

School support for siblings of patients with cancer

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Abstract

This research project investigated the importance of school-based support structures for siblings of patients diagnosed with and treated for cancer. These brothers and sisters have a range of emotional, social, academic, and physical support needs that tend to be overshadowed by the focus on the patient and parents/caregivers. Sibling members of CanTeen New Zealand (an organisation which supports young people living with cancer and their siblings) participated in a nationwide online survey followed by a focus-group session in Auckland, both exploring siblings' cancer journeys and their perceptions of school-based support. The research highlighted the disruption to siblings' everyday lives; the potential of school counsellors to provide support and coordinate its provision by others for this population; and the need for home-school partnerships. This research can provide valuable insight for staff in schools where students are living in families affected by cancer, and can act as a guide for how best to support the needs of this population.

Keywords: cancer, siblings, schools, school counselling, support structures

Having a sibling diagnosed with cancer can turn a child's world upside-down. Each year in New Zealand, an average of 196 children are diagnosed with cancer (Ministry of Health, 2010). The diagnosis impacts on each family member, dramatically changing their everyday routines as they try to incorporate the implications in their daily lives. Advances in multiple treatments, combined with earlier parental awareness of cancer symptoms, mean that childhood cancer is no longer classified as an inevitably fatal illness. Nevertheless, children's experience of treatment 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).

These distressing events are traumatic for patients and take a toll on the loved ones watching them suffer. For parents, this can lead to feelings of powerlessness and other intense emotions, including shock, denial, anxiety, guilt, sadness, despair, uncertainty, chaos, loneliness, and fear during their child's sickness (Björk, Wiebe, & Hallström, 2005; Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997; Patistea, Makrodimetri, & Panteli, 2000). Björk et al. (2005) have described this as a "broken life world" (p. 265), where the lives previously known to the family completely fall apart. Siblings can also experience grief regarding the loss of a normal life, anxiety about whether the disease can be cured, and fears of being forgotten or unimportant within the family's new priorities (Nolbris, Enskär, & Hellström, 2014).

Siblings' experiences are largely influenced by their parents' experiences, as decisions about where to live, who takes care of them, and how much knowledge they are given about their brother's or sister's illness lie in the parents' hands (Kobayashi, Hayakawa, & Hohasi, 2015). Parents of children with cancer often find themselves preoccupied by the needs of their ill child, and report difficulties associated with organising a life around treatment and periods of hospitalisation, all of which limit their time, energy, and ability to meet other family members' needs (Sidhu, Passmore, & Baker, 2005; Sloper, 2000). They experience stress and exhaustion over maintaining stability of the family unit, faced with dividing their time between home, work, school, and the hospital, and trying to keep the family connected (Kobayashi et al., 2015). Siblings may consequently experience shifting relationships with their parents and may try to repress their own feelings so they do not burden their parents (Kobayashi et al., 2015).

Although negative outcomes for siblings are not inevitable, they are a population at risk for anxiety, confusion, and personal suffering (Bendor, 1990). Daily stressors can affect their everyday functioning at home and in school. Alderfer, Labay, and Kazak (2003) conducted a study in the US, with a sample of 113 siblings between the ages of 10 and 20, exploring the prevalence of post-traumatic stress (PTS) in siblings of childhood cancer survivors. Alderfer et al. (2003) found that 49% of the sample reported mild PTS while 32% indicated moderate to severe levels of PTS. Over a quarter (27%) of the siblings believed that their brother or sister would die and over half (56.8%) of the siblings considered the cancer experience scary and difficult (Alderfer et al., 2003). Similar results were found in another US study by Alderfer and Hodges (2010) wherein 54% of their sample population of 161 siblings from ages eight to 18 reported moderate to severe post-traumatic symptoms related to their cancer journey.

Studies exploring siblings' responses to the illness have also revealed the physical reactions such as headaches and stomach aches that siblings can exhibit (Heffernan & Zanelli, 1997; Houtzager, Grootenhuis, & Last, 1999; Nolbris & Ahlström, 2014; Walker, 1988). 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).

Some siblings have reported difficulty controlling their emotions, for instance becoming angry at home with parents and healthy siblings, as well as in school with their friends (Nolbris & Ahlström, 2014). What presents as problem behaviour is likely to be a young person's response to distress and grief. Siblings may experience stigmatisation by peers, which can lead to shyness and social isolation at school (Barbarin et al., 1995). A US study by Fife, Norton, and Groom (1987) showed that 54.8% of their sibling sample of 31, aged six to 17, exhibited behaviour problems (including hostility, attention seeking, and withdrawal), while a decline in academic performance was noted in 38.7% of the siblings. Siblings' academic functioning can be influenced by fatigue, increased household responsibilities, and declining parental supervision and involvement in their school life (Barbarin et al., 1995). Such research suggests that school staff have a role to play in helping families when symptoms such as these are apparent and are adversely affecting a sibling's school performance.

Having a sibling with cancer, though, is an unfamiliar experience for many children and young people, and consequently, it may be uncomfortable for them to discuss or even acknowledge this at school. Parents noted that siblings were often isolated in school and felt unsupported by their peers (Sidhu et al., 2005). The situation can be intensified by the lack of social interaction outside of school, as altered family care-taking responsibilities may limit participation in after-school activities (Bendor, 1990).

However, research has found that siblings with high social support have fewer behaviour problems and fewer symptoms of depression and anxiety than those with less support (Barrera, Fleming, & Khan, 2004). These findings highlight the benefits of and need for sibling support from schools and the wider community.

Siblings can also experience post-traumatic growth from their cancer journey, which has been defined by Tedeschi and Calhoun (2004) as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (p. 1). There can be opportunities for them to demonstrate maturity, supportiveness, and independence in the face of adversity, to display acts of self-sacrifice and generosity in responding to the needs of others, and to experience a

greater sense of compassion with others who struggle (Barbarin et al., 1995). Trauma can bring new perspectives, 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).

The environments in which siblings are immersed either encourage or discourage emotional expression and candid discussion (Kilmer, 2006). School community members such as counsellors, teachers, and other students are uniquely positioned to form supportive relationships with siblings and help ease the burden they may be carrying. Ideally, schools aim to promote the self-knowledge and emotional acceptance of all students, while encouraging them to reach their potential and become content and productive individuals (Hornby, 2003). By helping young people disclose their distress and talk about their concerns, and by providing them with validation and appropriate support, schools can help siblings reframe their cancer journey in terms of personal growth, building resilience, and other unexpected positive outcomes (Kilmer, 2006).

In its review of how to improve guidance and counselling in secondary schools, the Education Review Office (ERO, 2013a) adapted a “Circle of Care” approach used in Manitoba, Canada (Manitoba Education, & Citizenship and Youth, 2007) for New Zealand schools. In this approach, the student is situated in the centre of several layers of care; guidance and counselling comprise just one of those layers, with the guidance counsellor as one of many sources of support in an in-school guidance and counselling team. 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). Counsellors play a key role in the promotion of pastoral care training which encourages other school staff to engage in pastoral care activities (Hearne & Galvin, 2015). To inform this approach, ERO (2013b) asked students who they would talk to about a variety of concerns, and found that students were more likely to confide in guidance counsellors than any other school staff regarding mental health issues, conflicts with friends, grief, and family problems, while they were more likely to turn to a form teacher or dean to discuss concerns about their learning (ERO, 2013b).

Emotional distress can affect students’ learning, and considering the amount of time spent at school, and the influence teacher–student relationships can have on school performance and wellbeing (e.g., Agee & Dickinson, 2008; Cooper, 2004; Hawk, Cowley, Hill, & Sutherland, 2002), it is not surprising that teachers are viewed by some siblings as important sources of support, hope, and information, providing them with comfort and a focus outside of the illness (Björk et al., 2005; Sloper, 2000). Alderfer and

Hodges (2010) found in their study that greater levels of teacher social support, as perceived by siblings, were significantly related to better school performance.

Guidance counsellors, however, seem pivotal in coordinating consistent, effective, and sustainable supports for students; without a dedicated staff member, support is often ad hoc and based on the goodwill of caring adults in the school. In New Zealand, schools with small rolls (100 to 400 students) are less likely to have guidance counsellors, and the employment of counsellors in pre-secondary schools is rare (ERO, 2013b; Hermansson & Webb, 1993). The New Zealand Association of Counsellors (NZAC, 2015) has advocated for counselling services to be available at pre-secondary schools, stating that “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” (n.p.). To create the conditions for trust between young people and counsellors, the provision of quality counselling services should be available early on in schooling, and allow for frequent informal as well as formal access (NZAC, 2015).

Nevertheless ERO (2013b) reports that only 65% of students participating in a survey on guidance and counselling said it was socially acceptable to seek support at school for guidance and counselling. The stigma attached to seeking guidance counselling is a challenge for some schools; work is needed to break down this and other barriers to students’ seeking help. Alongside the formal support from counsellors, vigilant teachers and deans are a critical resource; they are well-placed to recognise changes in students’ mental health and wellbeing, can often be the first to hear about a family’s circumstances, have positive relationships with the sibling, and can facilitate support from the counsellor or a multi-disciplinary “wrap-around” team (Mazzer & Rickwood, 2015). NZAC (2015) also stresses the importance of supporting whole families to resolve problems and connect with appropriate professionals or agencies as required.

International studies provide an insight into the nature of experiences of childhood cancer for siblings. Exploring perceptions of support for siblings of children with cancer in the New Zealand context as well seemed valuable to elicit information for families here, as well as for schools and organisations dedicated to improving the lives of young people affected by the childhood cancer experience. The current study therefore endeavoured to explore the types and importance of support structures provided within school communities for siblings in their cancer journey.

Method

The current study focused on answering the following four questions:

- Who/what are supports for siblings at school?
- How have siblings been 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?

The project aimed to contribute to providing appropriate support for siblings of patients with cancer. To enable others to gain a greater understanding of their experiences and the support they found helpful, siblings needed to be able to tell their stories and express their feelings and thoughts in their own words (Sloper, 2000; Wilkins & Woodgate, 2005). To this end, data were collected using predominantly qualitative methods in a nationwide online survey and a small semi-structured focus group. The survey consisted of a series of mainly open-ended questions which allowed participants to describe their experiences in their own words.

CanTeen New Zealand is an organisation that aims to support, develop, and empower young people aged 13 to 24 who are living with cancer, while also providing support to their siblings (CanTeen, n.d.). As researcher, the first author consulted with CanTeen staff, as well as a former CanTeen sibling member, to ensure that questions in the survey and focus-group session were appropriate. CanTeen staff also helped recruit participants for the study, and offered participants debriefing or support if needed during or after the study. The survey questions were adapted from the Nurse–Sibling Social Support Questionnaire developed by Murray (2000a) to explore support from school staff rather than health professionals. The project was reviewed and approved by the Massey University Human Ethics Committee.

Participants: Survey

Due to the sensitive nature of the research topic, the researcher ensured that participants had strong connections with an organisation such as CanTeen for any necessary follow-up support. Criteria were established to guide recruitment for the online survey through the population of sibling members of CanTeen: (1) the participant needed to be over 16 years of age; (2) to have a survivor sibling who was two or more years post-cancer treatment, and (3) to have attended school when their sibling was diagnosed with cancer and/or while their sibling received cancer treatment. Additionally, potential focus-group participants had to be able to attend a session in Auckland.

Invitations to participate in the online survey were placed on the Facebook pages of all the CanTeen regional offices in New Zealand. A link to the website hosting the survey was attached to the Facebook notices, and was also emailed to participants at the discretion of CanTeen staff or upon request of a member. The survey was available online for 12 weeks, and 10 CanTeen sibling members completed or partially completed the survey. The sample was made up of seven females, one male, and two participants who did not specify their gender. Participants were between seven and 18 when their sibling was diagnosed. The current age of the participants ranged from 18 to 24 years.

Participants: Focus group

CanTeen Auckland staff personally invited sibling members to participate in the focus group session. Focus groups were difficult to schedule due to staff and participant illness. As a result, only one focus group was conducted, with three females, aged 16, 17, and 21, and one male, aged 18, as participants. Two had been attending primary school when their sisters were diagnosed, while the other two were high school aged when that occurred.

The recruitment criteria were influenced by the knowledge that children and young people tend to have significantly higher distress levels and unmet needs when a sibling is undergoing cancer treatment or has relapsed (McDonald, Patterson, White, Butow, & Bell, 2015). Young people are not usually at high risk of psychological disturbance after their sibling has successfully completed cancer treatment (Van Dongen-Melman, De Groot, Hahlen, & Verhulst, 1995).

Survey and focus group questions

Survey participants were asked to consider who they perceived to be sources of support in school and whether or not they accessed counselling services. If applicable, they noted what they sought from counselling and rated the service. Siblings were asked what they wanted school peers to know about their cancer journey and how school staff helped them communicate with their peers regarding their situation. Participants were asked to describe ways in which members of a school community could help siblings of a young person with cancer, and answered questions on the helpfulness and frequency of school staff-members' support. The focus group, in turn, explored the two overarching topics: the effect on school life of having a brother or sister with cancer, and hopes for the future of school-based support for siblings.

Data analysis

Data were analysed thematically, in a process similar to Sidhu et al.'s (2005) research on parents' perceptions of the needs of siblings with cancer, and were "coded through a process of highlighting key words and phrases according to concepts and meaning, which formed constructs" (p. 278). Common themes emerged across each of the survey questions, and across the responses of each participant. The focus group was audio-recorded and transcribed verbatim by the researcher. Transcripts were then used for a similar thematic analysis, the results of which were compared with themes from the survey data. Pseudonyms are used here for focus-group participants.

Results and discussion

Disruption of everyday life

Siblings expressed a strong desire for school communities to understand the effect of the cancer journey on their everyday lives. When asked to give one key message to schools, six out of nine survey respondents suggested schools needed to be aware that living with a brother or sister with cancer is really tough for siblings and can take a great emotional toll.

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. (Survey respondent 5)

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. (Julia)

Having a brother or sister with cancer can complicate relationships in the family unit and siblings may struggle to deal with the ways other family members are coping with the child or young person's diagnosis. In the focus-group session, Steven described hearing his sister throwing up in her bedroom next to his room as a side effect of treatment, alongside dealing with the toll it was taking on his parents. Similarly, Belinda noted how her brother's reaction to cancer impacted on the whole family:

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. (Belinda)

In the focus group, Tessa and Julia discussed changes in family relationships in terms of loss of attention, with their parents spending more time with their ill siblings, lacking the time to support their other children in their activities.

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. (Julia)

While survey participants were not asked directly about the impact the cancer experience had on their home lives, some wrote of feelings of isolation in their family, and the serious consequences of the strain on all family members.

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. (Survey respondent 9)

Five out of the nine respondents in the online survey indicated that they took time off school while their sibling had cancer, firstly to come to grips with the diagnosis as a family and subsequently while their sibling was receiving treatment. One respondent took time off school to spend time with his family, to look after his brother when he was ill, and to look after his own mental health while struggling with depression during the cancer journey. Two focus-group participants mentioned taking time off school to avoid exposing their ill sibling to measles and chickenpox which were going around. One sibling indicated that they missed out on school because it was difficult for their parents to arrange transport to and from school. Involvement in extra-curricular activities was also affected, with one focus-group participant describing over-involvement in soccer as her parents were focused on looking after their other child. In contrast, another participant disclosed that the experience ended his promising involvement in golf:

My golf kind of took a sidestep 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...I could have got better, but I stopped that. (Steven)

In all of these scenarios, guidance counsellors and teachers would be well positioned to monitor the impacts on the sibling, and to coordinate practical, academic, and social/emotional supports.

All survey participants who responded to demographic questions indicated that they lived at home with their family during their cancer journey. For the majority, that meant living with at least one parent and their siblings. One respondent, who identified herself as Māori/Pākehā, lived with her grandparents while her brother was receiving chemotherapy. Another stayed at friends' houses when her parents needed to stay overnight at the hospital. Though none had to move so that their sibling could receive cancer treatment, two participants mentioned their parents and sibling travelling out of town for treatment, and one mentioned spending all of his school holidays away from home.

Such disruption to everyday life has been commonly recorded in the literature about siblings' cancer experiences. As described by siblings in the current research and in previous studies, parents of children with cancer are often most focused on the needs of their ill child and lack the energy to attend to their other children's needs (Sloper, 2000), and participants did not feel as important as their siblings with cancer (Bendor, 1990). Having a brother or sister with cancer can have long-lasting effects on a sibling's future directions, as in Steven's case with golf, and his experiences reflect Bendor's (1990) finding that siblings aged 14 to 19 years feel conflicted about continuing life as normal. He may have hidden his feelings to avoid putting further pressure on his parents (Kobayashi et al., 2015).

The fact that participants stayed with grandparents or friends at various stages of the cancer journey reflects the way a wider group of family or friends become involved in the responsibility of caring for siblings because of the demands of the illness (Sidhu et al., 2005). 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, 2000b).

It is important for school staff to be aware of the changes in siblings' routines and the possible consequences of those changes in order to find ways to support their emotional wellbeing and academic needs, boost a sense of belonging within the school community, and reduce the risk of further negative effects. With their access to students, school records, staff perspectives, and resources, school staff are in an ideal position to gain an understanding of siblings' school lives and to work with families to provide the best care for those in need.

Importantly, the cancer journey does not necessarily end for a family when the patient has finished treatment or the cancer has been eliminated. A focus-group participant, Tessa, who was in primary school when her sister was diagnosed with

cancer, reflected on the fact that the time when she needed most support was several years after her sister had finished treatment, when the realisation hit her about how different their young lives had been:

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. (Tessa)

Kobayashi et al. (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. Even with a brother or sister in remission, siblings may still struggle to come to terms with what the family has gone through. Developmentally, as they grow older they may gain a fuller appreciation of the threat cancer presented and be better able to process the journey. If a child or young person is still struggling with emotional, behavioural, social, or academic issues, support should be provided.

Role of school counsellors as providers and coordinators of emotional support and pastoral care

None of the participants in the focus group, and only two of the 10 survey respondents, had accessed school counselling services. Six of those 10 respondents were attending either high school or a combined intermediate and high school, and it was therefore probable that counselling services were available. When asked what they had hoped to gain from counselling services, both participants who accessed these services cited needing someone to unload their emotions to, as they felt that they did not have anyone else in their lives who could fully support them.

During the focus group, the possible value was raised of having counsellors available to children at pre-secondary schools. Two participants who had attended primary school at the time of their sisters' diagnoses indicated that they would have found this 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. (Julia)

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.
(Survey respondent 9)

When asked what they would have gained from counselling support at primary school, Julia indicated that she would want help understanding her situation, and to be able to talk about her feelings. 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 the difficulty some young people face in seeking help. Several siblings in the online survey, advising how school counsellors could provide support to siblings, used the word "offer," indicating that they wanted to know that help was readily available at school, if necessary. Survey participants also wanted school counsellors to provide emotional support to siblings and be someone that siblings could talk to about their cancer experiences.

Of all members in a school community, ERO (2013b) identified guidance counsellors as those with whom students were most likely to discuss grief and family problems. When siblings would benefit from talking with someone one step removed from events in the home environment, school staff can provide support and guidance to students from an adult perspective (Reddy, Rhodes, & Mulhall, 2003). At times this may involve direct support from the school counsellor, while at other times, other adults in the school have a part to play.

In a less direct manner, school counsellors play an important role in coordinating pastoral care in school: with the consent of, and working collaboratively with, the student, they can be sources of emotional and informational support for other students and teachers. Siblings wanted teachers to understand their situation; four

survey participants indicated that teachers need to have a level of understanding—for instance, that siblings may not always be able to complete work, or 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. Teachers are a key part of a support team for siblings as they usually know their students well and are in a position to build positive relationships (ERO, 2013a). Two of the survey participants noted ways in which teachers could cater to their emotional needs:

[By] giving the sibling a safe space to go to if they feel overwhelmed in class.
(Survey respondent 18)

If they are comfortable with that student...be someone to talk to. (Survey respondent 1)

One participant suggested that school counsellors support siblings in communicating with their peers. When asked how their school had helped them to communicate with their peers regarding their cancer journey, all respondents reported that no support was given. Three 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.
(Survey respondent 5)

In addition to the counsellor(s), dean or house leader, and teachers, staff involved in the support network for a sibling could include other members of the school community such as the nurse, a social worker, sports coach, or leader of an activity in which the student participates, or the Special Educational Needs Coordinator. The role of school counsellors within these teams includes the guidance and support of teachers in such a situation (ERO, 2013b). Counsellors, in collaboration with school nurses, can help teachers to understand what siblings of cancer patients may be experiencing and how best to support them emotionally, socially, and academically. They could work

directly with other students themselves or support teachers to help siblings' peers understand what their classmate may be experiencing and explore ways they can help their friend in a time of need. Bringing in appropriate resources to educate their students about cancer and the experiences of their affected classmate might help them, including the sibling, to understand the situation better and to spare the sibling from having to answer questions from their peers (Alderfer & Hodges, 2010). It is important that students participate in discussions and preventative classroom programmes which demystify some of the issues faced by children and young people, including physical and mental health issues, and to prepare them with suitable information in order to support their peers (ERO, 2013b).

There are several possible reasons why some participants did not access school counselling services. Siblings may not have been aware of available services, may not have felt they needed the services, may not have trusted the counselling system at their school, may have considered it socially unacceptable to seek counselling, or their school may not have employed a school counsellor. For some students, the issue was not one of needing support but perhaps one of not knowing how to ask for help, or of avoiding help. Further information is needed to understand why some siblings chose not to access school counselling if their schools did provide such services, and to identify the other ways they may have received informal and formal support, and what policies these students' schools had in terms of monitoring and responding to student wellbeing. What emerged from the results was the need for school counselling at primary and intermediate schools, and processes to ensure that all students, not just the sibling population, have access to counselling in times of need.

Need for home–school partnerships

Another theme emerging from this research is the importance of strong home–school partnerships to help siblings cope with school and the issues that evolve from dealing with their brother's or sister's illness. Siblings expressed their desire for parents to understand how they were performing academically and also emotionally, behaviourally, and socially. When asked how helpful they would find offers of assistance to the wider family, five reported it would be helpful or very helpful. However, in reality these needs were not met. Six siblings reported that their family never received such assistance from school, one reported that assistance was seldom provided, and the remaining two participants noted that the school sometimes provided help to their families. These results do not necessarily suggest that these

services are lacking in schools, but may reflect students' desire to have services *offered* rather than seeking out the services themselves. The realities of high counselling workloads may be at play (ERO, 2013a).

In order to help families experiencing stress in ways that are sensitive to personal and cultural diversity, educators need to show “responsiveness to the expressed needs of the families we serve; what is it that they see as their needs?” (Swick & Williams, 2006, p. 376). As Sloper (2000) suggests, it is the responsibility of health professionals to inform parents about the potential reactions of siblings to their brother's or sister's diagnosis; school staff can share the responsibility and help families identify reactions and issues that may arise. Families can respond most appropriately to their children's needs when they are aware of what happens in their lives at school.

Conclusion

This was a retrospective study exploring the lived experiences of a small group of siblings of children with cancer. Every sibling's experience is different, and will be different again for young people who lose a sibling to cancer; therefore, the results can never truly be generalised. 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 and support that they need. Schools need to be aware of students' circumstances and actively provide help by asking how students' needs can be accommodated at school and in general. Siblings of children and young people with cancer want the school community to understand how difficult the cancer journey is for them. A brother's or sister's cancer diagnosis can throw a family's world into chaos, with disruptions to everyday routines and shifts in family dynamics. Support from school counsellors and other staff, and strong home–school partnerships help to identify the needs of siblings and provide them with consistent support across settings.

Counsellors have a pivotal role to play in providing emotional and informational support to siblings directly and in helping other school community members to support the student. Through embracing the whole-school approach emphasised in the “Circle of Care” model and the promotion of pastoral care training, counsellors can encourage teachers to engage in activities to increase student wellbeing (Hearne & Galvin, 2015; Manitoba Education, & Citizenship and Youth, 2007). School personnel who have been appropriately educated about cancer can answer questions that arise from students or the siblings themselves or help them access appropriate resources and dispel the misconceptions some people have about cancer (Alderfer &

Hodges, 2010). Counsellors and teachers can help school peers understand what a cancer journey might entail and identify ways they can support their friend in need. The school has a critical role in engaging families and the community to convey when and how to help children in need, at the same time working collaboratively to reduce the stigma associated with guidance and counselling (ERO, 2013b).

Siblings themselves are the only ones who can give a full and accurate narrative of their personal lived experiences. As they do with countless other children and young people, counsellors are uniquely positioned to talk with siblings about their circumstances and their needs and what would help them feel welcome, supported, and safe at school. Hopefully, the current research will stress the importance to school communities of recognising the needs of this special group of students and their families, and of working collaboratively to care for and support them through their cancer journeys.

References

- Agee, M., & Dickinson, P. (2008). It's not an "either/or": Pastoral care and academic achievement in secondary schools. In C. Rubie-Davies & C. Rawlinson (Eds.), *Challenging thinking about teaching and learning* (pp. 357–370), Hauppauge, NY: Nova.
- Alderfer, M. A., & Hodges, J. A. (2010). Supporting siblings of children with cancer: A need for family–school partnerships. *School Mental Health, 2*(2), 72–81. doi:10.1007/s12310-010-9027-4
- Alderfer, M. A., Labay, L. E., & Kazak, A. E. (2003). Brief report: Does Posttraumatic Stress apply to siblings of childhood cancer survivors? *Journal of Pediatric Psychology, 28*(4), 281–286. doi:10.1093/jpepsy/jsg016
- Barbarin, O. A., Sargent, J. R., Sahler, O. L. Z., Carpenter, P. J., Copeland, D. R., Dolgin, M. J., ... Zeltzer, L. (1995). Sibling adaptation to childhood cancer collaborative study. *Journal of Psychosocial Oncology, 13*(3), 1–20. doi:10.1300/J077V13N03_01
- Barrera, M., Fleming, C. F., & Khan, F. S. (2004). The role of emotional social support in the psychological adjustment of siblings of children with cancer. *Child: Care, Health & Development, 30*(2), 103–111.
- Bendor, S. J. (1990). Anxiety and isolation in siblings of pediatric cancer patients. *Social Work in Health Care, 14*(3), 17–35. doi:10.1300/J010v14n03_02
- Björk, M., Wiebe, T., & Hallström, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing, 22*(5), 265–275. doi:10.1177/1043454205279303
- CanTeen. (n.d.). *Our Story*. Retrieved from <http://www.canteen.org.nz/our-story/>

- Cooper, B. (2004). Empathy, interaction and caring: Teachers' roles in a constrained environment. *Pastoral Care in Education*, 22(3), 12–21.
- Education Review Office. (2013a). *Improving guidance and counselling for students in secondary schools*. Wellington, New Zealand: Author.
- Education Review Office. (2013b). *Guidance and counselling in schools: Survey findings*. Wellington, New Zealand: Author.
- Enskär, K., Carlsson, M., Golsäter, M., Hamrin, E., & Kreuger, A. (1997). Parental reports of changes and challenges that result from parenting a child with cancer. *Journal of Pediatric Oncology Nursing*, 14(3), 156–163.
- Fife, B., Norton, J., & Groom, G. (1987). The family's adaptation to childhood leukemia. *Social Science & Medicine*, 24(2), 159–168.
- Hamama, R., Ronen, T., & Feigin, R. (2000). Self-control, anxiety, and loneliness in siblings of children with cancer. *Social Work in Health Care*, 31(1), 63–83. doi:10.1300/J010v31n01_05
- Hawk, K., Cowley, E. T., Hill, J., & Sutherland, S. (2002). The importance of the teacher/student relationship for Maori and Pasifika students. *Set*, 3, 44–49.
- Hearne, L., & Galvin, J. (2015). The role of the regular teacher in a whole school approach to guidance counselling in Ireland. *British Journal of Guidance & Counselling*, 43(2), 229–240. doi:10.1080/03069885.2014.952622
- Heffernan, S. M., & Zanelli, A. S. (1997). Behavior changes exhibited by siblings of pediatric oncology patients: A comparison between maternal and sibling descriptions. *Journal of Pediatric Oncology Nursing*, 14(1), 3–14.
- Hermansson, G. L., & Webb, S. B. (1993). Guidance and counselling in New Zealand: Weathering a decade of transformation. *International Journal for the Advancement of Counselling*, 16(3), 213–227.
- Hornby, G. (2003). Teachers and counselling. In G. Hornby, C. Hall, & E. Hall (Eds.), *Counselling pupils in schools: Skills and strategies for teachers* (pp. 1–11). London, England: RoutledgeFalmer.
- Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (1999). Adjustment of siblings to childhood cancer: A literature review. *Supportive Care in Cancer*, 75(5), 302–320. doi:10.1007/s005209900052
- Kilmer, R. P. (2006). Resilience and posttraumatic growth in children. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 264–288). Mahwah, NJ: Lawrence Erlbaum Associates.
- Kobayashi, K., Hayakawa, A., & Hohasi, N. (2015). Interrelations between siblings and parents in families living with children with cancer. *Journal of Family Nursing*, 21(1), 119–148. doi:10.1177/1074840714564061
- Manitoba Education, & Citizenship and Youth. (2007). *Manitoba sourcebook for school guidance and counselling service. A comprehensive and developmental approach*. Manitoba, Canada: Author.

- Mazzer, K. R., & Rickwood, D. J. (2015). Teachers' role breadth and perceived efficacy in supporting student mental health. *Advances in School Mental Health Promotion*, 8(1), 29–41. doi:10.1080/1754730X.2014.978119
- McDonald, F. E. J., Patterson, P., White, K. J., Butow, P., & Bell, M. L. (2015). Predictors of unmet needs and psychological distress in adolescent and young adult siblings of people diagnosed with cancer. *Psycho Oncology*, 24(3), 333–340. doi:10.1002/pon.3653
- Ministry of Health. (2010). *National plan for child cancer services in New Zealand*. Wellington, New Zealand: Author.
- Murray, J. S. (2000a). Development of two instruments measuring social support for siblings of children with cancer. *Journal of Pediatric Oncology Nursing*, 17(4), 229–238. doi:10.1053/jpon.2000.16398
- Murray, J. S. (2000b). Understanding sibling adaptation to childhood cancer. *Issues in Comprehensive Pediatric Nursing*, 23(1), 39–47.
- New Zealand Association of Counsellors. (2015). Huge need for school guidance counsellors in schools [Press release]. Retrieved from <http://www.scoop.co.nz/stories/ED1509/S00015/huge-need-for-school-guidance-counsellors-in-schools.htm>
- Nolbris, M. J., & Ahlström, B. H. (2014). Siblings of children with cancer: Their experiences of participating in a person-centered support intervention combining education, learning and reflection. Pre- and post-intervention interviews. *European Journal of Oncology Nursing*, 18(3), 254–260. doi:10.1016/j.ejon.2014.01.002
- Nolbris, M. J., Enskär, K., & Hellström, A. L. (2014). Grief related to the experience of being the sibling of a child with cancer. *Cancer Nursing*, 37(5), E1–E7. doi:10.1097/NCC.0b013e3182a3e585
- Patistea, E., Makrodimitri, P., & Panteli, V. (2000). Greek parents' reactions, difficulties and resources in childhood leukaemia at the time of diagnosis. *European Journal of Cancer Care*, 9(2), 86–96. doi:10.1046/j.1365-2354.2000.00204.x
- Reddy, R., Rhodes, J. E., & Mulhall, P. (2003). The influence of teacher support on student adjustment in the middle school years: A latent growth curve study. *Development and Psychopathology*, 15(1), 119–138. doi:10.1017/S0954579403000075
- Rollins, J. (1990). Childhood cancer: Siblings draw and tell. *Pediatric Nursing*, 16(1), 21–27.
- Sidhu, R., Passmore, A., & Baker, D. (2005). An investigation into parent perceptions of the needs of siblings of children with cancer. *Journal of Pediatric Oncology Nursing*, 22(5), 276–287. doi:10.1177/1043454205278480
- Sloper, P. (2000). Experiences and support needs of siblings of children with cancer. *Health and Social Care in the Community*, 8(5), 298–306.
- Swick, K. J., & Williams, R. D. (2006). An analysis of Bronfenbrenner's bio-ecological perspective for early childhood educators: Implications for working with families experiencing stress. *Early Childhood Education Journal*, 33(5), 371–378. doi:10.1007/s10643-006-0078-y

- Tedeschi, R. G., & Calhoun, L. G. (2004). Post-traumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15*(1), 1–18. doi:10.1207/s15327965pli1501_01
- Van Dongen-Melman, J., De Groot, A., Hahlen, K., & Verhulst, F. C. (1995). Siblings of childhood cancer survivors: How does this “forgotten” group of children adjust after cessation of successful cancer treatment? *European Journal of Cancer, 31*(13), 2277–2283.
- Walker, C. L. (1988). Stress and coping in siblings of childhood cancer patients. *Nursing Research, 37*(4), 208–211.
- Wilkins, K. L., & Woodgate, R. L. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. *Journal of Pediatric Oncology Nursing, 22*(6), 305–319. doi:10.1177/1043454205278035