in the home.

“Be understanding to the fact that the house and normal habits may have changed and be accommodating to that.”

“Things aren’t 100% normal and things are always changing.”

Change in routine. Living in a family affected by cancer can often disturb siblings’ ability to attend school. Five out of the nine respondents in the online survey indicated that they took time off school while their sibling had cancer. Four out the five siblings said that they took time off school to spend time with their families when their brother or sister was first diagnosed with cancer and/or while their sibling was receiving treatment. One respondent indicated that as well as taking time off school to spend time with his family, he took time off school to look after his brother when he was ill, and he also needed a break from school to look after his own mental health while struggling with depression during the cancer journey. Spending time with family and being part of their ill siblings’ treatment was important to participants. Two of the participants in the focus group session mentioned taking time off school to avoid exposing their ill sibling to measles and chicken pox which was going around the school. One sibling indicated that they missed out on school because it was difficult for their parents to arrange transport to and from school:

“My parents found it easier to take me to appointments than it was to organise school pick ups and drop offs. This actually made me happy because... my

parents were involving me in my brother's treatment. Prior to this, I had absolutely no idea what was going on. This time off school shed a lot of light on the cancer situation and allowed me to understand.”

During the focus group session, participants were asked about how the cancer experience impacted upon their school routines and their ability to participate in extracurricular activities. For three out of the four participants, their ability to participate in extracurricular activities continued after their sibling was diagnosed with cancer. Tessa felt like her involvement in soccer became a way to “fill up the time” when her parents were unable to care for her. One sibling, Steven, indicated that his sister's cancer diagnosis impacted his daily routines “quite a lot”:

“My golf kind of took a side step quite a lot, because I got accepted into an American golf scholarship programme thing, but I dunno... I didn't really want to do that because it was going to cost a lot of money... Yeah, so I dunno. I could have got better, but I stopped that.”

Steven's experiences reflect the finding of Bendor's (1990) research in which she found that siblings aged 14 to 19 years felt conflicted about continuing with their lives as normal. Although the cancer journey can disrupt the everyday lives of siblings while their brother or sister is ill and receiving treatment, it is also possible that there could be greater, long lasting effects on a sibling's direction for the future, as in Steven's case.

All participants in the survey who responded to demographic questions indicated that they lived at home with their family during their cancer journey. For the majority of those participants, that meant living with at least one parent and their siblings. One participant, who identified herself as Māori/Pākehā, indicated that she lived with her grandparents while her brother was receiving chemotherapy. Another participant discussed staying at friends' houses when her parents needed to stay overnight at the hospital with her sibling. While none of the participants had to move in order for their sibling to receive cancer treatment, two participants mentioned that their parents and sibling had to travel out of town for treatment, with one of them commenting that the drive to get treatment took over two hours. Steven discussed in the focus

group sessions that he spent all of his school holidays in Auckland, staying with his family in housing providing by the Child Cancer Foundation.

The disruption to everyday life has been commonly recorded in the literature surrounding siblings' cancer experiences. It is also possible that having a brother or sister with cancer could have greater, long lasting effects on a sibling's direction for the future, as in Steven's case. As expressed by the participants who discussed staying with their grandparents or friends at various stages of the cancer journey, the demands of an illness such as cancer can force families to pass on the responsibility of sibling care to others (Sidhu et al., 2005). Similar to the experiences of Tessa and Julia, who participated in the focus group, some siblings in Sloper's (2000) study reported changes to social activities due to the risk of infection. Families living with cancer have to be extremely vigilant when it comes to protecting their ill child from infections which may complicate their condition. Research has shown that a lack of social interaction outside of school hours can lead to feelings of loneliness in siblings and negatively affect their sense of belonging (Bendor, 1990; Murray, 2000). It is important for schools to be aware of the changes in siblings' routines and the possible consequences of those changes in order to find ways to boost a sense of belonging within the school community and reduce the risk of further negative effects.

The research looking at siblings' experiences rarely discusses over-involvement in school activities. Barbarin and colleagues (1995) made a brief mention in their research that when asked about what siblings handled least well, one parent responded with "becoming overinvolved in school activities" (p.15). The possible reasons for over-involvement could be further explored, as well, though from Tessa's experience, it appears that after-school activities can be helpful for parents preoccupied with hospital appointments and who are unable to pick up their other children straight after school finishes.

Change in family systems. Having a brother or sister with cancer can have an impact upon relationships in the family unit and siblings may also struggle to deal with how other family members are coping with the child or young person's diagnosis. In the focus group session, the researcher asked about what the hardest aspect of the cancer journey was. Steven discussed hearing his sister throwing up in her bedroom next to his room as a side effect of treatment, and having to deal with the toll it was taking on his parents, as well. Similarly, Belinda noted how the journey affected her brother with the cancer diagnosis and her parents:

“He kind of withdrew from us and my parents were kind of upset, so you kind of feel isolated... That was hard ‘cause I didn’t know who to talk to about it. So I didn’t know what was happening or how bad it was going to be.”

In the focus group, Tessa and Julia discussed changes in family relationships, as well, in terms of loss of attention:

“Mum and Dad spent a lot of time with Eden when she first got diagnosed and stuff... for the first whole two years everything just got put on hold for all of us. Like, we still did stuff out of school, stuff like sport, but they weren’t really as important to Mum and Dad.”

“I played soccer for a long time and that kind of continued. I feel like it continued because our parents didn’t really have much time for us.”

Changes in family and home were also commonly mentioned throughout the survey. While participants were not asked directly about the impact the cancer experience had on their home lives, some participants also noted feelings of isolation in their family and the strain on all family members. Some families pulled together and managed to work through the challenges together; other families struggled with the changes.

“At the time, I didn’t understand why, but if I knew why I felt the way I did, I would have wanted them to know how lonely I was and how cut off from my family I was.”

“This experience put a massive strain on my family. My parents got divorced, and I have broken relationships with my brother and sister that I am slowly mending after a solid 10 years on. Cancer sucks.”

When a child is affected by chronic health problems, the quality and quantity of intra- and extra-familial communication is expected to undergo change (McKeever, 1983). Parents may find it difficult to organise life around treatment and periods of hospitalisation. In dealing with the effects of such a disease and supporting their child with cancer through treatment, parents can find themselves stretched, trying to be present at home, work and at the hospital (Kobayashi et al., 2015). As expressed by siblings in the current research and in previous

studies, parents of children with cancer are often too focused on the needs of their ill child and lack the energy to attend to their other children's needs (Sloper, 2000). Similar to some of the participant responses in the current study, siblings who participated in Bendor's (1990) research indicated that they did not feel as important as their sibling with cancer. Some siblings may deal with the breakdown of their parents' relationship, which can be extremely difficult for a child without the added pressures of having a sibling with cancer (Cox & Desforges, 1987; Enskär et al., 1997). The results show that siblings' family lives do indeed undergo a lot of changes when a brother or sister is diagnosed with cancer, and it is important for schools to be aware of how these changes can affect their students' emotional wellbeing and academic performance.

Every journey is different

The final theme that was identified when looking at the data as a whole was that each sibling's cancer journey was unique to their circumstances. As stated by Carpenter and LeVant (1994), "Because families are neither isolated from the larger social systems in which they participate nor immune to the stressors and strains of everyday life, other non-illness-related events also pose additional stress on the family system." (p.122). Each sibling could be dealing with issues outside of the cancer journey that may influence how they deal with the threat to their brother or sister's life and how they adapt to their new reality.

"It affects siblings equally emotionally as it does the patient. Everyone deals with it in their own way, so people need to be able to recognise what a particular person needs."

Length of treatment and other demographic variables. From the focus group discussions, it was suggested that the length of time a child or young person is undergoing treatment could influence the degree to which their siblings' lives are disrupted and the amount or type of support that they would require. Belinda did not want the support of her teachers when her brother was diagnosed with cancer, but valued the support from her family and friends. Belinda acknowledged that her desire for support was linked to the length of time her brother was ill, and had the process been drawn out for a longer period of time, she would have wanted the teachers to know so they would understand if she needed to take time off school.

“I never told my teachers... I just talked to my friends and my family. I didn’t feel like they needed to know. I didn’t take time off school or anything... The whole process happened so fast... he got diagnosed... he didn’t go through chemo... so he had like a few weeks, and then he had an operation, and then, it wasn’t, like, over, but the tumour was removed... I guess I didn’t need the support from them [teachers].”

However, looking at the survey responses, there appeared to be no strong pattern of relatedness between the length of treatment and the amount or type of support that the siblings desired. For the participants that responded to the survey, the amount of time their siblings spent on treatment varied from six months to two years and three months. One participant (aged 18 at diagnosis) whose sibling was on treatment for six months indicated that many of the things that school staff could do to help siblings which involved a home-school partnership would be unhelpful, while help with school work was considered very helpful as it was her last year of high school. However, another participant (aged 15 at diagnosis) whose sibling was on treatment for eight months placed a lot of value in the support that could be provided to siblings by school staff, indicating that emotional support, academic support, informational support, or support that related to having a home-school relationship were all helpful or very helpful. Everyone responds to threats to the family system in different ways.

As there was no strong link between length of treatment and the degree of support siblings needed, the researcher explored how other demographic variables may mediate the need for support. The survey results yielded no strong connection between age of the participants at diagnosis and the amount or type of support that siblings want to be provided with. As previously discussed, though, some participants expressed that as primary school students, they did not need the same level of intensive academic support compared to older, high school aged sibling members. No relationship was found between need for support and age of patient sibling at diagnosis, position among siblings, or how many siblings are in their family. As only two participants in the research project identified as male, ten siblings identified as female, and two did not specify their gender, it was impossible to draw any conclusions on how gender may affect need for school-based support.

In the current study, participation criteria did not exclude participants based on their sibling's diagnosis or course of treatment, taken from the view point that all cancers pose a potential threat to the family unit and are likely to have a great impact on all family members (Sahler et al., 1994). These findings could provide support to the findings of Barbarin and colleagues' (1995) work which suggested that the severity of cancer diagnoses was unrelated to frequency of problems experienced by siblings of patients with cancer. As discussed in the literature review, there is some debate as to the role age and gender play in predicting how siblings of cancer patients will adapt to a brother or sister's cancer diagnosis and, therefore, their need for support. As well as severity of cancer diagnosis, Barbarin and colleagues' (1995) research found that sibling age, sibling gender, birth order were unrelated to the frequency of problems experienced by siblings. Sahler and colleagues (1994), however, did note gender and age differences among siblings of cancer patients in terms of frequency of problem behaviours and in levels of distress.

Addressing individual needs. As previously mentioned, some siblings felt that they lost the attention of their parents, who were preoccupied with the needs of their child with cancer. Within the school community, some survey participants and participants in the focus group felt their siblings were the focus of people's concern and people would ask how their patient sibling was doing rather than showing concern for the healthy sibling's wellbeing.

“A lot of people asked about Eden... not a lot of people asked us how we were... It was still tough on us too but they focused their attention on her just because she was sick, it's like, yeah, same... you can't be selfish about it, you know... you do just want somebody there to support you more.”

“I wanted them [school peers] to understand the impact it had on siblings. Everyone always asked how the patient was but never understood the importance of 'checking in' with the siblings and giving them complete attention.”

A description from one of the survey participants regarding her relationship with her school principal highlights the great effect school staff can have on a sibling's journey just by

acknowledging their feelings and making the effort to let them know that they matter and are well supported:

“The one thing that I thought was a pretty great thing was that my school principal made an effort to know who I was. Whenever he’d see me, he’d say hi and ask how I was doing, and even to this day (now I am 21) he still remembers my name, he says hi and asks what I have been up to with uni, etc. He’s quite the legend.”

As Kobayashi and colleagues (2015) described in the families’ efforts to maintain stability of the family unit, siblings seem to be aware of the struggles each family member bears, and may hide their feelings so as not to place further burden on their parents. As children and adolescents spend a large amount of their time at school, the school community is the perfect place to provide siblings with the attention that they need. In von Essen and Enskär's (2003) research on care and assistance for siblings of children treated for cancer from the perspective of parents and nurse, they stated that “in organising care and assistance... attention should be paid to discovering which aspects of care and assistance siblings perceive as important” (p.204). The same approach should be taken by schools when looking at the care and assistance they should be providing for their students who are on a cancer journey. Some siblings might find it hard to ask for help or attention as they do not want to take it away from their ill sibling, or appear “selfish” as was discussed in the focus group session. Therefore, school staff need to be aware of the student’s circumstances and actively provide help by asking how students’ needs can be accommodated at school and in general.

An ongoing journey. Another subtopic that emerged from the responses was that the cancer journey does not necessarily end for a family when the patient sibling has finished treatment or the cancer has been eliminated. One of the survey participants indicated that they wanted their school peers to know that their journey did not end when his sibling came home. One participant in the focus group, Tessa, was attending primary school when her sister was diagnosed with cancer. When asked to reflect on a time when she needed support the most, she talked about a time several years after her sister had finished treatment:

“In year nine, that was when I like, it hit me that she was in that, like, state, that she was really sick and that’s when I kind of felt the worst because I realised that I was... doing normal things... while she was in hospital... all the feelings hit me at once, because I didn’t really know what was going on when I was so young, and then I realised.”

Families go through changes throughout the course of the ill child’s treatment, with the final stage being the reunion of the family members (Kobayashi et al., 2015). This does not mean that the journey comes to an end but rather is a time when family members reflect on their journey so far, re-evaluate their interconnectedness as a family unit, and may need to take steps to repair relationships (Kobayashi et al., 2015). Kobayashi and colleagues (2015) found that once their brother or sister recovered from their illness, siblings had time to reflect upon their experiences, and their understanding of cancer and related events increased as they grew older. However, positive feelings towards having the family back together were overshadowed by the siblings' past feelings of loneliness (Kobayashi et al., 2015). Once their brother or sister is in remission, siblings may still struggle to come to terms with what the family has gone through, or not gain a full appreciation of the threat cancer presented until they are older and developmentally able to process the journey. If a child or young person is still struggling with issues, whether they are emotional, behavioural, social, or academic in nature, support should be offered and provided to help them adjust.

Need for home-school partnerships.

Related to the fact that all siblings have individualised needs, another theme that emerged was the importance of having a home-school partnership to help siblings cope with school and the issues that evolve from dealing with their brother’s or sister’s illness.

Importance of parental involvement. Siblings expressed that it was important not only for parents to understand how their child was performing academically but also that they be informed about how their children were emotionally, behaviourally, and socially.

“They [my parents] were connected to our school, as well... School was just... not as important because there are more important things, but they did care about our

school friends... they would check up on the school and make sure we were doing good and everything.”

“I feel like the biggest things teachers could do would be to communicate with the parents and let them know the behaviours of the sibling... I stayed with my grandparents and my parents weren’t involved in my life for about a year. I felt as though I was forgotten about. So a teacher or third outside party communicating that to parents I think would give the parents a wake up call and let them know they need to focus on all the kids, as opposed to just the patient.”

Half of the siblings who participated in the survey believed that having school staff encourage their parents to spend time with the other children in the family (aside from their ill child) would be helpful or very helpful. Eight siblings reported that, in reality, this never happened, or seldom happened. One participant reported that that school staff sometimes encouraged their parents to spend time with their other children. When asked how helpful it would be for school staff to provide assistance to families to help them meet the needs of the other children in the family, five siblings reported that it would be helpful or very helpful. Again, the reality did not meet these needs. Six siblings reported that their family never received such assistance from school; one sibling reported that assistance was seldom provided, and the remaining two participants noted that the school sometimes provided their families help in this domain.

While families would benefit from a home-school partnership, it is also important for the teachers to be aware of what is happening at home so that they can make adjustments to suit the sibling and their family’s needs.

“I think it is important to have that [home-school] partnership because you need the support from your teachers and your peers to get you through, even just to make sure that schooling doesn’t go down and to know that if it does, to know why and... say if you miss a test ... they know why or they can make, like, what’s that word? You can do it again.”

“It is important to shape learning around the student’s cancer journey.”

Working with families experiencing stress from a bio-ecological approach, Swick and Williams (2006) stated that in order to help people in ways that are sensitive to personal and cultural diversity, educators need to show first and foremost “responsiveness to the expressed needs of the families we serve; what is it that they see as their needs?” (p.376). While it’s possible to gain some insights related to patterns found in family responses to various stresses, it would be unwise to stereotype families or assume that all families will react in the same way to a stressor, such as cancer (Swick & Williams, 2006). As Sloper (2000) suggests, it is the responsibility of health professionals to inform parents about how siblings can react to their brother or sister's diagnosis, school staff can share the responsibility and help families identify reactions and issues that may arise. In order for families to respond appropriately to their children’s needs, they need to be aware of what happens in their school lives.

Need for supportive school climates. Not all siblings saw the school community as a valued source of support during their cancer journey. When asked what ways they wished school staff and peers would help young people who have a brother or sister with cancer, one focus group participant indicated that school wasn’t a place that he would look for support, and he would not expect the school to provide more support beyond knowing what the family was experiencing and letting them deal with it in their own way, “just like knowing about it, and if something happened, something happened.” Four of the siblings who participated in the survey expressed that they had no valuable support systems at school.

“I felt like I couldn’t talk to anyone because I hardly knew what was going on and I didn’t want to have to explain something that they wouldn’t understand. They didn’t know what I was going through and I felt they would judge me.”

“I did not turn to anybody at school for support – I didn’t quite understand what I was going through so I didn’t actually turn to anybody. Not even my family.”

“I rarely spoke about it at school as I was only 10 at the time and did not fully understand what was going on other than there was a lot of stress and that the family dynamic was very different.”

Unfortunately, this research did not explore what policies these students’ schools had in terms of monitoring and responding to student wellbeing. For some students, it appeared that it

was not a case of not needing support but perhaps not knowing how to ask for help, or avoiding help. A report by the Education Review Office (2015) on student wellbeing in primary schools in New Zealand noted that most schools relied on an overall positive school culture to promote wellbeing but that “there were very few examples of teachers deliberately promoting wellbeing in curriculum or exploring the relationship between values, achievement and wellbeing.” (p.2). Children in schools that excel at promoting wellbeing and responding to students' needs should have good relationships with their school peers and teachers, be able to turn to their teachers for help when they are experiencing hardship, and teachers should be building student resiliency (Education Review Office, 2013c). While students may not actively seek out support, schools should have a moral obligation to make sure that appropriate support is available and offered, and/or that the child or young person is being supported outside of the school community by friends, whānau, hospital staff, or an organisation such as Child Cancer Foundation or CanTeen.

Chapter 5: Conclusion

“Become a possibilitarian. No matter how dark things seem to be or actually are, raise your sights and see possibilities — always see them, for they’re always there.”

— Norman Vincent Peale

Limitations

In order to understand the conclusions of this research, it is important to understand the limitations. The greatest limitation to the current research was the small sample size which means the findings should be viewed as representative of the lived experiences of the participants in this research but cannot be generalised to the wider population of siblings of cancer patients. It must be kept in mind that all participants were members of CanTeen New Zealand. Siblings of patients with cancer who are not members of a peer support organisation or network may have different perspectives on school-based support compared to the participants in this project. As the study took a retrospective approach to siblings’ experiences, memories have likely changed over time. It also important to note that the cancer experience for young people who lose a sibling to cancer could be markedly different, and therefore the findings of this study should be approached with caution when trying to generalise to the bereaved sibling population.

As with any research method, there are limitations on the use of online surveys and focus groups. One of the downfalls of using online surveys for data collection is the heavy reliance on the willingness of people to actually complete the survey (Couper, 2000). Non-response error occurs when "not all people included in the sample are willing or able to complete the survey" (Couper, 2000, p. 473). Due to the high non-response rate in the current study, the sample population cannot be considered representative of the sibling population in New Zealand. The majority of the participants were female and identified themselves as New Zealand European.

Online surveys also face the limitation of self-selection bias, as there are surely some people in any given community who are more likely than others to respond to participant requests (Wright, 2005). It is difficult to gain some indication as to why some members of the sibling population did not respond to the survey invitation, but it could be that siblings who were most traumatised or distressed by their cancer journey did not want to participate in research that might cause them stress, or that some siblings did not feel strongly enough that the school

community was a source of support for them on their journey. It is also possible that for the specific participation criteria, which required participants to have a sibling who was at least two years post-treatment, CanTeen may not have been the most appropriate recruitment agent. According to one CanTeen staff member, siblings who have a brother or sister two years post-treatment are unlikely to require any further support from CanTeen and may be disengaged from the CanTeen community, including contact made over CanTeen Facebook sites. This could have contributed to the large non-response rate.

Unlike in interviewer-administered surveys, there are no opportunities in online surveys to encourage the participant to continue, probe further when there are incomplete or inadequate answers, or explain when a question has been phrased in unclear terms (Couper, 2000). A couple of the questions posed to survey participants to gather demographic information were framed in ways that were either ambiguous or written in the wrong tense, and therefore the researcher did not gain the anticipated responses, or have the opportunity to prompt the participants. For instance, one of the questions was framed as “Where were you living when your sibling was diagnosed with cancer?” The researcher wanted to know what city/town or region participants were living in, however the first four participants responded along the lines of living at home or with family. Another question asked the participants “who *do* you live with?” rather than “who *did* you live with?” Once these errors had been identified, the researcher edited the questions to clarify the types of responses she was looking for. Unfortunately, due to these researcher errors and the small sample size, no connections could be made between geographical location and the need for support, or between living arrangements and need for support.

While there is value in using focus group methodology, there is a risk that participants may adjust their own behaviour, by censoring or conforming to other members’ responses (Carey & Smith, 1994). Though this did not seem to be the case in the current study, it is difficult to measure whether or not the participants were adjusting their behaviour in any way. Due to the difficulties that arose from CanTeen Auckland being understaffed and having a few focus group sessions postponed or cancelled due to staff or participant illness, only one focus group was able to be conducted within the limited timeframe of the research project. Naturally, had more focus groups been conducted, there would have been more narratives to draw data from and perhaps provide a greater picture of the lived experiences of siblings of patients with cancer.

Conclusion of findings

Despite the research limitations, this study makes a valuable contribution to the literature surrounding the experiences of siblings of patients with cancer and their need for support from the school community, and was successful in answering the four questions that the researcher set out to explore:

- Who/what are supports for siblings at school;
- How were they supported during their cancer journey;
- What do siblings wish people understood about the impact of a cancer diagnosis on their lives; and
- What supports do siblings wish had been available?

In terms of who supported siblings in school, siblings were able to find support from school peers, teachers, other school staff such as deans and principals, and school counsellors. These various school community members differed, however, in how they provided support. While the support of school peers was highly valued, many siblings expressed that their friends found it hard to provide appropriate support and did not fully understand their situation. Many siblings wished they had had greater support from their school peers throughout their journey. Participants suggested that school peers should provide siblings with normality, continue to treat them the same as before, spend time with the sibling and their family, and ask how they are doing, rather than only asking about their ill sibling.

Teachers were predominantly viewed as a source of academic support, by giving siblings time and space to complete course work to accommodate the struggles of their cancer journey. Age did not appear to mediate need for academic support, though could naturally influence the type of academic support required. Some siblings sought emotional support from school staff. As one of the participants suggested to teachers, “if they are comfortable with the student... be someone to talk to.” These are the kind of relationships all teachers should be striving for. Many of the participants noted how important it was for teachers to understand how the cancer journey may be affecting their behaviour and academic performance.

Although many of the siblings indicated that they could have turned to a school counsellor for support, only two siblings reached out to counselling services and none of the focus group participants received counselling. The siblings who did access counselling reached out to counsellors as a source of emotional support. Some siblings suggested that there is potential for counsellors to act as sources of informational support for siblings. Siblings who attended primary school while their brother or sister underwent treatment highlighted the need for counsellors in pre-secondary school settings and wished that they had that support during their journey. At their young age, primary-aged siblings found it hard to understand what was happening and the gravity of the situation. Some of the siblings indicated that, had counselling services been available, they would have wanted a counsellor's help to understand what they were going through.

Predominantly, participants wanted the school community to understand how difficult the cancer journey is for siblings. A brother's or sister's cancer diagnosis can throw a family's world into chaos with disruptions to everyday routines and impacting upon family relationships. Naturally, such changes in the home are likely to affect how a child or young person thinks and behaves at school, whether they externalise different behaviours or internalise their problems. How the cancer journey affects each sibling, though, is an individualised experience, which could be based on a number of factors as no one is immune to other stresses that exist in everyday life and trying to handle the challenges of navigating childhood or adolescence. These discussions also exposed the need for a family-school partnership to help identify the needs of siblings and provide them with consistent support across settings.

Recommendations for future research

As previously mentioned, the demographic data collected from survey participants did not give a clear picture of where in New Zealand the siblings were living geographically during their cancer journey. The majority of participants who did identify their region lived in Auckland, close to Starship Children's Hospital where their siblings would be able to get cancer treatment. It is likely that families who live in rural communities or small towns would experience different challenges to those living in major cities in New Zealand. Scott-Findlay and Chalmers (2001) noted, in an exploratory study of rural families living with a childhood cancer, that the families struggled with challenges relating to the fact they lived a great distance away

from cancer treatment centres. To gain a greater idea of sibling experiences across New Zealand, research needs to be conducted with a larger sample population with participants from all regions in New Zealand.

It would also be valuable to have more ethnic and cultural diversity in the sample population. As previously mentioned, the majority of the participants in the current research identified as New Zealand European or Pākehā. This does not reflect the true ethnic and cultural diversity that exists in Aotearoa. There is a need to look at sibling wellbeing and the cancer experience from other perspectives, such as how the journey may look for siblings who identify as Māori or Pacific Islander. Due to differing concepts of family and other cultural factors that may influence how a family adapts to a cancer diagnosis, future research in the area of sibling wellbeing in New Zealand needs to be conducted with a larger sample population which represents a wider range of cultural backgrounds.

There also needs to be further exploration of the factors that mediate how siblings adapt to the cancer journey. Though the current survey asked participants to disclose information such as their gender, age at diagnosis, age of sibling at diagnosis, position among siblings, and how many siblings are in their family, it was difficult to assess how those factors affected their need for support with such a small sample population.

The criteria for this research process placed limitations on who could participate in the survey and focus group and, therefore, provides just a small window into the experiences of siblings of patients with cancer. If approached in an ethically sensitive manner, there is room for exploration in the New Zealand context of younger siblings' experiences and the experiences of siblings who have lost a brother or sister to cancer.

One of the most interesting topics to come out of the research was the lack of contact siblings had with counselling services. Further research is needed to find out why counselling services were not accessed and what would make these services more accessible, if necessary. It would be useful to create more research opportunities looking at how counselling services could work in pre-secondary schools on a wide scale, and not just for children who have a sibling with cancer but for any child who is struggling and could benefit from counselling services.

Implications for practice

One of the implications for practice which has arisen from the current study is the importance of asking siblings directly about their needs and experiences. While a number of previous studies have focused on asking parents and hospital staff about the needs of healthy siblings (O'Shea et al., 2012; Sidhu et al., 2005; von Essen & Enskär, 2003), these figures may not always recognise the siblings' need for support outside of the home and hospital settings. Siblings themselves are the only ones that can give a full and accurate narrative of their own lived experiences. Teachers, counsellors, and other school staff should ask the affected student about their needs and what would help them feel welcome, supported, and safe at school.

In an effort to improve the school experiences of siblings, family members, members of the medical community, and cancer support groups, such as CanTeen, should form collaborative relationships with school staff. School personnel who have been appropriately educated about cancer may be in a position to answer questions that arise from students or the siblings themselves and also dispel misconceptions some people may have about cancer (Alderfer & Hodges, 2010). Teachers can help school peers understand what a cancer journey may entail and find ways they can support their friend in need.

The formation of home-school relationships is also important to put into practice. While it is not in the job description for school counsellors to provide family counselling, collaboration with parents is an important part of the job when it is in the best interests of students' personal, social, and educational development (Manitoba Education & Citizenship and Youth, 2007). It is important for the school to engage families and the community to convey when and how to help children in need, and work collaboratively in reducing the stigma surrounding seeking guidance and counselling (Education Review Office, 2013a). Hopefully, the current research will stress to school communities the importance of attending to the needs of the sibling population and provide schools with ideas on how they can help their students in need.

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Appendices

Appendix A - Advertisement for participation

Recruitment for participation in the national online survey involved advertisement on the Facebook pages of the CanTeen offices around New Zealand, and was posted by CanTeen staff on behalf of the researcher.

Are you a sibling member of CanTeen?

Are you 16 years or over?

Do you have a sibling who is two or more years post cancer treatment in their cancer journey?

If the answer is yes to all of the above, we would like to invite you to contribute to a research project which explores perceptions of support in schools for siblings of cancer patients. Research in this area is important for developing resources aimed at helping families of cancer patients and for helping school communities to better understand the needs of the siblings. If you would like to contribute to the project, please consider taking the time to fill out the online survey at

<https://www.research.net/s/schoolbasedsupportforsiblings>.

If you have questions regarding the project, feel free to contact your local CanTeen office or the researcher, Erika Lamb, at erikalamb.nz@gmail.com.

Appendix B – Focus group advertisement

**Are you a sibling member of
CanTeen?**

Are you 16 years or over?

**Do you have a sibling who is two or
more years post cancer treatment
in their cancer journey?**

If the answer is yes to all of the above, you are invited to participate in a focus group session at the CanTeen Auckland offices as part of a research project which explores perceptions of support in schools for siblings of cancer patients. Research in this area is important for developing resources aimed at helping families of cancer patients and for helping school communities to better understand the needs of the siblings.

If you have questions or to express an interest in participating in the study, please contact your

CanTeen youth worker or the researcher, Erika Lamb, at erikalamb.nz@gmail.com or



Appendix C – Letter requesting access to CanTeen New Zealand



May 2015

Claudine Young
CanTeen National Office
PO Box 56-072
Dominion Rd
Auckland 1446
New Zealand

Dear Claudine,

School Support for Siblings of Patients with Cancer

I am a student at Massey University. I recently completed a Postgraduate Diploma in Education with an endorsement in Educational Psychology. This year, I am working on a research thesis as part of the requirement to gain a Master of Educational Psychology. I am writing to seek your permission, as the general manager of CanTeen New Zealand, to conduct research with your members. The purpose of this project is to explore sources of support in schools which siblings perceive as being the most important/influential to them, what schools do to help siblings socially, emotionally and academically, and also to identify what siblings wish their teachers, peers and other school staff would do to help them. Together, I hope we can develop our understanding of how school communities can best help siblings cope during their cancer experience.

Project Description and Invitation

The data for this research project will be collected in two parts. In the first part, I would like to invite CanTeen sibling members to complete an online survey to contribute information on the questions posed above.

In the second part, CanTeen sibling members in the Auckland region will be invited to participate in small focus group interviews. The focus group sessions will allow the participants to lend their unique voices to issues that directly involve them and hopefully help others to understand how to best help this population cope during a particularly stressful time in their lives.

Participant Identification and Recruitment

For participation in the national online survey, members could be invited to participate via email or on an online forum frequently used by your membership, such as a Facebook page.

For recruitment for the focus group sessions, I also seek your permission to provide information to potential participants at a social meeting for sibling members at the CanTeen offices. A CanTeen staff member would facilitate the social meeting. I can personally give members a brief overview of the study, and request expressions of interest via email.

To be considered for the research project, each participant must be:

- A sibling member of CanTeen
- 16 years or over
- Have a sibling who is a cancer survivor and is two or more years post cancer treatment in their cancer journey

For inclusion in the focus group interviews:

- Satisfy the above criteria
- Based in the wider Auckland area
- Able to participate in one 45-minute group interview
- Interested in engaging in the private focus group.

Project Procedures

The questions on the nation-wide online survey would revolve around the following themes: who/what supported you at school, what they did to support you, what support you would have liked to receive, and what you want people to understand about your experience. The survey will be a mix of open-ended questions and questions that require a response on a scale. The survey will be kept short to minimise inconvenience.

I would conduct up to three focus groups with a small number of CanTeen sibling members. The group session will require participants to reflect on their time at school, starting from when their sibling was first diagnosed with cancer. Their reflections could focus on the events between this

point and when their sibling stopped treatment, or when the participant left school, or beyond, if their sibling suffers from late effects. The group session will involve questions around the same themes that appeared in the online survey. I would audio record and take notes during the focus group session. The recording is to accurately record the information provided, and will be used for transcription purposes only.

Participant's Rights

Students will be assured that they are under no obligation to accept this invitation. If they decide to participate, they have the right to:

- Decline to answer any particular question;
- Withdraw from the study at any time;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that their name will not be used;
- Be given access to a summary of the project findings when it is concluded;

To participate in the focus group sessions, participants must give consent for the entire focus group session to be audio recorded. However, participants will be given a summary of the analysed focus group discussion and will have the opportunity to change, alter, or remove any material they have personally contributed to the discussion that they do not wish to have included in the data for the research.

It should be noted that due to the nature of the research, CanTeen may be identifiable in any research published on this project.

Project Contacts

My supervisors are Tracy Riley (T.L.Riley@massey.ac.nz) and

Wendy Holley-Boen (W.Holley-Boen@massey.ac.nz)

Please feel free to contact me or either of my supervisors, if you have any questions about the project.

Thank you for your time.

Erika Lamb

erikalamb.nz@gmail.com

Appendix – D – Letter of permission from CanTeen

Gmail - Research project https://mail.google.com/mail/u/0/?ui=2&ik=4931d26295&vi

 Erika Lamb <erikalamb.nz@gmail.com>

Research project
1 message

Claudine Young <claudiney@canteen.org.nz> Tue, Jun 2, 2015 at 8:37 AM
To: Erika Lamb <erikalamb.nz@gmail.com>

Hello Erica,

I am pleased to be able to confirm that we are happy for you to go ahead with your research. I am satisfied that you have appropriate procedures in place and that you will be able to work with the young people in a way that is sensitive and respectful of their experiences. I look forward to reading your findings.

Regards Claudine

Claudine Young
General Manager Member Services



National Office
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F 09 303 4433
www.canteen.org.nz
www.facebook.com/CanTeenNZ
www.twitter.com/CanTeenNZ



Appendix E – Information for participants



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MATĀURANGA

Information for participants

School Support for Siblings of Patients with Cancer

Introduction and Purpose

Kia ora, Talofa lava, Malo e lelei. My name is Erika Lamb. I am a graduate student at Massey University, studying towards a Masters degree in Educational Psychology. I would like to invite you to take part in my research study, which concerns the experiences of siblings of patients who have had cancer. I would like to find out what source of support in schools is perceived by siblings as being the most important/influential to them, what schools do to help siblings, socially, emotionally and academically, and also find out what siblings wish their teachers, peers and other school staff would do to help them.

Participant Identification and Recruitment

After hearing an overview of the project at today's CanTeen social meeting, please email me with your expression of interest within the next week. To be considered for the research project, you must:

- Have a sibling who is a cancer survivor and at least two years post treatment in their cancer journey
- Be aged 16 or over
- Have attended school when your sibling was diagnosed with cancer and/or while your sibling was receiving cancer treatment
- Based in the wider Auckland area

Procedures

If you agree to participate in my research, I will conduct a focus group with you and a small number of other CanTeen sibling members at the CanTeen Auckland offices. The group session will ask you to reflect on your time at school from when your sibling was at the beginning of their cancer journey and the time that followed. You may also choose to discuss any late effects your sibling has. Late effects are health problems, physical or emotional, that occur months or years after completing cancer treatment. The group session will involve questions about who/what supported you at school, what they did to support you, what support you would have liked to receive, and what you want people to understand about your experience. The session should last about 45 minutes. With your permission, the session will be audio recorded and I will take notes during the focus group session. The recording is to accurately record the information you provide, and will be used for transcription purposes only. If you agree to being recorded but feel uncomfortable at any time during the interview, I can turn off the recorder at your request. Or if you don't wish to continue, you can leave the group session at any time. Your name will not be used in the write up of the project findings.

You are also invited to participate in a national online survey which will cover questions similar to the one that will be addressed in focus group sessions. The website link can be emailed to you upon request.

Benefits

It is hoped that the research will allow you, as siblings, to lend a voice to issues that directly involve you and hopefully help others, especially school staff, to understand how to best help siblings cope during a particularly stressful time in your lives.

Risks/Discomforts

The discussions held in the focus group session are intended to be interesting and thought-provoking. However, if any of the research questions make you feel uncomfortable in any way, you have the right to decline to answer any question or to end your participation in the group session.

Confidentiality

As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. Consent forms will be kept in a locked filing cabinet in my office; all data will be kept in a different locked filing cabinet. All data will be destroyed after a set storage period.

Rights

Participation in research is completely voluntary. You are free to decline to take part in the project. You can decline to answer any questions and are free to stop taking part in the project at any time. Whether or not you choose to participate in the research and whether or not you choose to answer a question or continue participating in the project, there will be no penalty to you or loss of benefits to which you are otherwise entitled. You will be given your own transcripts of the session to review and verify. You have the right to modify and /or remove any material you do not wish to have included in the data for the research.

Questions/concerns

If you have any questions about this research, please feel free to contact me. I can be reached at erikalamb.nz@gmail.com.

Alternatively, you can contact my supervisors:

Tracy Riley – T.L.Riley@massey.ac.nz

Wendy Holley-Boen – W.Holley-Boen@massey.ac.nz

If you require further support, I urge you to contact your CanTeen youth worker.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/29. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

Thank you for your time.

Appendix F – Focus group consent form



MASSEY UNIVERSITY
 INSTITUTE OF EDUCATION
 TE KURA O TE MATĀURANGA

School Support for Siblings of Patients with Cancer

FOCUS GROUP PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

My participation in this project is voluntary. I have the right to decline to answer any question or to end my participation in the group session at any time.

I am happy for the session to be audio recorded. I will be given a summary of findings to review and verify. I have the right to modify and /or remove any material I do not wish to have included in the data for the research.

I have been given a copy of this consent form to keep for my own records.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

Date:

.....

Full Name - printed

.....

Appendix G – Confidentiality agreement for CanTeen staff



MASSEY UNIVERSITY
 INSTITUTE OF EDUCATION
 TE KURA O TE MATĀURANGA

School Support for Siblings of Patients with Cancer

FOCUS GROUP CONFIDENTIALITY AGREEMENT – CANTEEN STAFF

I have read the Participant Information Sheet. I understand the nature of the study and the precautions that will be taken to preserve confidentiality.

I understand that my role in the project is to introduce the researcher to the participants, act as a comforting presence for sibling members, and intervene if any of the participants become distressed.

I understand that the researcher will not identify me by name and that my confidentiality as a facilitator in the focus group sessions will remain secure.

I agree not to disclose anything discussed in the focus group or name the participants in the focus group.

Signature:

Date:

.....

Full Name - printed

.....

Researcher

Signature:

Date:

.....

Full Name - printed

.....

Appendix H – Online survey: ‘School-based Support for Siblings of Patients with Cancer’

Kia ora, Talofa lava, Malo e lelei. My name is Erika Lamb. I am a graduate student at Massey University, studying towards a Masters degree in Educational Psychology. I would like to invite you to take part in my research study, which concerns the experiences of siblings of patients who have had cancer. I would like to find out what source of support in schools is perceived by siblings as being the most important/influential to them, what schools do to help siblings, socially, emotionally and academically, and also find out what siblings wish their teachers, peers and other school staff would do to help them.

To be complete the survey, you must:

- o Have a sibling who is a cancer survivor and at least two years post treatment in their cancer journey
- o Be aged 16 or over
- o Have attended school when your sibling was diagnosed with cancer and/or while your sibling was receiving cancer treatment

It is hoped that this research will allow you, as siblings, to lend a voice to issues that directly involve you and hopefully help others, especially school staff, to understand how to best help siblings cope during a particularly stressful time in your lives.

Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

Participation in research is completely voluntary. You are free to decline to take part in the project. You can decline to answer any questions and are free to stop taking part in the project at any time. Whether or not you choose to participate in the research and whether or not you choose to answer a question or continue participating in the project, there will be no penalty to you or loss of benefits to which you are otherwise entitled.

If you have any questions about this research, please feel free to contact me. I can be reached at erikalamb.nz@gmail.com.

Alternatively, you can contact my supervisors:

Tracy Riley – T.L.Riley@massey.ac.nz

Wendy Holley-Boen – W.Holley-Boen@massey.ac.nz

If you require further support, I urge you to contact your CanTeen youth worker.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/29. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz

Please confirm you meet the criteria for participation in this study:

I am a sibling member of CanTeen New Zealand. YES/NO

I am 16 years of age or over. YES/NO

My sibling is two or more years post cancer treatment in their cancer journey. YES/NO

I was attending school at the time my sibling was diagnosed with cancer and/or undergoing cancer treatment. YES/NO

I have read the information sheet and understand the details of the study. I agree to participate in this study under the conditions set out in the information sheet. YES /NO

Sources of support in school

Please respond to each question below from your perspective as a sibling of a cancer survivor and in relation to support in a school environment.

What does the word “support” mean to you?

Who at school could you / did you turn to for support? (You may choose more than one response) Multi-choice: Teacher(s), Guidance Counsellor, School Nurse, Principal, Assoc/Deputy Principal, Coach, Dean, Form Class Teacher, Peer Support, Friends, Other (please explain):

From the list of people in the previous questions, whose support did you value the most?

As far as you are aware, which of the following made contact with your school to teach them about how they might support you with your brother/sister's cancer? (You may choose more than one response.) Multi-choice: My parents/family/whanau; Hospital staff; CanTeen; None of the above; Other:

Emotional Support

At school, who provided you with emotional support?

Did you access school counselling services? YES / NO

If YES, what did you hope to receive from accessing counselling services and did the service meet your expectations?

If YES, please rate the service on the following Likert scales

Accessibility – difficult to access --- easy to access

Confidentiality – none – unsure – somewhat confidential - highly confidential

Quality of Support — Poor, I would not recommend to others --- Great! I would recommend to others

Social Support

At school, who provided you with social support?

What did you want school peers to know about your cancer journey?

How did the school help you to communicate with your peers, regarding your cancer journey?

How schools can help

Listed below are ways school staff can help children who have a brother or sister with cancer. For each question, please rate on a Likert scale **how helpful** you think each item was to you by circling the appropriate response. Then indicate **how often** your school's staff helped you with this item.

Supported me in talking about my feelings – not helpful --- extremely helpful; never --- always.

Helped my parents to notice my good behaviours (i.e. achievements in school, sports, etc.) – not helpful --- extremely helpful; never ---always.

Provide me with extra help on school work - – not helpful --- extremely helpful; never --- always.

Help my parents to get me involved in hobbies, school activities - – not helpful --- extremely helpful; never ---always.

Encourage my parents to spend time with the other children in the family - – not helpful -- extremely helpful; never ---always.

Provide assistance to my parents to help them meet the needs of the other children in our family (aside from my sibling with cancer) - – not helpful --- extremely helpful; never --- always.

Allow me to visit my brother/sister during school time - – not helpful --- extremely helpful; never ---always.

Help me to find others that understand having a brother/sister with cancer – not helpful -- - extremely helpful; never ---always.

Give me / help me find more information to help me learn about cancer - – not helpful --- extremely helpful; never ---always

What supports could each of the following groups provide young people who have a brother or sister with cancer?

Teachers:

School Counsellors:

School Peers:

Did you ever take time off school? YES / NO

If YES, For what reason/s?

What are the top three things that teachers/school counsellors/school peers have done that was helpful for you?

Academic support

Who provided you with academic support at school?

What supports did you receive around assignments and exams? –multichoice –compassionate consideration; extension of deadlines; tutorial; online support; no support; other

A message to schools

From your experiences, what is the one key message schools need to know about the cancer experiences of siblings?

About you and your sibling

What is your gender?

What is your current age?

How old were you when your sibling was diagnosed with cancer?

What type of school did you attend while your sibling was undergoing treatment? (select all that apply)

- Primary school (Years 1-6)
- Primary and intermediate combined (Years 1-8)
- Intermediate (Years 7-8)
- Intermediate and high school combined (Year 7-13)
- High school (Year 9-13)
- Other (please describe)

How old was your sibling when they were diagnosed with cancer?

How long did your sibling spend on treatment?

Does your sibling have any late effects from treatment?

Who did you live with in your home/s?

How many siblings are in your family?

Which word best describes your place amongst your siblings? (Oldest, middle, youngest, other:)

Where were you living when your sibling was diagnosed with cancer? (i.e. city/town)

Did you have to move in order for your sibling to receive treatment? If so, where did you move to?

What is your ethnicity?

Which best describes your current occupation (you may choose more than one): Secondary Student, Tertiary Student, working part-time, working full-time, apprentice, other:

Anything else?

Please use the space below to provide any further comments about yourself and your experiences.

Thank you for taking time to complete this survey.

If you live in the Auckland area and are interested in further research involvement, please let CanTeen know or contact me by email at erikalamb.nz@gmail.com

Remember, if you need support in any way, CanTeen can help you. Please contact your CanTeen youth worker.

Appendix I – Focus group interview schedule

All questions were developed in collaboration with CanTeen youth workers.

Introductions

Please introduce yourself to the group and tell us a little bit about yourself. For example:

- How old are you?
- How old were you when your sibling was diagnosed with cancer?
- How long did your sibling spend on treatment?
- Does your sibling have any late effects from treatment? Late effects are health issues, physical or emotional, that occur months or years after completing cancer treatment.

Meaning of support

In the survey, support was described as ... [add responses from national online survey]. How would you define/describe “support”?

The impact on school life

How much did your teachers and school peers know about your situation?

How did they find out?

When did you feel like you needed support the most?

How did your sibling’s cancer experience impact upon your school routines?

Were you able to participate in extracurricular school activities? (E.g. participating in school sports, attending camps, school balls, etc.)

What ways did your school show support?

What factor influenced the level of support you received? (For example, amount of family support, geography)

What were some of the positive experiences that emerged? (E.g. fundraising events organised by the school)

Hopes for the future of school support

In what ways do you wish school staff and peers would help young people who have a brother or sister with cancer?

What services would you like to see in schools for siblings of patients with cancer? You can draw on your own experiences to describe or demonstrate the need for services you would want to create.

What factors would need to be considered when creating these services? What do you need to know about family life?

What should schools know about the cancer experiences of siblings?

Additions from survey responses:

For those of you who were at primary school or intermediate school while your sibling was undergoing treatment, do you think a counselling service would have been helpful? Why?

Is there any value in having a partnership between home and school?

From the survey responses, not many people accessed peer counselling services. Why do you think people don't turn to these services? Were there any? What would have made you more likely to access these services?

Are there any other comments you would like to make about school-based support?