“Cancer is a family diagnosis and it just hits everybody in a different way”:

The Non-shared Experiences of the Siblings of Pediatric Cancer Patients

by

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ABSTRACT

“CANCER IS A FAMILY DIAGNOSIS AND IT JUST HITS EVERYDOBY IN A DIFFERENT WAY”: THE NON-SHARED EXPERIENCES OF THE SIBLIGS OF PEDIATRIC CANCER PATIENTS

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This thesis is an investigation of the non-shared experiences of two siblings from the same family when a third child is diagnosed with pediatric cancer. Three dyads consisting of two siblings of a third child who survived or died from cancer at least a year ago were recruited. Semi-structured retrospective interviews were completed and participants were asked to reflect on their past experiences as the sibling of a child with cancer, as well the present and future impacts of being the sibling of a child who survived or died from cancer. The interviews were analysed using phenomenology. Siblings from the same family were found to have more differences than similarities in their experiences. Differences between siblings were explained by differing ordinal positions and relationships as well as the survival status of the child with cancer. When providing care and services for the siblings of children with cancer, two siblings from the same family may have different program and support requirements.
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Introduction

The Canadian Cancer Society in partnership with Statistics Canada estimates that 836 Canadian children from birth to fourteen years old will be diagnosed with cancer each year (2009). When a child is diagnosed with cancer, the entire family is affected, (Labay & Walco, 2004) yet most social science research has focused on the experiences of only part of the family: the ill child and his or her parents. To date, research on the experiences of the siblings has been less extensive. However, researchers have uncovered a multitude of socio-emotional difficulties which healthy siblings experience, including coping with dwindling parental attention (Dolgin et al., 1997), shifts in the family structure and alterations to the functional roles of family members (Giovanola, 2005), as well as experiencing intense negative emotions (Houtzager, Grootenhuis & Last, 2001). These challenges are often evidenced by a high proportion of siblings who experience an impaired quality of life (Houtzager et al., 2005), that is defined as an individual’s well-being across multiple life domains, such as physical, emotional, and social; with attention paid to health-related issues (O’Connor, 1993). These family dynamic shifts, emotional difficulties, and experiences of impaired quality of life can sometimes last for months and even years, resulting in chronic issues for some siblings (Houtzager, Oort et al., 2004). There is a demonstrated need for more investigations into the lived experience of the siblings of children diagnosed with cancer, given that the well child’s needs are frequently not being met (Murray, 2001; Murray 2002).

Although this situation appears bleak, there exists a subset of siblings who experience more positive outcomes. Sloper (2000) identified four such outcomes which siblings of pediatric cancer patients reported experiencing: increased maturity, a new outlook on life, empathy, and resiliency. This group of children still experiences the negative emotions and family changes associated with the cancer experience; however they were capable of more adaptive coping such
that their long term outcomes are more favorable. Once this group of siblings was identified, researchers set out to determine what factors were associated with positive outcomes in order to determine which factors set this group of siblings apart from those who had long term and/or chronic difficulties (Murray, 2000).

This research identified several protective factors that may help children adapt and cope with being the sibling of a child with cancer. There are several family based factors, such as having a close and sensitive caregiver (Sloper, 2000), maintaining open lines of communication within the family (Dolgin, Somer, Zaidel, & Zaizov, 1997), having high family cohesion, as well as having a moderately adaptive family system (Houtzager, Oort et al., 2004). Furthermore, the sibling’s ability to maintain his or her personal interests as well as an ability to remain optimistic are associated with more positive outcomes (Houtzager et al., 2005; Sloper, 2000). A child’s ability to maintain his or her own interests may depend largely on his or her family, depending on age. A younger child requires transportation to activities whereas an older child or adolescent may be capable of arranging for his or her own transportation. Furthermore, a child’s ability to remain optimistic is closely tied to his or her family, as about 23% of a child’s score on a test of optimism is accounted for by genetics and an additional 13% of the variance is accounted for by shared environmental factors (Plomin et al., 1992). The remaining 65% of the variance in optimism is accounted for by non-shared environmental factors. Accordingly, all of the presently known factors associated with adaptive outcomes for healthy siblings are either family based factors or are related to the family a child grew up in and/or presently resides in to some degree.

Due to the high association between family functioning and child outcomes, it would be logical to assume that two healthy siblings from the same family would have similar long-term outcomes from the cancer experience. However, in a recent study, the present author found that a
pair of siblings from the same family can have very different experiences despite residing in and
growing up within the same family (Calvert, Lollis, & Hamelin, 2009). Presently, no researchers
have attempted to explain why or how two siblings of a single pediatric cancer patient can
experience different events and emotions during and after treatment. Accordingly, the present
study aims to determine if siblings often have similar or different experiences. Furthermore, the
present study will draw upon behavioural genetics to identify possible factors that may account
for some of the similarities and differences in sibling’s experiences.

The goal of this research was to determine if there are differences between two siblings
from the same family when a third sibling is diagnosed with cancer. To do this, two fields of
research will be brought together: the experiences of siblings of pediatric cancer patients and
behavioural genetics. The following literature review will provide more information on the
experiences of healthy siblings by exploring the common positive and negative outcomes for
siblings of pediatric cancer patients, followed by a description of the protective factors and how
these entities help siblings to adapt. Next, this paper will draw upon behavioural genetics
principles to explain some of the differences visible in siblings from the same family. Finally, the
research questions will be described through an integration of behavioural genetics and previous
research on the experiences of siblings of pediatric cancer patients.

Negative Experiences and Outcomes

When a child is diagnosed with cancer, his or her healthy sibling(s) often experience
numerous difficult events and emotions. The socio-emotional climate changes abruptly for these
healthy siblings upon the diagnosis of cancer. The well child is often forced to adapt to an
environment with less parental attention and contact (Houtzager, Oort, et al., 2004; Sloper, 2000;
Walker, 1988), where parents often spend the majority of their time at work or visiting the ill
child at the hospital (Houtzager, Grootenhuis, et al., 2004; Terzo, 1999). During the treatment phase of cancer, siblings report feeling that their family is disjointed, with half the family at the hospital and the other half back at home (Calvert & Lollis, 2011). This can create a shift in the structure of the family, which necessitates a change in the roles and responsibilities of each family member. Healthy siblings often gain responsibilities within the household, frequently including performing additional chores and taking on roles such as becoming a caregiver for younger siblings (Dolgin et al., 1997; Nolbris, Enskar, & Hellstrom, 2007). These changes can be difficult for children, especially considering the emotional struggles they are also navigating.

A large proportion of siblings have been found to experience low quality of life, with more siblings being adversely affected in the earlier stages of the illness (Houtzager, Grootenhuis, et al., 2004; Houtzager et al., 2005). Each of these negative experiences will now be discussed in more detail.

**Limited Parental Attention.** Although the ill child requires copious amounts of the family’s attention, it is arguable that the well child is also in need of attention, guidance, and assistance. The relationship between the parent and the healthy sibling changes drastically once the ill child is diagnosed with cancer. Parents spend less time at home and more time either at work or at the hospital (Calvert & Lollis, 2011; Houtzager, Oort, et al., 2004; Terzo, 1999). This equates to parents spending less time with the child who does not have cancer. Having a pediatric cancer patient in the family seriously disrupts the relationship between the parents and the sibling of the ill child, often leaving the sibling feeling neglected (Dolgin et al., 1997). Furthermore, siblings often perceive their parents to be emotionally unavailable even when they are in close physical proximity (Bendor, 1990). The decrease in attention that the healthy sibling is receiving from his or her parents can have detrimental effects on the child, including feeling
unloved, unimportant, isolated, lonely, and/or insecure (Houtzager, Oort, et al., 2004; Terzo, 1999).

Furthermore, due to parents’ decreased availability for the healthy siblings in the family, instrumental supports are often neglected or passed on to extended family members or family friends (Sloper, 2000). Instrumental supports includes performing necessary daily activities such as feeding, bathing, and sheltering children, as well as transporting them to school, doctor’s appointments, and after school activities (House 1981, as cited in Murray, 2002). Healthy siblings also need to be driven to support groups, interventions, or programs; if they are to be involved in them. This responsibility often falls to parents and is commonly a reason why these siblings are not included in programs: parents do not have the time or energy to bring the siblings to the intervention (Ballard, 2004). Even considering the decrease in parental time and attention that siblings receive, these children still report that their parents are their most important means of social support (Walker, 1988) but that, at the same time, they require more support from their parents (Calvert & Lollis, 2011).

In the event that parents become too overburdened and simply cannot care for both the child in the hospital as well as their healthy children, extended family members (Giovanola, 2005), older children (Nolbris et al., 2007), and community members (Barrera, Chung, Greenberg, & Fleming, 2002) are often asked to stand in as caregivers for the younger healthy siblings. Extended family members and community members generally offer healthy siblings instrumental support, most commonly in the form of a place to stay while their parents are at the hospital with the ill child (Giovanola, 2005). The closer siblings are to the stand-in caregiver, the better the siblings are able to cope (Sloper, 2000). It appears that the initially close relationship increases the support offered by the part-time caregiver, as well as the comfort the
child experiences with their new living situation. Unfortunately, Sloper (2000) found that when healthy siblings were not close to the new caregiver before the diagnosis of pediatric cancer, then the children’s needs may not be met.

**Changes in Family Structure and Function.** Whether siblings are cared for in their home by their less available parents, cared for by older siblings, or in a neighbors’ or extended family’s home, they inevitably experience numerous changes in the structure and functions of their family and its individual members. In a meta-analysis of the psychosocial impacts of being the sibling of a child with cancer, Wilkins and Woodgate (2005) found that the most predominant theme in the literature was that siblings perceived that their family relationships, dynamics, and routines changed remarkably. Mothers tended to accompany the ill child to the hospital (Harding, 1996), leaving fathers and older siblings to perform the mother’s usual roles (Wilkins 2001, as cited in Wilkins & Woodgate, 2005). Oftentimes this includes early-born children performing caretaker tasks for their later-born siblings (Dolgin et al., 1997; Nolbris, Enskar, & Hellstrom, 2007), necessitating changes in the relationships between family members because different people are seen as caregivers and care-receivers. Older children and adolescents also tend to become responsible for more chores and household tasks (Barrera et al., 2002; Houtzager, Oort, et al., 2004; Labay & Walco, 2004). In some cases older children and adolescents demonstrate more maturity and more responsibility, however some siblings report that this experience made them ‘grow up too fast.’ (Calvert & Lollis, 2011).

Family routines also change once a child is diagnosed with cancer. Families containing a child with cancer have a tendency to have their schedules revolve around the ill child’s schedule and appointments (Wilkins & Woodgate, 2005). Social activities as a family are oftentimes planned and held if and only if the child with cancer is healthy enough to attend (Freeman,
O’Dell, & Meola, 2000). As well, after the diagnosis of cancer, there may be less time and monetary resources available to allow the healthy siblings to continue to participate in extracurricular activities and interests (Calvert & Lollis, 2011). Furthermore, as previously mentioned, many siblings are unable to fully partake in interventions because their parents are unable to commit to transporting the child to and from the program (Ballard, 2004). Interventions which are held at the same hospital as the cancer treatment have had some success with sibling attendance (Ballard, 2004), further demonstrating how family schedules revolve around the ill child’s treatment schedule.

**Negative Emotions.** Arguably, the most challenging portion of coping with having a brother or sister with cancer is learning to deal with the extreme negative emotions and relative lack of positive emotions that the sibling most likely experiences. Commonly reported negative emotions include the following: sadness (Packman et al., 2004), anger (Dolgin et al., 1997; Houtzager, Oort, et al., 2004), guilt (Houtzager et al., 2001), feelings of isolation (Houtzager, Oort, et al., 2004), anxiety (Houtzager, Grootenhuis, et al., 2004), jealousy, and fear (Dolgin et al., 1997).

Sadness in siblings is reported both during treatment and especially if the ill child does not survive the treatment process (Packman, Horsley, Davies, & Krammer, 2006). Children additionally experience sadness because they miss both their parents as well as the life they used to lead (Wilkins & Woodgate, 2005). Anger is reported more in younger siblings, as they tend to express their emotions behaviourally, thus acting out in anger is common (Giovanola, 2005). Children felt angry because of unequal treatment (Wilkins & Woodgate, 2005), changes in family routines, and restrictions to participation in extracurricular activities (Freeman et al., 2000; Murray, 1998).
The sibling’s experience of guilt can be complex. They often report feeling guilty about not being the one who is sick; they felt guilty years later about how they interacted with their sibling; they felt guilty about wanting more attention and being jealous or angry at the child with cancer; or, if the ill child died, they report feeling guilty about not saying good-bye or for not apologizing about something (Packman et al., 2006; Houtzager et al., 2001). Several authors mentioned that siblings experienced feelings of isolation, yet none attempted to explain why (Ballard, 2004; Creed, Ruffin, & Ward, 2001; Houtzager, Grootenhuis, et al., 2004; Houtzager, Oort, et al., 2004; Houtzager et al., 2001). It is possible that children feel isolated because they are often left with extended family members or neighbours for care (Sloper, 2000). This separation from the immediate family may leave healthy siblings feeling isolated, and if the sibling feels that they do not fit into the family they are staying with, they may experience further feelings of isolation. Furthermore, siblings may feel isolated from their peers because they are experiencing different situations and emotions than other children their age and this results in age-mates being unable to relate to these healthy siblings.

Anxiety is also common. Siblings’ experience of anxiety differs depending on age and sex: older siblings reported more anxiety than younger siblings and girls reported more anxiety than boys (Houtzager, Grootenhuis, et al., 2004). The authors suggested that age differences were likely because older siblings are more capable of understanding the possible long-term implications of cancer and that older siblings may be more emotionally and instrumentally involved in the cancer treatment than younger siblings. Furthermore, the authors suggested that girls may experience more anxiety because they may become responsible for more household tasks than male siblings. It is important to note that peer-group interventions have been useful in
decreasing the anxiety that is experienced by siblings (Barrera et al., 2002; Houtzager et al., 2001).

Many siblings also report feeling jealous of their ill brother or sister. A common reason for this jealousy is that the ill child received far more attention than the healthy siblings (Terzo, 1999). Fear and worry are also experienced by healthy siblings, and often related to a fear that the ill child may not survive; a fear that the illness will run in the family; an irrational fear that the healthy child may catch the illness; and other irrational fears developed through receiving inaccurate or incomplete information about cancer or simply through rudimentary cognitions and young children’s inability to understand these complex circumstances (Houtzager et al., 2001). Accordingly, younger children are likely to experience more irrational fears than older siblings due to the higher likelihood of misunderstanding. When considering both these emotional difficulties as well as the changes in family structure and function, it is not surprising that 63% of siblings of pediatric cancer patients experience psychological adjustment difficulties (Barrera et al., 2002).

Quality of Life. Quality of life can be measured via standardized tests (Houtzager et al., 2005) representing children’s daily functioning across physical, emotional, and social settings (O’Connor, 1993). Once a child’s score on a quality of life measure is determined, the score can be compared using standardized normal scores. Standardized quality of life tests are useful for looking at sibling adaptation to the cancer experience, because one can measure the quality of the sibling’s life and compare it to the quality of life in the average child. As well, it is possible to place a child on a percentile range and determine how many children in the general population would score higher or lower than the child in question. Children who score in the lowest 20% of
scores (children scoring in the twentieth percentile) are said to have an impaired quality of life (Houtzager et al., 2005).

When the quality of life of a sibling is measured one month after the diagnosis of cancer, between 26 percent and 56 percent of siblings have an impaired quality of life (Houtzager et al., 2005). Considering that only 20 percent of the general population has an impaired quality of life, this shows that the siblings of pediatric cancer patients are at a higher risk for difficulties related to a low quality of life. It is important to recognize that the aspects of quality of life that are the most impaired in siblings are the experience of ‘positive emotions’ and ‘negative emotions’ (Houtzager et al., 2005). This demonstrates that these children are experiencing an absence of positive emotions and a large number and intensity of negative emotions: these children are having emotional difficulties to such a significant degree that it is impairing their quality of life.

Sibling quality of life has been reported to be lower than normal one month after diagnosis, however as time passes, sibling’s quality of life increases (Houtzager, Grootenhuis, et al., 2004). Although it was found that over time, sibling quality of life approached normal levels, at two years post-diagnosis, 42 percent of siblings still reported impaired emotional quality of life and 34 percent reported an impaired social quality of life (Houtzager, Grootenhuis, et al., 2004). Since only the bottom 20 percent of individuals score in the impaired range for quality of life, these results demonstrate a need for social and emotional interventions for these children. Lastly, it is important to recognize age differences in the quality of life in the siblings of pediatric cancer patients. Houtzager, Grootenhuis et al. (2004) found that at two years post-diagnosis, 50 percent of younger children- aged seven to eleven- had an impaired quality of life, while only 33 percent of adolescent siblings did. It is possible that these findings are explained by the younger child’s dependence on over-burdened parents, while adolescent children are able to become more
self-reliant. This demonstrates a need to focus interventions on school-aged children, but not to
the exclusion of adolescent siblings.

**Positive Experiences and Outcomes**

Although siblings of pediatric cancer patients will experience some or all of the
difficulties listed above, some of these siblings will also have positive experiences and outcomes.
There are four positive outcomes that have recently been identified in the literature for siblings
of pediatric cancer patients: increased maturity, a new outlook on life, empathy, and resiliency.
(Packman et al., 2006; Sloper 2000). Siblings are thought to experience these four positive
outcomes by learning to live in a family with a child who has a life threatening illness and/or by
coping with the death of a sibling.

**Increased Maturity.** It is common that siblings of pediatric cancer patients express
increased maturity following the experience of cancer. This is true both when the ill child
survives the cancer and when they do not. Children and adolescents who have a brother or sister
with cancer have been described as more independent and more mature (Sloper, 2000). This
independence and maturity may be a result of the healthy siblings receiving less parental
attention, and thus being forced to care for themselves. Alternatively, increased maturity may
come from parents and families expecting and demanding that healthy siblings perform more
household tasks during the illness. Both Davies (1991) and Packman et al. (2006) report that
bereaved siblings gain a sense of psychological growth and that they report feeling different than
their peers. For example, Creed et al. (2001) describe a situation where a girl explained how she
never went through the ‘invincibility’ stage. She continued to say that while other teenagers
believed nothing could happen to them, she had learned earlier that bad things could happen to
anyone, including herself and her sibling: cancer had made her mature beyond that step as a
child. Bereaved siblings may also feel different than their peers because they have gained a new outlook on life, and so some of the antics of other children seem meaningless. For example, while most children spend time playing at parks, bereaved siblings may feel like there are more important things they could be doing, such as school work.

**Gaining a New Outlook on Life.** After a child with cancer dies, healthy siblings often reported having a new outlook on life (Davies, 1991). This trait was not mentioned for healthy siblings when the ill sibling survived cancer. It is unknown whether this is because children who do not lose a sibling do not have a new outlook due to cancer, or if no one has specifically asked them. Some healthy siblings reported psychological growth due to experiencing death (Davies, 1991). Others reported gaining new moral values (Packman et al., 2006). Most commonly however, healthy siblings reported that experiencing the death of their ill sibling caused them to be driven to live life to its fullest and to make the most out of each experience (Packman et al., 2006; Sloper, 2000). These siblings realized the fragility of life and discovered that anything can happen to anyone at any time; so they aspired to ‘get the most’ out of the time they have.

**Increased Empathy.** Empathy is also reported among the siblings of pediatric cancer patients. The development of empathy can be viewed as a coping mechanism for siblings, since research has demonstrated that siblings with greater empathic abilities experienced fewer psychological difficulties (Packman et al., 2006). This may be because more empathetic siblings are capable of perceiving the difficulties that their ill sibling is experiencing, and thus they may have a greater understanding and appreciation for the imbalance of attention and care. By learning to be flexible, empathetic, and adaptable during the cancer experience, siblings of pediatric cancer patients develop a greater capacity for compassion, cooperation, understanding, and sensitivity to other’s feelings (Packman et al., 2006; Sloper, 2000). As well, siblings who
lost their brother or sister were found to be more comfortable with death at a later date, and they were also more willing than the average person to help others who were facing a death in the family (Packman et al., 2006). Empathy was also found to be significantly correlated with age (Lambay & Walco, 2004), with older siblings having an increased ability to express more empathy than younger siblings (Lambay & Walco, 2004). It is possible that this is due to the advanced cognitive development required to be empathetic: you need to be able to ‘put yourself in another’s shoes.’

**Resiliency.** Resiliency is the idea that one can overcome challenges, adversity, and difficult times through personal and environmental factors (Smith & Carlson, 1997). Resiliency in the healthy siblings of pediatric cancer can be seen as a protective factor which helps them to adapt better and remain more positive during and after treatment. Being optimistic and feelings of hope are both important protective factors when times become challenging (Packman et al., 2006). Resilient individuals are able to remain optimistic, always attempting to see the positive side of events. It is unclear whether being optimistic allows siblings to be more resilient or if more resilient siblings become more optimistic in difficult situations. Either way, both resiliency and optimism are important factors for healthy sibling adaptation. Houtzager, Grootenhuis et al. (2004) found that siblings who remained optimistic throughout the cancer experience tended to have better emotional reactions.

Children who are more resilient also tend to view situations differently than other children. According to Walker (1988), potentially stressful events can be seen as a loss, something potentially harmful, something threatening, or as something challenging. According to this idea, the more resilient child would likely use the more optimistic perspective and view ‘stressors’ as challenges. These individuals would view fewer events as threatening and
according to Lazarus and Folkman’s (1984) Stress and Coping Theory, this would result in fewer stressful event appraisals. Accordingly, more resilient children would likely experience less stress and fewer of the negative outcomes associated with highly stressful situations.

These positive outcomes were all identified before researchers began to question why some healthy siblings were faring better than others. Once it became clear that some children were adapting more positively to being the sibling of a child with cancer, several studies were undertaken which attempted to identify factors which were associated with these positive outcomes: factors that protected these children from some of the commonly seen negative outcomes.

**Protective Factors**

Although the term ‘protective factors’ is commonly used in the literature, its meaning can be misleading. These factors are associated with positive outcomes in healthy siblings and help to protect these children from some of the negative emotions, experiences, and outcomes; however they do not stop children from experiencing these negative things altogether. Children with some protective factors may have less severe or fewer negative experiences, but they will almost certainly still experience negative situations or emotions (Murray, 2000; Sloper, 2000).

Thus far, the factors that have been identified as decreasing the severity or number of negative outcomes and/or increasing the likelihood of positive outcomes are mostly family based factors. As mentioned earlier, even those factors that are not strictly family based are influenced by the family. Having a well functioning family before, during, and after the cancer experience appears to be incredibly important for child development and adaptation. In order to consider how two siblings from the same family may have different experiences, the discussion on the protective factors will be divided in two sections: those factors which are family based and thus
potentially common to all children in the family and those which are specific to the individual children in the family.

**Family based protective factors.** From the literature, four family based protective factors have been identified. First, healthy siblings benefit from having an emotionally and physically close caregiver who is sensitive to the sibling’s needs. Second, when siblings live in a family with a high level of family cohesion they have the most desirable levels of adaptation. Third, moderate to high levels of family adaptation are related to better sibling adjustment. Fourth, open family communication helps to produce positive outcomes in siblings and protects from negative outcomes and experiences.

*Close, sensitive caregiver.* Emotionally close caregivers are important for healthy siblings because these caregivers are able to provide support to healthy siblings as well as a safe place to express thoughts and feelings (Sloper, 2000). A more emotionally close caregiver is more capable of recognizing the needs of the healthy siblings, probably because they have previous experience with the behavioural representations of the sibling’s emotional reactions; therefore, they may recognize that some challenging behaviour is due to emotional difficulties as opposed to simply misbehavior. Being able to recognize the emotional experiences of the healthy sibling enables emotionally close caregivers to respond in more appropriate ways. Sloper (2000) found that when extended family members cared for the healthy siblings, children experienced more comfort and support when they were close to the relative before the diagnosis of cancer because the relative was more sensitive to the child’s feelings. The physical closeness of the caregiver is also important for optimal adjustment in healthy siblings. Due to subject overlap, the importance of parent-child closeness will be discussed in the following section on family cohesion.
In order to be sensitive to a child’s needs, the caregiver’s own wellbeing must also be considered. In the event that a parent is incapable of dealing with his or her own emotional difficulties, he or she will be less capable of caring for and supporting a child. This is evidenced by several studies that show that emotional difficulties in parents are related to adjustment problems in healthy siblings. Depression in the parent is related to adjustment difficulties in the sibling (Cohen, Friedrich, Jaworski, Copeland, & Pendergass, 1994); psychological distress in a parent was associated with lower wellbeing in the sibling (Houtzager, Oort, et al., 2004); and when a parent has difficulties coping with having a child with cancer, the healthy sibling tends to experience more school related problems (Fife, Norton, & Groom, 1987). The relationship between parental depression, psychological difficulties, and coping difficulties is explained by Houtzager, Oort, et al. when they state that “the amount of distress experienced by parents may determine the amount of time and energy they have left for the sibling in the family and may therefore determine the sibling’s wellbeing” (2004, p.592). Furthermore, mother’s reports of wellbeing are positively correlated to sibling’s adaptation (Dolgin et al., 1997). Apparently parents need to be physically and emotionally stable in order to provide the warm, sensitive care giving that healthy siblings require.

**Family cohesion.** Healthy siblings benefit when their family is able to stay together as a single cohesive family unit (Gogan & Slavinm 1981, as cited in Houtzager, Grootenhuis, & Last, 1999). High family cohesion is related to fewer behavioural problems in preschool aged children (Horwitz & Kazak, 1990), less stress, and fewer adjustment problems (Cohen et al., 1994). Siblings felt comforted when they were able to remain in close proximity to their parents and when the family unit was described as cohesive (Calvert & Lollis, 2011). Conversely, low family cohesion is related to more externalizing behaviours, social competence problems (Cohen et al.,
and higher levels of distress (Sahler et al., 1997). More specifically, healthy siblings experienced the most adjustment problems and distress when they were separated from their parents (Sahler et al., 1997).

During the treatment phase of cancer, extremely cohesive, or ‘enmeshed’ families were found to produce the most adaptive outcomes in healthy siblings (Cohen et al., 1994). The authors suggest that this is because siblings in highly cohesive families do not experience the difficulties associated with decreased parental attention and parent-child separation. In a longitudinal study that gathered data on sibling adjustment both during and after the treatment phase, Houtzager, Oort, et al., (2004) found that extremely cohesive families were actually detrimental for healthy siblings following the treatment phase. Instead, a highly cohesive, but not enmeshed family was found to be the most adaptive environment for healthy siblings when considering sibling outcomes following the cancer treatment. Perhaps an enmeshed environment is the most beneficial for siblings during the treatment phase if and only if the family becomes less cohesive and enmeshed upon the conclusion of treatment. Although it is clear that high levels of family cohesion are beneficial, more research is required to determine the optimal level of family cohesion for sibling adaptation. Finally, more research is required to explain why an enmeshed environment appears detrimental to healthy siblings following the treatment phase of cancer.

**Family Adaptation.** The level of adaptation in a family is also an important protective factor for healthy siblings. The concept of family adaptation considers the family’s ability to shift and change when faced with difficult situations. When a family is capable of shifting to accommodate the new schedule and needs of the illness, healthy siblings tend to be better adjusted (Cohen et al., 1994) with fewer behavioural problems (Horwitz & Kazak, 1990). On the
contrary, low adaptability is related to more externalizing problems as well as social competence issues (Cohen et al., 1994). Although the family’s ability to adapt during the cancer experience is important, extreme levels of family adaptation can actually be detrimental to healthy sibling (Houtzager, Oort, et al., 2004). When families were extremely adaptive, healthy siblings experienced more anxiety, loneliness, and psychosocial problems (Houtzager, Oort, et al., 2004). The authors suggested that this was due to changing roles and responsibilities in the family, which Sloper (2000) identified as very difficult for healthy siblings to adjust to.

Moderate levels of family adaptation appear important for healthy siblings, as low adaptation can be problematic for siblings, and the changes to family roles and responsibilities associated with high adaptation can also be difficult for siblings. The family needs to be capable of making changes to accommodate having a very ill child in the family, however too many changes are detrimental to healthy sibling adjustment.

**Family communication.** The healthy siblings of pediatric cancer patients benefit from open communication within the family (Calvert & Lollis, 2011). Open communication is positively related to social competence (Cohen et al., 1994), while closed family communication is associated with higher feelings of jealousy and guilt (Gogan & Slavin, 1981, as cited in Houtzager et al., 1999). Furthermore, when siblings are able to communicate with the family about the cancer, healthy siblings’ lives are less impacted by the illness (Havermans & Eiser, 1994). Finally, healthy siblings report that they would prefer to receive information about the cancer through communication with parents as opposed to from medical professionals (Calvert et al., 2009; Evans, Stevens, Cushway, & Houghton, 1992), however siblings report not receiving enough information from parents or any other source (Calvert et al., 2009; Dolgin et al., 1997; Nolbris et al., 2007). Although open communication within the family is clearly important, there
are many barriers to family communication, as evidenced by Evans et al.,’s., (1992) estimate that only one in four healthy siblings talk to their parents about the illness while approximately one third of siblings talk to no one.

Communication problems between healthy siblings and their parents are common in families with a child who has cancer (Breyer, Kunin, Kalish, & Patenaude, 1993; Van Veldhuizen & Last, 1991, as cited in Houtzager et al., 1999). Parents may have difficulty talking about their child’s illness, even with their healthy children. Fathers talk about the illness less with their children than mothers do (Powazek, Payne, Goff, Paulson, & Stagner, 1980, as cited in Houtzager et al., 1999) and younger siblings communicate less with either parent than older siblings (Cohen et al., 1994). As well, only about half of children with cancer communicate with their healthy siblings about the illness (Van Veldhuizen & Last, 1991, as cited in Houtzager et al., 1999). The reasons for communication breakdown are not fully known, however it is possible that it is emotionally painful for the family members to talk about the illness. As well, families are often physically separated during the treatment phase of cancer, which may act as a barrier to open communication. Finally, it is well documented that healthy siblings attempt to protect their parents by not talking about their own worries and by hiding their negative emotions (Cairns, Clark, Smith, & Lansky, 1979; Houtzager et al., 2001; Packman et al., 2006). Regardless of the reason, healthy siblings often do not communicate with their family members, even though open communication within the family is conducive to sibling adaptation.

**Individual protective factors.** Two protective factors which have been identified in the literature are more individualistic than the previously discussed factors. A healthy sibling’s ability to continue his or her own interests as well as his or her ability to remain positive and hopeful have both been identified as individual protective factors.
When healthy siblings are able to continue to participate in activities that interest them, they are able to maintain a sense of normalcy in their lives and are given a chance to forget about the illness for a while (Calvert & Lollis, 2011). This gives children the chance to act like kids and to have fun. When asked what they do to cope with being the sibling of a child with cancer, two of the most commonly listed coping mechanisms were participating in extracurricular activities and maintaining normalcy in their lives (Sloper, 2000). When healthy siblings of pediatric cancer patients participate in extracurricular and after-school activities, they are less isolated and likely feel less lonely. Teachers have also reported less anxiety in siblings who are more involved at school and who miss fewer days (Fife et al., 1987).

The ability to be optimistic and hopeful is an important protective factor for healthy siblings of pediatric cancer patients (Packman et al., 2006). Healthy siblings described optimism and maintaining hope as a coping mechanism used to remain positive and to not be overwhelmed by negative emotions during the difficult times in their brother or sister’s treatment (Sloper, 2000). Houtzager, Grootenhuis, et al. (2004) found that siblings who remained optimistic throughout the cancer experience tended to have better emotional reactions. Furthermore, optimistic children often experience high levels of resiliency. However, as discussed earlier, optimism and resiliency are intertwined in such a way that it is difficult to discern if resilient children are optimistic or optimistic children are more resilient. Either way, children who are optimistic are likely to also be resilient and thus, by definition, be more capable of overcoming the difficulties associated with being the sibling of a child with cancer.

Although these factors are more individualistic than the family factors discussed in the previous sections, they are still influenced by family factors and events. For instance, family adaptation and cohesion may limit a child’s ability to continue his or her interests if he or she is
now expected to travel to the hospital with the family and to care for younger siblings. Also, about 35% of a child’s score on the optimism subscale of a personality test is accounted for by genetics and shared environmental factors (Plomin et al., 1992). Accordingly, all of the protective factors associated with being the sibling of a child with cancer are shared by siblings within the same family to some degree; with four factors being completely shared and the remaining two being partially shared. Research on the experiences of healthy siblings of children with cancer has not yet explained how two siblings from the same family can have different experiences considering these shared environmental factors. It is now known that siblings experience their environments differently. This is the field of ‘non-shared environments’.

**Non-Shared Environments of Siblings**

For years researchers have been attempting to determine if genetic factors or environmental factors are responsible for the different traits we see between individuals. From this debate, the field of behavioural genetics has arisen, where researchers believe that both nature as well as nurture influence the development of traits. Presently, researchers within the behavioural genetics field are attempting to determine the proportion of certain traits that can be attributed to nature, or genetics, and how much is accounted for by environmental factors. By using twin and adoption studies, researchers have determined that similarities between twins exist based on genetics and possibly shared environmental factors, provided the siblings were reared together (Dunn & McGuire, 1994). When identical twins are reared together, the differences visible in them can only be accounted for by non-shared environmental factors (Plomin, Chipuer, & Neiderhiser, 1994).

In an attempt to understand the differences visible in healthy siblings of a child with cancer who grew up and lived in the same family, the work of behavioural geneticists
surrounding the concept of non-shared environments and experiences might be useful.

Researchers within the field of behaviour genetics consider non-shared environments as consisting of (a) objective differences in the environment and (b) subjective differences in the environment. This means that (a) there is a concrete, observable difference in the two children’s environments and (b) the two siblings perceive, understand, or attribute different meaning to similar environments (Daniels, 1986; Dunn & McGuire, 1994; Hoffman, 1991).

**Objective Environmental Differences.** It appears relatively straightforward to determine when an objective environmental difference exists, as this occurs when one sibling actually has a different experience or environment. Examples of objective differences that may occur between siblings include different peer groups; participation in different extracurricular activities; or attendance at different schools, classes, or grades. It becomes more difficult to observe objective differences in children’s experiences and environments when examining at a more micro level; two siblings may both have a relationship with the same peer; however, their relationships may be objectively different. Although this appears to complicate the measurement of objective differences in siblings, there is a solution: researchers have found that an individual’s perceptions of the quality of a relationship are more important than the actual, objective and observable quality of that relationship (Dunn & McGuire, 1994). Even when objective differences exist between siblings, it is their subjective interpretation of their environments that is critical to how each child experiences a situation. Because of this, it becomes critical to consider children’s perceptions of their relationships, environments, and experiences. This relates to the examination of subjective environmental differences, or when people have different perceptions or interpretations of the same situation.
**Subjective Environmental Differences.** When two siblings experience the same situation, such as having a brother or sister with cancer, they may understand or perceive this situation differently, resulting in different outcomes for each of the siblings. There are several different models which attempt to explain how two people come to appraise the same situation differently; however, Folkman’s (1997) reworking of the Lazarus and Folkman (1984) Stress and Coping Theory appears to be the best model to explain the subjective interpretation of the experiences of the healthy siblings of children with cancer.

**Stress and Coping Theory.** According to the original model, an event is initially appraised as benign/irrelevant, a threat, a challenge, or harmful. If the event is benign or irrelevant, the individual does not need to cope with the event. Any other appraisal requires the individual to choose a coping mechanism, either problem-focused coping or emotion-focused coping. Problem-focused coping is attempting to change the problem so it becomes less threatening, while emotion-focused coping is lessening the intensity of negative emotions regarding a stressful situation (Houtzager et al., 2005). Next, the stressful event is either resolved successfully, unsuccessfully, or not resolved. If the event is resolved, a positive emotion is expected to occur, while both unsuccessful and non-resolved events are expected to produce negative emotion (Lazarus & Folkman, 1984). This is where Folkman’s (1997) reworking comes in and adds several steps to the appraisal process.

When an event is resolved unsuccessfully (such as when a child remains ill after chemotherapy), or not resolved (such as when the child dies from cancer), Folkman (1997) argues that individuals may experience distress, however some individuals use what Folkman termed ‘meaning based coping.’ Meaning based coping entails enacting one of four coping techniques: positive reappraisal, revised goals, spiritual beliefs, or creating positive events.
Positive reappraisal involves reevaluating a negative situation into a positive light. For example, if a treatment was unsuccessful, a healthy sibling may reframe the negative situation into a positive one by thinking ‘at least my brother or sister is still alive.’ When an individual revises goals, he or she creates realistic, attainable goals and uses problem focused coping. This may be difficult for the healthy siblings of pediatric cancer patients, as cancer is relatively uncontrollable, especially for siblings. However, simple goals such as keeping the child with cancer hydrated by getting him or her a drink whenever his or her cup is empty may help the healthy sibling feel more control over the situation. Using spiritual beliefs or practices usually involves feeling comforted by the idea that the person who is ill will go somewhere safe or will be watched over when or if he or she dies. Finally, creating positive events refers to infusing ordinary events with positive meaning. For example, if a child with cancer is able to go for a short walk with his or her siblings after being bed ridden for days, the siblings may view this ordinary event as positive because it is a sign that the ill child is beginning to feel better.

According to Folkman’s reworked model, these meaning based coping techniques can lead to positive emotions even when events do not get resolved successfully (1997). Furthermore, using meaning based coping techniques sustains the coping process and allows individuals to continue to use emotion or problem focused coping.

There are multiple steps within this model where siblings could differ, creating different outcomes and experiences for the children. Siblings could differ on their initial appraisal of the event (as irrelevant, threatening, challenging, or harmful); the coping methods employed (problem- or emotion-focused coping); whether or not they use meaning based coping; and if they both use meaning based coping, the type of meaning based coping employed (positive reappraisal, revised goals, spiritual beliefs, or creating positive events). It is important to
consider each of these steps when exploring how healthy siblings from the same family have different experiences. Furthermore, it is also important to consider the factors that may contribute to different appraisals and choices of coping techniques. For example, children of different ages have different cognitive abilities, which foster the use of different types of coping techniques.

**Possible Reasons for using different appraisals and coping techniques.** According to Hoffman (1991), there are five factors which influence sibling differences, three of which will be described in this paper because they are important for the present study, the children’s ages, ordinal positions, and gender. These three factors are important in determining the way a child appraises an event as well as the coping techniques he or she is capable of using. As well, it is theoretically significant to include a fourth factor, the survival status of the child with cancer. The coping techniques used by siblings whose brother or sister survived cancer need to be different than those used by siblings whose brother or sister dies from cancer. This is partially because they now must learn to live without their sibling being physically present (Packman et al., 2006) and also because bereaved siblings need to cope with different family situations, such as deep parental depression following the death of the child who had cancer (Detmer, Lamberti, 1991, as cited by Packman et al., 2006).

**Age.** A child’s age has a large impact on his or her experiences with respect to being the sibling of a child with cancer. First, age largely determines a child’s cognitive abilities. Older children usually have more advanced cognitive capabilities, enabling them to understand more complex situations and to use more complicated coping techniques (Hoffman, 1991). For example, younger children may not be capable of using meaning based coping techniques, which may leave them feeling distress every time there is an unfavorable outcome. Conversely, older
children tend to understand the long term implications of cancer more than younger children, which results in older siblings experiencing more anxiety and distress than younger siblings (Houtzager, Grootenhuis, et al., 2004). It is possible that these older children are appraising the cancer as more threatening because they understand that the ill child may die from the cancer, whereas some very young children cannot reach this conclusion. As well, due to different developmental stages, children at different ages may focus on different aspects of the cancer experience (McGuire, Manke, Eftekhari, & Dunn, 2000). For example, younger children may focus on the loss in family routines because that may be the most challenging aspect of being the sibling of a child with cancer for them, whereas older children may focus more on the health related concerns for the child who is ill (Hoffman, 1991). These different aspects of the stressful event may result in different appraisals of the stressfulness of the situation.

**Ordinal Position.** The ordinal positions of the children in the family will also impact each child’s experiences. First-born children are treated differently than any later-born children, with different expectations and responsibilities (Rothbart, 1971). For instance, when a child is diagnosed with cancer, the oldest healthy sibling often takes on the role of caregiver or parent for his or her younger siblings (Nolbris, et al., 2007). These different experiences would create different environments for the children to appraise situations. For example, in a family where the parents spent the majority of the time at the hospital with the child who is ill and the oldest child was left to care for the younger siblings, the younger siblings would still have someone acting as a caregiver while the oldest child would not. This might create a difference in the importance of an event, such as parental availability. Furthermore, parents tend to provide later-born children with more attention (Brody & Stoneman, 1994), which may affect how children appraise situations or cope. For instance, later-born children may be given more support in coping efforts.
than earlier-born children. On the other hand, if parents traditionally provided more support to later-born children but were unable to support any of their healthy children during the cancer experience, the later-born children may find the lack of attention more challenging than earlier-born children.

Contrarily, Dunn, Plomin, and Daniels (1986) found that mothers tend to treat first-born children at a certain age approximately the same as later born children when they became that age. In the event of a swift family transition such as the diagnosis of childhood cancer, later-born children will experience different care giving than their older siblings did at the younger child’s present age. Many earlier-born siblings of children with cancer report that the youngest healthy sibling had the worst daily experiences because their parents were not around at an earlier age like they had been for the older children (Calvert et al., 2009).

**Gender.** Similar to earlier-born children being expected to take on more responsibilities, the child’s gender influences the amount and type of responsibilities he or she is expected to have. When a child in the family is diagnosed with cancer, female healthy siblings tend to become responsible for more care giving and household tasks (Houtzager, Oort et al., 2004). Boys tend to receive more autonomy and are controlled less than girls (Fagot, 1978). Accordingly, girls may appraise it as more threatening if parents are unavailable during the ill child’s cancer treatment because girls not only have to care for themselves, but also for their other siblings. Boys may appraise the situation as less threatening because they may already be used to more autonomy and less parental attention and control.

Although this is true, female children tend to be given assistance more quickly when they need it, whether they request help or not, and their attempts at maintaining proximity and contact during the early years are met with more positive responses than male children (Fagot, 1978).
may be that girls are supported more than boys and that, in the North American culture, it is more acceptable for girls to be comforted emotionally than boys. Furthermore, female siblings of pediatric cancer patients tend to express their emotions more often than male siblings, which may mean that girls attain more assistance with emotional difficulties than boys (Hamana, Ronen, & Rahav, 2008). Females’ higher rate of expressing their emotions may result in girls receiving more emotional support and coping assistance than boys. Furthermore, differing rates of emotional expression may alter event appraisals and the coping techniques used by boys versus girls.

Survival Status. It is important to consider the survival status of the child with cancer when exploring the differences in healthy siblings. Children whose brother or sister died will have very different environments and experiences that those children whose brother or sister survives cancer (Packman et al., 2006). When a child dies from cancer, many siblings report negative feelings, such as enduring regret and jealousy of their deceased sibling, as well as general sadness and grief (Packman et al., 2006). These feelings can last for years (Davies, 1991) and tend to be most prominent during significant occasions, such as holidays, birthdays, and events like weddings or graduations (Packman et al., 2006). Healthy siblings who experience the death of the child who had cancer have to continue to cope with intense negative emotions while also attempting to cope with the physical loss of their brother or sister. When the family is supportive and close, healthy siblings report positive coping; but a lack of stability and security can be detrimental to grieving siblings (Packman et al., 2006).

Interactions between factors. Inevitably there will also be interactions between the aforementioned reasons for using different coping techniques. For instance, an interaction between age and ordinal position exists when the first born child in the family is not old enough
to care for his or her younger siblings. As well, in some families the first born is male and the second born child is female, leaving ambiguity around who is more likely to provide care for the younger siblings: the eldest or the female? Finally, the interaction between survival status of the ill child and the age of the healthy sibling is important to consider. If the healthy sibling is not old enough to understand the long-term implications of death, he or she will likely not be as upset by the death than an older child.

Objectives

The objective of this research was to learn about the similarities and differences in the experiences of children within the same family who had a brother or sister diagnosed with cancer. There were three goals of the present study: 1) How were siblings’ descriptions of their past experiences of having a sibling with cancer similar and dissimilar? Specifically, did age, ordinal positioning, gender, and survival status seem to influence the differences in the description of the past? 2) When siblings described their present experiences related to having a sibling who had cancer, how were their descriptions dissimilar? Specifically, did age, ordinal positioning, gender, and survival status seem to influence the differences in the description of the participants’ present experiences? 3) When siblings described the anticipated future experiences of having had a sibling who was treated for cancer, how were their descriptions dissimilar? Specifically, did age, ordinal positioning, gender, and survival status seem to influence the differences in the description of the predicted future?

Methodology

Research Design and Paradigmatic Considerations

This research was conducted through an interpretivist perspective where my ontology and epistemology reflected subjectivism and constructed realities. Accordingly, I understand that an
individual’s description of his or her experience will be based on individual’s subjective interpretation of his or her life events as well as being constructed through the participant’s individual attentions and the interviewer’s agenda and interests. Furthermore, I understand that individual attributes such as age, gender, and social standing will influence the participant’s recollections of his or her experiences through socially constructed meanings. From this perspective, I chose to use an interpretive or hermeneutic phenomenologic methodology, which can be used to understand and interpret individual’s perceptions of their daily lives (Sutherland, personal communication, January 26, 2010). Additionally, the aim of interpretive phenomenological research is to “explore in detail how participants are making sense of their personal social world” (Smith & Osborn, 2008, p. 53). This method fit well with my research questions about participant’s interpretations and recollections surrounding their experiences as the sibling of a child with cancer.

In order to follow a hermeneutic phenomenologic design, retrospective semi-structured interviews were be used. Smith & Osborn (2008) suggested that a semi-structured interview is the most appropriate data collection strategy for the phenomenologic researcher because the method is flexible and allows for an engaged dialogue which is capable of eliciting rich data while still ensuring that the interviewer covers all key areas of interest. Furthermore, phenomenologic designs often use retrospective data (Smith & Osborn) so that participants have had a chance to reflect on the significance and meaning of certain events or experiences (Valle & Steen, 1989). The Interview protocol will be discussed in a later section, as well as a description of how the interview data was analysed using hermeneutic phenomenologic principles (see Data Analysis section).
The use of retrospective data also allowed for an important analysis across time. Participants were asked to think about the past, during their brother or sister’s cancer, and to reflect on how these experiences affect them presently as well as how participants anticipate that these past experiences will influence the future. Lollis (2003) argues that past experiences are used as reference points when individuals attempt to anticipate what will happen in the future. What has happened in the past is often expected to reoccur, which allows people to prepare for similar situations. During the treatment for cancer, family life often changes abruptly, rendering past experiences from before the treatment phase of cancer less useful as reference points. Later into the treatment phase, siblings can use their experiences from the early treatment phase as reference points. It is unclear, however, what happens after the cancer experience (i.e., after the death of the child with cancer or after he or she enters remission). The present study aimed to learn more about if/how individuals who were the sibling of a child or adolescent with cancer presently think the cancer experience affects them how they would perceive these effects to continue in the future.

Participants

The participants in this study were the siblings of children who were diagnosed with cancer. They had to be at least 17-years-old to participate and the family must have been at least one year past the cancer experience, meaning that the child who had cancer needed to have been in remission for at least one year or he or she had died at least one year prior to the study. This year allowed time for the healthy siblings to reflect on their experiences and allowed individuals to think about how their past experiences had influenced their lives past the immediate experience. Two healthy siblings from the same family needed to be willing to participate and they had to have concrete and sufficient memories of their experiences to be interviewed.
Furthermore, the child who was diagnosed with cancer had to have been 18-years-old or younger at the time of diagnosis to be considered a pediatric cancer patient.

Sample size. The present study consisted of three sibling dyads from families where a third child was diagnosed with cancer. Researchers using interpretive phenomenologic analysis tend to use small sample sizes gathered through purposive techniques so that a select group of individuals with specific characteristics can be sampled (Smith & Osborn, 2008). Furthermore, phenomenological researchers place a higher value on developing a deep understanding of each individual participant’s complex experiences than on having large sample sizes. As the sample size becomes larger in a phenomenological study, researchers may become less able to immerse themselves in each participant’s story (Smith & Osborn, 2008). For these reasons, the guidelines for samples sizes offered in the literature on phenomenological methods tend to be small. For example, Boyd suggested using two through ten participants (2001), Dukes proposed a sample of three to ten participants is ideal (1984), while Smith and Osborn suggested student researchers use a sample size of three to six participants (2008). Accordingly, a sample size of three dyads, totalling six participants, is considered adequate considering the chosen paradigm and analysis strategy. Finally, a sample of 3 dyads allowed for sufficient individual analyses, within dyad analyses, and between dyad analyses.

Sample characteristics. At the time of diagnosis, participants ranged from one year to sixteen years old, with an average age of 8.7 years old (SD=6.5 years). The average age of the sibling with cancer was 6.7 years old at diagnosis (SD=5.09 years), with the children with cancer ranging from two years old to thirteen years old. Presently, participant’s ages ranged from 17 to 33 years old, with an average age of 24.7 years (SD= 6.5 years). The time since diagnosis ranged from 10 to 22 years, with an average of 16 years (SD= 5.37). Five of the participants were
female and one participant was male. In two of the three families the sibling who had cancer died from the illness. In the family where the sibling survived, the child who had cancer has multiple long-term difficulties due to his/her treatment for cancer (including removal of a portion of the brain). At the time of diagnosis, two of the families had four children and one family had three. All of the siblings in the study were biological siblings. All of the families included in the study remained intact following the illness, with no separations or divorces.

Recruitment Procedure

The research was first reviewed by the Ethics Boards at the University of Guelph and at Wilfred Laurier University. In order to recruit the three dyads, an extensive recruitment procedure was required. In order to reach potential participants who were early adults, information posters (Appendix A) were displayed across the University of Guelph and Wilfrid Laurier University campuses. Furthermore, the primary researcher gave short presentations to several of the larger undergraduate classes at these institutions in order to inform the students about the research project. The script for the recruitment presentations is available in Appendix B.

In order to recruit a non-university sample, several agencies were also be contacted, including The Pediatric Oncology Group of Ontario (POGO), HopeSpring, B.r.a.i.n.Child, and The Brain Tumour Foundation of Canada. As well, camp counselors and volunteers from the following three camps for children with cancer and their siblings were recruited from: Camp Trillium, Camp Oochigeaus, and Camp Quality. The recruitment letter sent to these organizations is available in Appendix C. Finally, the online community was also be sampled through the use of social networking and advertisement websites, including Facebook, Craig’s List, and Kijiji.
Researchers and Researcher Training

The researchers consisted of a 22-year-old graduate student working on her master’s thesis, Ms. Laura Calvert; her faculty advisor, Dr. Susan Lollis; and her committee member, Dr. Susan Cadell. Dr. Susan Lollis is a registered clinical psychologist and faculty member in the Department of Family Relations and Applied Nutrition at the University of Guelph. Dr. Susan Cadell is the acting dean of the faculty of Social Work at Wilfrid Laurier University and the director of the Manulife Centre for Healthy Living.

Ms. Calvert had received extensive training prior to recruiting or interacting with any participants, including taking courses on research methods and communication and counseling, as well as performing a literature review on the topic, reading previous research transcriptions on the topic, reading Kerry Daly’s ‘Qualitative methods for family studies and human development,’ reading Johathan A. Smith’s ‘Qualitative Psychology: A practical guide to research methods,’ interviewing several healthy siblings for her undergraduate thesis, and performing a mock interview with Dr. Susan Lollis.

Interview Protocol

In accordance with hermeneutic phenomenologic principles, retrospective semi-structured interviews were conducted. Using semi-structured interviews allowed participants to lead the discussion and to disclose what was of most significance to them, while still ensuring that the researcher’s key areas of interest were covered (Smith & Osborn, 2008). The interview was conducted in several stages, with each flowing right into the next. First, the study was briefly explained to each participant so that he or she was informed about the proceedings and what was expected of them. At this time, the participant’s rights were described, including his or her right to leave the study at any time. Next informed consent (Appendix D) for participants who were
over 18 and informed assent (Appendix E) for the 17-year-old participant was received. Parental consent was also received for the 17-year-old participant (Appendix F).

After this initial phase, information on the type of cancer and length of treatment was collected (Appendix G). The final step before proceeding with the main interview was to create a genealogic map of the family, outlining the structure of the family during the cancer experience. This included family members, extended family members, close friends, etcetera and identifies the name and gender of each individual. The legend for the family tree diagram is available in Appendix H.

The main phase of the interview began with the interviewer asking broad, open-ended questions such as “When you think back about the time of your siblings’ illness, how do you feel it affected your life?” The interview first focused on the participant’s past experiences and what happened during the cancer experience, followed by a discussion of what the participant’s life was presently (at the time of the interview), and finished with a discussion of the participant’s anticipations about his or her future. The interviewer facilitated the discussion using prompts and attentive remarks. Between discussing each time period (for example when transitions between talking about the past and present), a new genealogy tree was drawn to depict the next time period to be discussed. These genealogy trees were used as prompts for participants when they talk about their close relationships and family dynamics. Furthermore, the genealogy trees acted as a visual reminder of the family structure for the interviewer and also demonstrated stability and change in the family over time. For example, refer to Appendix I to see one participant’s genealogy trees from all three time periods. The interview finished with discussions of what the participant thinks his or her future will be like and if/how he or she thinks the cancer experience will impact his or her future. The interview protocol is available in Appendix J. At the end of the
interview the participant was thanked for his or her time and contribution to the study. Before departing, each participant received a copy of the Resources Handout (Appendix K).

**Data Analyses**

The key principle of analysis through a phenomenologic perspective is that researchers must first examine each individual’s interview as a whole before splitting the data into themes and quotations and before looking for themes across participants (Hycner, 1985). Accordingly, the first step in analyzing the interviews was to listen to the recordings and transcribe the data. Next the transcripts were read several times until the researcher had a sense of the whole interview. In order to be able to compare individuals within each dyad, individuals across dyads, as well as each dyad compared to each of the other dyads, Smith and Osborn’s (2008) technique of developing theme tables was used. After familiarizing oneself with the first transcript, the researcher reread the interview and noted interesting or significant points in the right hand margin of the page. Both open and closed coding were used at this point, with the researcher using line-by-line coding to note all significant statements from the transcript. Next, the researcher reread the transcript and used the left hand margin to document emerging meaning unit titles, which were drawn from the notes as well as the transcript. Following this the researcher created a list of all of the emerging meaning units and collected quotations from the transcript to support each meaning unit. Once the evidence for each meaning unit was gathered, their titles were reworked to ensure they still represented the data.

The next step was to list the meaning units on a piece of paper and to look for connections between them so that they can be clustered together meaningfully to form themes. After reorganizing the meaning units into themes, the researcher revisited the transcript to ensure that the connections fit well with the interview data. Finally, the researcher analyzed the themes
to see if they could be meaningfully clustered together into clusters of themes. These steps were repeated for each participant, creating theme tables for each individual. These tables were then used as comparison tools within individual dyads, across individuals, and across dyads.

Please refer to Appendix L for an example of the tables of themes and clusters of themes. Table L1 represents a selection of themes from Family 3, Participant 2. In this table, the theme titles are in bold across the top of the table, with meaning units from the interview in italics directly beneath the corresponding theme. Table L2 represents a selection of the clusters of themes for Family 3, Participant 2. In this table, the title of each cluster of themes is in bold along the top, with the themes in each cluster written below the title of the corresponding cluster of themes. From these two tables, you can see how meaning units were clustered together into themes and then themes were clustered together into clusters of themes. The clusters of themes were useful in understanding the experiences of each individual, however the themes were more useful in cross-case analysis as this is where similarities and differences could be observed.

Results

The objective of this research project was to learn about the similarities and differences in the experiences of two siblings who had a third sibling diagnosed with pediatric cancer. Participants were asked to talk about their past experiences during the treatment phase of cancer, their present experiences of being the sibling of a child who survived or died from cancer, and their expectations about their future experiences. The researcher was interested in determining if the participants’ ages at the time of diagnosis, ordinal position, gender, and/or the survival status of the child with cancer would be related to different experiences in two siblings from the same family during each of these three time periods. The researcher was also interested in learning if
there are any similarities between two siblings from the same family that are common across dyads.

First, the themes that are present across all or none of the three time periods will be reported in the ‘Overall Results’ section. Next, the similarities and differences in themes between siblings from the same family will be discussed in each of the three time periods: past, present, and future. The results reported for each time period will be reported in sections based on the situation or event associated with the difference, such as ordinal position or the survival status of the child with cancer. When quotations are used to demonstrate the themes being discussed, a reference to the family number (one through three) and the participant number (one or two) will be made. Each family has a participant one, the elder sibling, and a participant two, the younger sibling. For example, ‘family 3 participant 1’ is the elder sibling in family three.

**Overall Results**

When looking across all three time periods, there were several important findings: there were more differences than similarities between the two siblings from the same family, age was not a factor that influenced differences between two siblings, and the survival status of the child with cancer was the only situation that was found to be related to differences in siblings’ experiences across all three time periods. It is also important to note that gender differences could not be examined in the present study because there was only one male participant.

Although there were similarities between the siblings in all three dyads, more differences within each dyad were found. This was true for all sibling dyads across regardless of the participants’ ages, ordinal positions, gender, and the survival status of the child with cancer. Not only were the individuals within each dyad found to be different through analysis, but the participants also identified that they had different experiences than their sibling(s). When asked
if her sibling would have experienced their sister’s death the same way she did, one participant explains, “No, I think everyone experiences it differently and we all have different coping mechanisms ... I don’t think anyone in our family handled it the same way” (Family 3, Participant 1). This was a common sentiment, which each participant in the study reporting that he or she had different experiences that their sibling(s). There were numerous differences between siblings in each family that were not common differences- that is, not all three families shared the same differences. The differences between two siblings that were seen in only one family will not be discussed in this paper, only the common differences will be discussed.

Age was not found to be a factor that impacted differences between two siblings in the same family during any of the three time periods. When age was combined with the other factors that were predicted to be related to differences in siblings, the only differences between siblings from the same family were seen in the past when age and ordinal position were merged together. Furthermore, in each of the families the participants talked about how age was becoming less important for sibling relationships as time passed. The results considering the decreasing importance of age for sibling relationships are reported in the section on present similarities between siblings from the same family.

The survival status of the child with cancer was the only situation that was found to impact differences in the experiences of siblings across all three time periods. However, the survival status of the child with cancer had different impacts at the various time periods. For instance, in the past only the participants whose brother or sister died from cancer experienced shock that the child actually died. When talking about the present impact of having a brother or sister who died from cancer, the participants talked about the importance of keeping the deceased child ‘alive’ and ‘present’ in their lives. Finally, when explaining how the deceased sibling will
impact their future, the participants whose brother or sister died from cancer identified that it is important that future family members (such as spouses and children) will know about and feel close to the deceased sibling.

The researcher was interested in examining if there were differences between who siblings from the same family based on their genders. However, there was only one male in the present study, so gender differences could not be studied. Instead, this paper will reveal some of the experiences that the female siblings reported. In each of the three time periods (past, present, and future), female participants were found to have common experiences.

**Past**

When the participants described their past experiences of having a sibling who had cancer, it is important to first note that both siblings in each dyad expressed that they had many different experiences than the other children in their family. As well, all of the participants mentioned that their sibling(s) used different coping mechanisms than they did during and after the illness. There were also similarities between siblings from the same family, including mothers being seen as absent in the past and changes in familial routines. The differences in sibling experiences can be explained by differences in the sibling’s ordinal positions, the integration of age and ordinal position, and the survival status of the child with cancer. No differences could be attributed to age differences alone. As well, the female participants talked about their experiences of difficult emotions during their sibling’s illnesses. Finally, in their descriptions of the past, participants talked about several unanticipated events and situations which resulted in differences in the experiences of two siblings from the same family.

**siblings perceived that they had different experiences.** During the interviews, all participants were asked to talk about their own experiences at the time of the illness as well as to
speculate about the experiences of their siblings. A theme emerged in the way participants talked about their sibling’s experiences: they compared and contrasted their own experiences to those of their siblings, even though they were not specifically asked to make this comparison. For instance, the participants were asked “Were there any positive experiences that you remember when your sister was sick?” One participant continued to talk about a situation she and her brother had both experienced. The participant was then asked “How do you think he dealt with it at that time?” The participant continued to compare her experience with her perception of her brother’s experience. Through these comparisons, the participants talked about who had more or less attention, who experienced an easier or harder time dealing with the familial changes, who was closer or more distant with their parents, and who communicated more or less about cancer. For example, when asked if she had received enough attention during her sibling’s treatment for cancer, one participant expressed:

Oh yeah! I definitely, my parents really made an effort to, uh, keep uh, enough attention to all three of us, cause we were like, we were still children when he was sick, so uh, my sister had uh, more of a difficult time dealing with it, but um, I had no problem. (Family 1, Participant 2)

Through these comparisons, there was a resounding theme of differential experiences. As one participant states, “I really believe that cancer is a family diagnosis and it just hits everybody in a different way” (Family 3, Participant 2). This sentiment was echoed by all of the other participant’s descriptions, as they expressed thoughts such as “I think [my sister without cancer] would have a very different response [than I did] to that [question]” (Family 1, Participant 1). Although the siblings in these dyads were raised in the same family and were both coping with having a sibling with cancer, they still had very different experiences.
**Siblings thought they used different coping mechanisms.** As the participants considered the differences between their own experiences and their siblings’ experiences, the participants all began to talk about the different ways they each had coped with having a sibling diagnosed with cancer. A theme that occurred within each dyad was that the siblings stated that they had used different coping mechanisms than their sibling(s): “I think everyone experiences it differently and we all have different coping mechanisms... I don’t think anyone in our family handled it the same way” (Family 3, Participant 1). This participant continued to explain how her brother “would never show us that he was upset... he was very quiet and withdrawn” whereas her own “way of coping was just to get more involved, like I started volunteering at the hospital and at camp” (Family 3, Participant 1). In this case, the siblings in the same family were using different coping mechanisms after the death of their sister. One sibling was more reserved while he dealt with his pain internally while the other sibling became very open and worked through her pain by helping others who were also experiencing illness in their families.

In one dyad, the participants had a difficult time expressing how their sibling coped with being the brother or sister of a child with cancer. The theme of expressing that they had used different coping mechanisms was evident, but the participants could not directly explain how their siblings coped: “My older brother ... I think he dealt with it wrong. You know, I went to therapy and he didn’t” (Family 2, Participant 2). Although this participant does not describe how her brother coped with being the sibling of a child with cancer, she does identify that they dealt with the experience in different ways. She is also able to express how she coped with being the sibling of a child with cancer.

**Shared Similarities.** All of the participants in the study were asked “When you think back to when [insert name] had cancer, how do you feel it affected your life?” Although the
responses differed somewhat, two similar and interrelated themes arose: participants’ mothers were absent during the treatment phase of cancer and the routines in the family changed.

When a child is diagnosed with cancer, families need to adapt to different demands on their time, including taking the child with cancer to and from the hospital. By increasing the demands on parents’ time, the routines in the family must inevitably change. For all of the families in the present study, the mothers stayed at the hospital with the child who had cancer during his or her treatments while the fathers continued to work. One participant described this: “my mom would be at the hospital and my dad would be at work” (Family 1, Participant 1). She later continued:

My mom used to leave for the hospital before I’d wake up in the morning, so she’d leave at five, and she’d come back way b- after I was already asleep. Um, so there was times that I definitely, I didn’t get to see my mom a lot. (Family 1, Participant 1)

When mothers began spending more time at the hospital, the activities and household chores they performed before the cancer diagnosis often were discontinued, including activities that were done with the siblings of the child who has cancer. One participant described the interrelation of the themes of changing routines and absent mothers by explaining that routines changed the most when her mother was at the hospital with her sister: “it was very life altering and everyone’s routines were different, especially during the time that [my sister] had to do chemotherapy at the hospital and my mom was never home” (Family 3, Participant 2). All of the participants reported that their mothers were often absent during the treatment phase of cancer.

For some participants, the routines changed drastically when substitute caregivers were involved. One participant described how her grandparents cared for her and her brother during her sister’s illness: “I had no parents, they were never around. They made me go stay with my
grandparents ... And they didn’t deal with it very well” (Family 2, Participant 2). She continued to explain how the mealtime routines changed during her sister’s illness because her grandparents treated her differently than her parents did:

I’m a very fussy eater, very much, my grandparents didn’t accept that. And it was ‘you’re going to eat that.’ And my mom never, my dad never forced us because my dad was a fussy eater, so it was like ‘I’m not eating that.’ They wouldn’t make me eat it and, I was feeling like I was getting punished because she was sick. (Family 2, Participant 2)

In this family, other changes in routines included the participants not being able to see the child with cancer, being in a different household from their youngest brother, and taking a different bus to school.

In another family, the entire family was involved at the hospital with the child who had cancer. For these participants, the theme of routines changing was evident in their descriptions of spending less time participating in the activities they had previously enjoyed because their free time was spent at the hospital. One participant described how she wanted to spend time with her sister instead of with her friends:

Throughout the illness, and like, kindof like be there with [my sister] and do that kind of stuff. Whereas probably why that zigzag line for my friends was, it’s because it’s like ‘d’you, do you wanna get out, wanna get away, wanna do this?’ and I was like ‘no, why don’t,’ like in my head I think ... maybe it would have been different if they wanted to like come with me, maybe to the hospital, and like, or, ‘oh, can we come and see [your sister],’ or, cause I, I didn’t wanna escape it. (Family 3, Participant 2)

For this individual, spending time with her sister was a high priority. She lost contact with many of her high school friends because they were not interested in spending time at the hospital with
her and the child with cancer. Because of her priorities, this participant experienced changes in her routines during her sister’s illness.

**Perceived differences based on ordinal position.** As participants described their experiences during the treatment phase of cancer, differences between the siblings in the same family because of birth order became evident. A theme arose from first born children all having reported being responsible for, caring for and/or supporting their later born siblings, while later born siblings all recall being cared for by their older siblings. This was true regardless of the children’s ages, gender, and the survival status of the child with cancer. As one eldest child explained,

> I sort of got pushed into becoming one of the adults in the household very quickly. Um, maybe for a while even the most dominant adult probably in some ways just because my mom was in a lot of ways non-existent and my dad was busy in working and trying to get back to the way things were so probably in a lot of ways I had become, not the dominant but certainly the more responsible adult in the house. (Family 2, Participant 1)

This participant’s description of becoming responsible within the household was a common theme for first-born siblings. The first-born children from the different families had various responsibilities in their respective households; however the shared responsibility across families was caring for the later-born children in the family.

When parents became too busy to care for their children, the theme where first-born children became responsible for the care of their later born siblings even included when temporary caregivers were present. Neighbours and extended family members often stepped in to care for these children, however first-born children retained their high levels of responsibility for their later-born siblings. One participant describes a situation where an aunt was watching her
and her siblings, yet she was the one who cared for her younger brother when something went wrong:

When my brother was little, he didn’t sw- he swallowed a grape and it lodged in his throat ... and she didn’t know what to do. And at four, I was the person that called the ambulance and um, like put him into the right position, and tried to tell him to cough it up, and, while she sortof just stood there and had a panic moment. Um, and since then, I’ve never really, I don’t trust other people in doing something that I know I could do myself. (Family 1, Participant 1)

As evident in this situation, temporary caregivers were present; however the first-born child was the one who took on the responsibility to care for her later-born siblings. The younger siblings also relied on their elder siblings to care for them, again regardless of the presence of temporary caregivers. One participant describes living with her grandparents during the illness, but still relying on her first-born brother; “During [the illness] I was really close to … my older brother … like [my brother] was all I had … my grandparents would pick on me, [my brother] would defend me” (Family 2, Participant 2).

For the first-born siblings, becoming a responsible caregiver had different meanings. One participant wanted to care for her later-born siblings; her sense of self had been developed around her image of herself as a caring individual. When asked if she felt like she had to care for her later-born siblings, she replied “I think I enjoy doing it. Um, it’s a responsibility for sure, but um, but I enjoy doing it. I think because I know that it’s good and I know it’s a good thing to do” (Family 1, Participant 1). This participant has taken these experiences of caring for her younger sibling in the past and presently retains this trait by caring for her family and friends if they are not feeling well. For this individual, taking on the caring role for her siblings in the past was
internalized as a positive quality. In another family, although the first-born child cared for his younger siblings, he felt like he should have been more supportive:

I think that I have guilt in that I probably wasn’t as good a big brother as I should have been. I think I have guilt, as much as I, I think that I became very mature in a lot of ways, I did a lot things. I think that becoming another parent maybe isn’t what L and P needed, as much as somebody closer to them. (Family 2, Participant 1)

For this participant, he presently experiences guilt that he was not as supportive as he could have been for his siblings in the past. He admits that he took on the role of being another parent and supporting his siblings that way, however he presently feels like they needed something different from him. Instead of internalizing his past caregiving into a positive personality trait, this participant has developed feelings of guilt for not doing enough to help his younger siblings.

Children from the same family who have a sibling diagnosed with cancer have different experiences based on their birth order. First-born siblings take up the role of caregiver for their later-born siblings, while younger siblings are cared for by their elder siblings. Although first-born siblings tend to adopt the responsibility of caring for their younger siblings, this role can have different meanings and long-term implications for the child.

**Perceived differences based on the integration of age and ordinal position.** One of the common reasons that participants cited when trying to explain the differences in experience between themselves and their sibling(s) was that they were ‘older’ or ‘younger’ than the other children in the family. The nature of being ‘older’ or ‘younger’ than your sibling integrates age and ordinal position into one factor. One way that participants used to explain differences in experiences based on the integration of age and ordinal position was through the theme of describing the configuration of sibling relationships. Participants also integrated age and ordinal
position when, in the families with young children, the younger children were perceived as having experienced more difficulties during and after the illness than their older siblings. In the families where none of the children had reached adolescence, the first-born child talked about having to grow up quickly, whereas younger siblings did not report this. Finally, when participants talked about the impact of changing parental attention, differences were found based on the integration of age and birth order.

**Perception of the configuration of sibling relationships.** A theme among the participants in the study was they all described the configuration, structure, and closeness of their sibling relationships during the time of the illness based on age and birth order. This theme was evident when all of the participants talked about being closest to the sibling who was closest in age to them: “when I was little, I was closer to my older brother, because we were closer in age, and those two were closer in age” (Family 2, Participant 2) In the families with four children, the siblings split into two groups of two, with the eldest two siblings being close as a dyad and the youngest two siblings having a close relationship. When asked what the relationships in her family were like in the past, one participant expressed:

> We did a lot of stuff together. [My sister] and I were really close in age. We’re just over a year apart, and so we shared, like we shared a bedroom and went to school together, like shared a locker at school. Um, she was one grade higher than I was. Um, so it was a big changed when she passed. Like before she passed away we took the bus to school together, we walked home together, and like [my other sister] and [my brother] were close in age, because they’re a year apart. So they would do all their stuff together and we were still in elementary school and they would be in high school. (Family 3, Participant 2)
The theme where the configuration of sibling relationships within the family was based on age and birth order in the past was maintained during the illness, regardless of the ordinal position of the child with cancer. In all of the families, the child who was closest in age to the child with cancer remained closest to that child for the duration of the illness. This does not mean that the closeness of sibling relationships remained static during the illness. On the contrary, the sibling relationships shifted and changed during the treatment phase of cancer, but the sibling that each child in the family was closest to before the illness remained the sibling that child was closest to throughout the illness. The youngest child in one family described her changing relationship with the child who had cancer, who was the second youngest child in the family:

> But I think that like, when I was spending time with her, it was almost always positive, because our relationship never changed. If anything, it got like stronger because we just had more time together ... our relationship just every year of our lives just got stronger and stronger. (Family 3, Participant 2)

In this case, the youngest two siblings in the family became closer during the illness because they were able to spend more time together.

In the family with three children, the theme where the configuration and closeness of siblings relationships was based on the combination of age and birth order was still present, where the youngest child reported being closest to the middle child and the eldest child also reported being closest to the middle child. One sibling describes this configuration of sibling relationships: “But the middle is always the peace [keeper], he can hang out with her fine, and he can hang out with me fine, but the two of us can’t hang out alone fine” (Family 1, Participant 1).

In this family, the child with cancer was the middle child and both of his siblings were closer to him than they were to each other. When asked why she was closer to her brother than to her
sister, one sibling stated: “I guess it was a little harder to be uh, to have more of a relationship with my sister because ... she’s four years older so there’s somewhat of an age gap” (Family 1, Participant 2). As children, the closeness of sibling relationships was based on a combination of age and birth order, regardless of gender or which child was diagnosed with cancer.

**Older siblings’ perspective that younger siblings experienced more difficulties.** In families where the children were younger and required more parental care, a theme arose where the youngest children in the family were perceived as having the most difficulties. This was because the younger children in the family were perceived as needing more parental care than the older children in the family. In the family where the children were all adolescents at the time of diagnosis, the siblings of the child with cancer were able to be more self-sufficient and this is possibly why the theme was not observed. One participant’s description represents this theme when he explains how, after his sister’s death, his parents were so upset that their parenting practices were not as good during his younger brother’s formative years as they had been during his:

My youngest brother ended up with the worst, I don’t want to say childhood, but, I think suffered more than everybody else. And I think because of my age and being able to look back at it, when I look at things like the way my dad was with me, compared to my younger brother, I mean we have eight years between us, so I was eleven, he was three. When I was five, six, seven, you know, my dad came to every hockey game, we played baseball every night, we did stuff like that. I don’t think [my youngest brother] ever got that. Because my dad was a different person, it changed him... But I think that [my youngest brother] got screwed in the deal, for lack of better terms, you know what I mean? Because of what happened, and the age that he was. Those three or four years that
followed, when I had certain advantages, he never got them I think. (Family 2, Participant 1)

From this perspective, the older children in a family received higher quality parenting for a longer duration than the younger siblings in the family. It is possible that this phenomenon either is a result of or interacts with how well parents are able to cope with the diagnosis, treatment, and survival or death of the child with cancer. If parents were able to continue providing high quality care through and after the illness, then it is possible that the younger children in the family would not have more difficulties. The present study did not measure parental coping, however future research should examine if the observed differences attributed here to age and ordinal positions are impacted by parental coping.

*Eldest siblings felt like they grew up quickly.* When the siblings of the child with cancer were not yet teenagers, the theme growing up quickly was evident in the eldest children in the family. None of the later-born children in the study mentioned that they had to grow up quickly. Often the theme where participants experienced growing up quickly was related to the eldest child in the family having increased responsibilities, such as caring for younger siblings. When asked how the diagnosis affected his life, the oldest child in one family expressed: “I think it forced me to grow up much quicker than under different circumstances” (Family 2, Participant 1). The eldest child in these families was expected to perform tasks at a younger age than they would have if their brother or sister had not been diagnosed with cancer. In one family, the elder child described how she “used to give [her] brother his nightly injections, as a ten-year old,” how she would “talk him through” his radiation treatments, and how she was “exceedingly protective” of her brother (Family 1, Participant 1). In comparison, the younger child in the family described her involvement in her brother’s care: “I’d be with my mom and then I’d go
into the doctor’s office and I’d like sit patiently and um, yeah, I would just more or less keep him company” (Family 1, Participant 2). The elder sibling here found herself becoming highly responsible as a young child, which forced her to grow up quickly. The younger sibling, however, retained a more normal role within the family so she was not forced to grow up quickly. The theme of growing up quickly only occurred for the oldest child in the family.

When the eldest child in a family grew up quickly, he or she also experienced changes in priorities and subsequent changes in peer relationships. The themes of changes in priorities and changes in peer relationships appear to be related to the theme of growing up quickly. Again, these themes were only present in the descriptions of the first-born child in each family. For the oldest child in the family, these themes were often clustered together into a cluster of themes about growing up and becoming more responsible. Eldest siblings often described how they became more focused on family concerns and their education and less interested in the ‘frivolous’ activities that their peers were involved in. One participant described how her peers were interested in boys and she was more concerned about her brother’s health:

People would be talking about dances and boys and stuff like that, I did not understand it. Like why would you waste your time doing that? Um, just for the, like, just because it was sorta like, my brother was very sick and I should be putting all of my attention on that, and, you’re sitting here talking frivolously about boys. And so I didn’t really get it.

(Family 1, Participant 1)

This individual distanced herself from her peers because she had different interests and priorities. Similarly, another participant described how he grew up quickly and this maturity helped him become focused on education:
I think that it probably forced me to grow up quicker, and in doing so though, it probably forced me to … I think that like education became a bigger thing for me, like in high school, you know I had goals of going to University and doing things where a lot of my friends were more concerned with drinking and partying. And I was already sort of past a lot of that. (Family 2, Participant 1)

For the eldest siblings in these families, growing up quickly had drastic changes on their lives. They often became more focused on personal and familial betterment while becoming distanced from peers. On participant even expressed that he began to consider some adults his friends, while he was only 11-years-old. Growing up quickly, having changed priorities, and subsequently changing peer relationships was a large factor in the experiences of the eldest child in the families with young children.

In the family where the children were all adolescents, neither of the children reported growing up quickly. This is likely because they were already fairly grownup and responsible. The tasks that the siblings of children with cancer often become responsible for seem to be tasks that are suitable for teenagers to perform. It is when young children perform these tasks that they see themselves as growing up quickly.

The perceived impact of changes in parental attention. When a child is diagnosed with cancer, his or her parents have to drastically change their lifestyles to include extended hospital trips and other healthcare considerations. For the families in the present study, when this happened, a theme of changes in parental attention arose. In some families the change is drastic and children are left feeling like no one is caring for them. One participant described this when she recalled that “from the end of August ‘til the beginning of November, so we always say two months. It was hell. I had no parents, they were never around” (Family 2, Participant 2). In other
families, the changes were less drastic, but the theme still persisted because changes still occurred: “my parents really made an effort to, uh, keep uh, enough attention to all three of us, cause we were like, we were still children... [we received attention] but a different kind of attention” (Family 1, Participant 2). In this family, the parents continued paying attention to the children, but the type of attention changed.

There were two situations discussed by participants in the present study where changes in parental attention at the time of diagnosis had less of an impact on the siblings of the child with cancer: when the sibling was young enough not to notice the difference and when the siblings were old enough to already be fairly autonomous.

In one family, the youngest child was born a month before the middle child was diagnosed with cancer. When the parents had to spend large amounts of time caring for the child with cancer, the youngest child did not perceive a change in parental attention. Instead, the participant grew up accustomed to the different level of attention:

Because I grew up with him being sick, that he was sick from basically day one for me, that um, that that was, the attention that I was given was like, it seemed fair,

(Interviewer: yeah, it was normal) it was normal, it hadn’t changed at all. (Family 1, Participant 2)

In this situation, the child had not perceived a change in attention, although she recognized that a change had occurred when her sibling was diagnosed and she was a month old. The participant felt that she was not affected by the change as much as her elder sibling was because she had not been accustomed to the level of attention she had received before the diagnosis: “my sister had uh, more of a difficult time dealing with [the change in attention] but um, I had no problem”
(Family 1, Participant 2). In the event that the child is young enough not to perceive a change in attention, it appears that the change has less of an impact.

When a child is diagnosed with cancer, pre-teen and adolescent siblings seem to be less affected by the change in parental attention than younger children. As children age, they generally become more autonomous and increase their capacity to care for themselves. One participant demonstrated this by explaining that his younger siblings needed more care than he did: “I guess as an eleven year old I was old enough that I didn’t need my parents the way my younger siblings did” (Family 2, Participant 1). In this case, the child was less dependent on his parents and so he was less impacted by the change in attention.

Another reason that older children and adolescents may be less impacted by the changes in parental attention is that older children are more capable of adapting to changes in their environment. One adolescent participant expressed that the diagnosis “was very life altering and everyone’s routines were different, especially during the time that [my sister] had to do chemotherapy at the hospital and my mom was never home” (Family 3, Participant 1). She continued to explain how the entire family adapted their schedules and “all tried to be at the hospital and alternate so that [the child with cancer would] always have somebody there” (Family 3, Participant 1). In this situation the adolescent siblings of the child with cancer were able to adapt to a) less parental attention and b) changes in personal and familial routines and schedules. It appears that older children who can adapt fairly well to changes in their environment may be less impacted by alterations in parental attention than less adaptive, often younger, children.
Perceived differences based on the survival status of the child with cancer.

Participants whose sibling with cancer passed away had different experiences that those whose sibling survived cancer. In the families where the child with cancer died, a theme arose where the siblings experienced shock that the child actually died. These siblings knew that it was a possibility that the child with cancer might die, however they were shocked when it really happened. One participant whose sister died explained how she had been at their house in the morning and then when he returned in the afternoon she was gone. He recalled being shocked that she was gone because she had died:

I remember coming in the house, coming in and they brought us to the table at the kitchen, they sat us down and they told us that she had died. And I remember almost kind of being shocked, like, Hmm. But I, you know in hindsight, as a kid… How did I not know? You know like, what else would it have logically been? (Family 2, Participant 1)

In this situation, the participant knew his sister was dying but was shocked when it actually happened. In another family, one participant was completely unaware that her sister might die until just before the death. She describes how it was shocking to her when her mother told her that her sister was going to die because the possibility had never occurred to her before:

I thought ‘there’s no way my sister’s going to die.’ Like you know, it’s going to be a hard like what, one year, two years, but you know, after that we’ll get over it and you know, we’ll move on. Never once, until like three weeks before she passed away and my mom actually told me ‘she doesn’t have much longer’ that it even crossed my mind that she was going to pass away. Ever. (Family 3, Participant 2)

It seems like children know that cancer is a deadly disease, however it is possible that the feeling of ‘it won’t happen to me’ makes them think that their sibling won’t actually die. This could
explain why these siblings experience shock when the child with cancer dies. This shock was clearly not present for the siblings in the family where the child survived cancer.

Another difference based on the survival status of the child with cancer was the theme of how, after the death, the siblings in the families where the child with cancer died often experienced displeasure at being treated like “the [person] whose [sibling] died of cancer” (Family 3, Participant 2). Often times after the child with cancer died, peers and teachers treated the siblings differently. Sometimes peers and teachers were trying to be sympathetic, but the sympathy was actually acting as a reminder of the loss:

I appreciated um, felt the like sympathy I guess, but like most of the, like the teachers, they, I didn’t want to be treated differently. I didn’t, I didn’t want to be like called down to guidance and them be like ‘I just wanted to see how you were doing today’ and then I’d be like ‘well I was doing fine until you came and like called me down here.’ (Family 3, Participant 2)

This individual did not want the constant reminders of her sister’s death from peer’s and teacher’s expressions of sympathy. This participant was so upset by being treated differently that she changed to a school where most of the people did not know about her sister. This decision made her more comfortable going to school because she did not get the constant reminders of her sister’s death: “it was just taking a break from, like from the reality and, cause at the new school, I would go to school every day and at school every day it was like I didn’t have a sister that died” (Family 3, Participant 2).

Another participant experienced a similar situation, where she did not want people’s sympathy for her sister’s death. This participant describes how she does not like when people ask
if she has sisters because she does not want the sympathy when she explained the situation and she does not feel comfortable saying she does not have any sisters:

Now, that is probably the hardest question that I have to answer ... Do you have any sisters? I never know what to answer. I say, now that I can answer it better, I say “Yeah. I had one”. And then you know you do the “Oh, what happened?” “Oh she died of a brain tumour”. And then you get the “Oh my God, I’m so sorry”. You know? Like, I’m not doing this for sympathy, I’m not doing it…..but I don’t want to ever say that I don’t have a sister. To me that’s wrong. If I died, I wouldn’t want my brothers to say that they had no sisters. (Family 2, Participant 2)

Evidently it is upsetting to the siblings of children who died from cancer when people offer them sympathy. It appears that these siblings would rather be treated normally, especially recently after the death when expressions of sympathy act as reminders of the loss.

**Females’ perception of their experience of emotional distress.** When describing their experiences during the time that their siblings were being treated for cancer, the female participants shared a theme of having experienced a lot of emotional distress. They talked about experiencing a plethora of emotions, with each girl reporting that she experienced at least five intense emotions during her sibling’s treatment for cancer. All of the girls differed on their descriptions of the emotions they experienced, but the most common emotions experienced were sadness, frustration, fear, and anxiety. When asked how she felt during her sister’s illness, one female participant expressed “mostly I would say scared and sad” (Family 3, Participant 2), while another female participant reported that she “just really [felt] a lack of control, helpless, sad, why did this have to happen to her?” (Family 3, Participant 1) Other emotions that the female participants experienced within the theme of having experienced emotional distress
include confusion, rejection, anger, helplessness, lost hope, being misunderstood, lack of control, feeling uncomfortable, and questioning why this was happening. One female participant explained how she experienced more difficult emotions when she was not busy with her family,

Mostly I would say scared and sad. But it would, because of [my sister’s] personality, and my family, it would some days be turned into a positive and not be. But that’s just in the, in moments and like when we’re doing things. Stay positive and happy, but then when that’s, when those activities or those like things are done and it’s just me, it’s, it’s just scared and sad I think, because it’s, and, and a lot of frustration too. Like why is this happening? (Family 3, Participant 2)

In this case, the family worked hard to keep things positive, however once the participant was alone she experienced many difficult emotions. The female participants reported experiencing these difficult emotions both during the treatment phase of cancer and, in the event that their sibling passed away, after the death.

**Unanticipated events/situations related to perceived differences in siblings.** Four unanticipated interrelated events and situations were found to influence the differences in the experiences of two siblings from the same family: being in different locations; experiencing different situations; experiencing the same situation but appraising it differently; and experiencing differences in relationships.

**Being in different locations.** For some families, siblings were in different locations than each other, which impacted the way they experienced the cancer diagnosis and treatment. This ranged from the siblings being in different schools to living in different houses during the treatment phase of cancer. Being in different locations altered who the siblings interacted with, often changing family relationships and family dynamics, and also creating differences in
experiences. When asked how he viewed his relationship with his siblings at the time of the cancer experience, one participant explained

[My sister] and I were with my grandparents, [my brother] had gone to live with a cousin, one of our cousins, so I think that, [my sister] and I were together….I don’t know that we would have similar opinions of our time though, like, [my brother] obviously was sort of the outcast, so [my brother] had got pushed to living in [another part of the city], when we were all in [part of the city], so he, we saw him once or twice a week. You know, basically on the weekends or something was about the only time we tended to see him, so you know, we, we, [my brother] kind of fell apart in a way, well not fell apart but, you know was moved away from us for a little bit. (Family 2, Participant 1)

In this family, the youngest sibling lived in a different household than the elder two siblings during the treatment phase on cancer. The elder siblings both reported having a compromised relationship with the youngest sibling during this time because they did not have as much contact with him. When the family was able to stay together as one cohesive unit, the participants reported closer familial relationships in the past and presently than when the family was physically distant.

In another family, the youngest sibling reported different relationships and experiences than her siblings because she was still in high school when her sister passed away while her older healthy siblings had moved to university.

I dunno, it wasn’t, it was awkward, and at that point I was the only one of us that was still at the high school, because my sister and J like were, moved onto university so I dunno, I think it was just hard to be alone there. (Family 3, Participant 2)
This participant talked about how it was uncomfortable to be treated like the “girl whose sister died from cancer” while she was at school. Her friends and teachers all treated her differently and it ultimately caused her to switch schools so that she could be more comfortable. Her older sibling explained how she did not experience being treated differently by teachers and peers because “in my high school they didn’t know her” (Family 3, Participant 1). As well, once she moved to university at the end of the illness, the elder sibling was able to chose who knew about the illness, while everyone at the younger sibling’s school knew about the illness and death.

Being in different locations altered the relationships that the siblings had with family members and peers and also created differences in objective experiences. These differences created overall differences in each sibling’s experience of being the sibling of a child with cancer.

**Experiencing different situations.** All of the siblings in the present study experienced different situations than the other siblings in their family. These different situations provided differing perspectives through which to view their entire experience as the sibling of a child with cancer. For example, in one family, the eldest two children were told earlier than the youngest sibling that their sister was going to pass away. The younger sibling reported remaining optimistic and relatively happy throughout her sibling’s illness because she did not think her sibling would die. She explained how she was glad that she did not know about her sibling’s impending death sooner because she would have focused on the possibility of her sibling’s death instead of trying to focus on the positive experiences.

You couldn’t think about anything else other than ‘what, is she going to die today?’ like what, what do I do today? ... Because I think that if I had known, I think my experience would have been a lot worse. I think I would have been a lot more upset and it would
have been a lot harder to find the positive things and just, like I lived that two years that she was sick, like to the best. Like it was, it was like she was, like our relationship was still the same and I think I, you know, you try not to act different, but I would have acted different if I had known, like what, how this could end. (Family 3, Participant 2)

This participant thinks that her entire outlook on her experience would have been different if she had been told that her sibling was dying earlier, as her other siblings had been told. When the older sibling was asked about her emotional reaction to her sister’s illness, she reported “feeling a lack of control, helpless, [and] sad” (Family 3, Participant 1) during the treatment, while the younger sister was able to remain optimistic until the end of the treatment when she was informed that her sister was dying. By experiencing this different situation, these siblings experienced the course of their sister’s illness very differently.

**Experiencing the same situation but appraising it differently.** When two siblings from the same family experienced the same event, they often described the occurrence in a similar manner, however their reaction to the event often differed. The participants often focused on different aspects of the event and/or the event was appraised at different levels of importance for the siblings. When this happened, the siblings’ experience of the event differed. In one family both participants described the event when their father told them that their sister was dying. The older sibling remembers more vividly the fact that their father broke down as he explained that their sister was going to die:

I can remember sitting in the car and having him, basically say to us, and I mean at this point [my sister] had been sick for a few months, or whatever, or a month or two, I don’t remember exactly what it was, but I just remember him saying to us, you know, she’s
dying, and breaking, my dad breaking down and, and trying to explain to us. (Family 2, Participant 1)

Conversely, when describing the same situation, the younger sibling focused on the fact that her father had not taken them to get ice cream before telling them that their sister was dying:

My dad came to pick [my brother] and I up, just we were, [my brother] and I were so excited, he said we were going to Dairy Queen, we were almost there, then we turned, and we were like “We’re not going to Dairy Queen, where are we going?” He said we were going to get my [other] brother, so we went to my cousin’s house and when we got there he stopped the car and started crying and he said she wasn’t going to make it and she was going to die. We didn’t get any Dairy Queen (Laughs). It’s stupid what you remember, but you know, why, why didn’t we go to the Dairy Queen? (Family 2, Participant 2)

Although both siblings are recalling the same event, they have focused on different aspects of the event. The older sibling appeared to be focused on what his parents were experiencing and this may explain why he reported experiencing fewer difficult emotional reactions in the past and presently in comparison to his younger sibling: instead of focusing on how the events impacted him, he focused on how the events impacted other people. The younger sibling has an opposite outlook, where her memories are focused on how each event negatively impacted her. In this situation she focuses on how upset she was. By focusing on different aspects of the situation, these siblings reacted differently to it in the past and upon recollection of the event presently.
Experiencing differences in relationships. Many of the participants in the present study talked about which child in their family had the most difficulties dealing with being the sibling of a child with cancer. In all of the families, the child who was closest in age to and who had the closest relationship with the child who died from cancer was seen to have “had it worst.” In all of the families in the present study, the closeness of sibling relationships was based on age and ordinal position: each child in the family was closest to the sibling who was nearest to him or her in age. When describing how her family members reacted to her sister’s death, one participant expressed: “My younger brother he was only three … his life was most affected by it, because they were so close in age. There was only 15 months between them. And he didn’t understand where she went” (Family 2, Participant 2).

In another family, the girl who died was very close to her younger sister, who said that before the illness, they “pretty much did everything together.” She continued by saying:

[My sister] and I were really close in age. We’re just over a year apart, and so we shared, like we shared a bedroom and went to school together, like shared a locker at school. Um, she was one grade higher than I was. Um, so it was a big changed when she passed.

(Family 3, Participant 2)

For this participant, her sister’s death was incredibly difficult to deal with. She had been so close to her sister that they were inseparable; she described her sister as her other half: “after [my sister] died I feel like I just lost myself completely. Cause she was like my other half, like my partner in crime” (Family 3, Participant 2). For this participant, she had to redefine herself after her sister died because her identity was so highly intertwined with her sister. The process of redefining herself was painful as it took her several years to learn to live without her sister and she described this process as unnatural:
I think that the first couple of years after she passed away, maybe like 2, 3, even like 4, were for me at least, just really confusing. And sad and hard. Because you were still trying to figure it out. Like how am I going to live without her? It was just a big shock that took a lot of adjusting and it was so unnatural and hard to come back from. (Family 3, Participant 2)

The other participant from this family was closer to her brother than to the sibling who died and although she was also highly upset by the death, she did not have the same sense of being lost without her sister. The results of the present study suggest that the sibling who had the closest relationship with the child who died from cancer had the most difficulties coping with the loss—possibly because they had the most to lose.

**Present**

When the interviews transitioned from talking about their past to their present experiences as the sibling of a child who survived or died from cancer, all of the participants expressed that their sibling’s battle with cancer still affected their lives. This is an important finding because these interviews were conducted ten, sixteen, and twenty-two years after the cancer diagnosis. Apparently being the sibling of a child with cancer has impacts on a very long-term basis. In some situations, all of the siblings reported having similar experiences. These similarities include that all participants experience challenging emotions presently, that age differences are becoming less important for sibling relationships, and that each participant’s occupation/volunteer work is impacted by their sibling’s illness. Participants also reported several differences in their experiences based on the gender and survival status of the sibling who had cancer. Presently, the sibling’s ages and ordinal positions did not explain any of the differences in siblings’ experiences.
Shared Similarities. When they described the present impacts of being the sibling of a child who survived or died from cancer, all of the participants in the study expressed three things in common: they all experience difficult emotions; they all feel that as they got older, age is less of a factor in the closeness of sibling relationships; and their present occupations/volunteer positions are impacted by their experiences as the sibling of a child who had cancer.

Experience of emotional difficulties. When participants were asked about their present emotional state, a theme of the continued experience of difficult emotions emerged. Each participant reported that they presently experience at least two difficult emotions. The most common emotions that participants currently experience being sadness followed by fear and then anger.

The participants expressed that they were sad for two reasons: they miss the sibling who died and/or they feel sad that their sibling had to go through so much. For example, when asked how her sister’s death impacts her now, one participant said “it still makes me sad” (Family 3, Participant 1). When the interviewer probed “do you feel sad that she is gone or do you feel sad about what she went through,” the participant responded “Everything. What she went through, how unfair it was, the fact that she put up with so much and then in the end she didn’t get to live” (Family 3, Participant 1). When another participant was asked about her present emotions, she expressed “I get sad and miss her, even 22 years later, I still cry like a baby” (Family 2, Participants 2). These former quotations are from families where the child with cancer died, however the experience of sadness is not restricted to participants whose sibling died from cancer. One participant whose brother survived cancer expressed:
I have depression from it, and I, um, I’m in active treatment for it. And uh, that was a very big negative impact and I ended up failing my classes last semester, so I’m under academic consideration to have them wiped. (Family 1, Participant 1)

The experience of sadness is widespread in the siblings of children who survived or died from cancer.

Several participants also expressed that they presently experience fear, however there was a difference based on the survival status of the child who had cancer: female participants whose sibling survived were afraid that the illness would return, while the female participants whose sibling died from cancer presently experienced fear because they were afraid that someone else they loved might die. One of the females whose sibling survived stated that she presently fears that her brother might get sick again: “there’s always a worry that the cancer might come back” (Family 1, Participant 2). One of the females whose sister died from cancer expressed her greatest fear: “my biggest fear in life is that someone close to me, someone that I love will pass away” (Family 3, Participant 1).

Participants presently experience anger when they think about what their sibling went through and when they consider that other families are still going through cancer. When asked about her present emotions, one participant explained “[I’m] just angry that this is still happening and we spend so much time and money and effort, why can’t we just stop cancer from happening?” (Family 3, Participant 2). Other emotions that participants presently experience include guilt, frustration, jealousy, loneliness, and anxiety. Being the brother or sister of a child who survived or died from cancer is related to the experience of difficult emotions across long periods of time.
Age is perceived as less important for closeness of sibling relationships. In each of the families, a theme emerged where the participants expressed that age was becoming less important as a factor in the closeness of sibling relationships. One participant described how he has become closer with his brother recently because the age difference seems narrower as they get older:

It wasn’t until he basically got to college age, or high school, that we became more friends. You know, and I think only because we, that gap narrowed a lot more when he was twenty and I was twenty-eight, as opposed to you know, uh, you know a thirteen and a you know five year old. (Family 2, Participant 1)

Similarly, another participant described how her relationship with her sister has gotten closer as they get older because the age difference seems less drastic:

My sister and I have definitely gotten a lot closer. [My brother] and I were always close because of our age, but now when you get older, 24, how 22 and 26 is not that much of a difference than like 14 and 10, so we talk about everything now and we’re pretty close.

(Family 3, Participant 1)

Although the difference between the ages of the siblings will never change, clearly the significance of the difference in their ages is decreasing as the siblings get older. This is likely because children develop and change at faster rates than adults do, making the difference between a five-year-old child and a ten-year-old child more pronounced than the differences between a 25-year-old adult and a 30-year-old adult.

Occupation choices made because of experiences as a sibling of a child with cancer.

During participant’s descriptions of their present lives, a theme arose where participants reported that are working in the jobs they are now because their sibling had pediatric cancer. Some
participants work with children because of their experience with cancer, some work (or are in school to eventually work) at hospitals, and many work or volunteer with children who have cancer. One participant explained how he started working with children who were the same age as his sister was when she died:

And that sort of was the first time I ever really worked with kids before, like and they were about the same age, you know, they were junior kindergarten, would have been about four or whatever so, so about the same age as my sister, and, and it kind of just, it’s, the idea of working with kids has always been a big thing for me. (Family 2, Participant 1)

More recently he has begun teaching older children as well, but his first introduction to his career was through children who were the same age as his sister was when she died.

The theme of occupational choices being made because of their experiences as the sibling of a child who had cancer was evident in one participant’s choice to dedicated all her research on cancer survivors to the way her sister battled with cancer: “when I dedicate my working career to cancer survivorship research, it really is a tribute to the way that she fought cancer” (Family 3, Participant 1). For this individual, the sister who died is a cancer survivor because she never let cancer change her personality. Her sister’s battle with cancer has changed the way she, as a researcher, views and conceptualizes survivorship. This has changed the course of her research, where she does not consider living through cancer to be the same concept as surviving cancer. When explaining the difference, this participant said:

She was always happy. She was just a simple person who had simple demands in life.

She never was like ‘oh, I’m always stuck at home and this sucks’ and was all bitter about things. I mean that is cancer survivorship. I don’t know like, if you go through treatment
and you’re just such a depressed, kind of hopeless person who is always feeling sorry for yourself and never seeing the bright side of anything, and you live at the end of your treatment, whoop-di-do, you survived cancer, but really I don’t think you did. (Family 3, Participant 1)

This participant reported that she does this research to help other children and their families when a child is diagnosed with cancer. This is a common sentiment among the siblings of children who had cancer, as other participants also expresses that they work and/or volunteer with children who have cancer. One participant explained that she wanted to help others deal with cancer because she had received so much help when her sister was sick, “I did the TIC match for that year ... I tried to be there as much as I could, and I was hoping that I could be their [specific friend]” (Family 3, Participant 2). This specific friend was an individual who had survived cancer and who helped her through her sister’s illness. Helping other people who are experiencing childhood cancer was a common theme for the siblings of children who died from cancer. Most of the participants in the present study work or volunteer at camps for children with cancer so that they can help children and families who are presently dealing with pediatric cancer.

Perceived differences based on the gender of the child who had cancer. When participants described their present experiences as the sibling of a child who survived or died from cancer, participants reported feeling jealous of other people’s sibling relationships only when the child who had cancer was the only child of that gender in the family. This theme occurred regardless of the survival status of the child who had cancer.

The participants talked about presently feeling jealous when they see other people’s sibling relationships with individuals of the same gender as the child who had cancer, provided
the participant does not have another sibling of the same gender. For instance, in one family, two female participants had a brother who had cancer and they reported feeling jealous of other people’s relationships with brothers. In another family, there were two girls and two boys. One of the girls had cancer and her sister reported feeling jealous of other people’s relationships with their sisters. Her brother did not express jealousy of other people’s relationships with their sisters, possibly because he had a sister who did not have cancer. Finally, in the family where there were 3 girls and one boy, one of the girls had cancer and neither of the female participants reported feeling jealous of other people’s relationships with their sisters.

In the family where the sibling survived, the individual who had cancer has long-term physical and mental difficulties from the cancer treatment. His siblings report feeling jealous of their peer’s different style of sibling relationships with their brothers:

You get very jealous of people’s relationships with their siblings. I get very, I don’t understand it. Um, I get jealous of having brothers that you can joke with and like, I get very jealous of my roommate and her brother. Like her br, her brother is like, you’re two years younger and like, talking about her brother’s friends like being, like hot and like ... you know when you wanted to have crushes on your brother’s friends, and like, I never had that and I think that that was always, always disappointing. (Family 1, Participant 1)

In this family, although their brother is still alive, these female participants see that their friends have different sibling relationships with their brothers.

When the sibling did not survive cancer, the participant who lost her only sister felt jealous that she no longer had a physical sibling relationship with a sister. The physical sibling relationship is highlighted here because the participant felt that she still had a relationship with her deceased sibling, however it was not a physical relationship. As this participant describes,
she felt jealous when other people talked about the things they did with their sisters because she will never be able to do those things with her sister:

   Like I often think how great it would have been to have a sister, like you know, she was gone so quickly. I always hate it when people talk about their sisters (laughs). You know, for clothes sharing, and I think, hmm, wonder if we would have [shared clothes]. (Family 2, Participant 2)

Participants expressed the theme of presently experiencing jealousy of other people’s sibling relationships when the only sibling they had of a single gender was diagnosed with cancer. This happens when the participants compare their relationship with the brother or sister who survived or died from cancer to the sibling relationships that their peers have.

**Perceived differences based on the survival status of the child who had cancer.** There were several differences between the present experiences of the siblings in the family where the child survived cancer and those of the siblings in the families where the child died from cancer. In the families where the child died from cancer, the siblings talked about the importance of keeping their sibling alive and how their deceased sibling has a positive influence on their lives presently.

**Keeping the deceased sibling alive.** When the child with cancer died from the illness, a clear theme was developed where all of the siblings in the study talked about the importance of keeping him or her alive and present in their lives. Some participants reported that they were able to keep their sibling alive by talking about him or her. When asked how she kept her sibling alive, one participant responded “mostly just talking about her” (Family 3, Participant 2). Another participant explains how open familial communication about the sibling who died is what keeps her alive: “that’s our way of making her present with us. So that’s our way of
keeping her alive” (Family 2, Participant 2). This participant continued to explain that keeping her sister alive through communication means that her sister is never forgotten: “I can’t imagine never speaking about somebody again ... I wouldn’t want to be forgotten” (Family 2, Participant 2). This sense of never forgetting the deceased was common in the siblings of children who died from cancer. Another participant talked about the importance of her sister being kept alive in other people’s memories as well as her own. Specifically, this participant mentioned that her deceased sister’s friends are keeping her sister’s memory alive and that she wants her future children to know about her sister so her memory is preserved. She said that “it’s nice to know that [my sister]’s memory is being kept alive elsewhere” (Family 3, Participant 2). For this participant, the theme of the importance of keeping her sister alive was so strong she wanted her sister’s memory to go beyond their family so that her sister will be remembered even when her immediate family is gone.

For some participants the sibling who died is kept alive by maintaining the presence of his or her possessions and pictures. One participant talked about keeping some of her sister’s most cherished belongings: “Like just things that meant a lot, like some of her special stuffed animals that she’s had since she was little, they’re still on her bed and God knows we’ll keep them forever” (Family 3, Participant 1) These items were retained to keep her sister’s memory alive and to keep her sister present in the house. In one interview the participant points out a picture of her deceased sibling on the wall. When asked how her sister was kept alive, this individual said “if you turn around there’s a picture of her. There’s a picture of her in almost every room in the house” (Family 3, Participant 2). For this family, having pictures of the child who died on the walls reminded them daily of her and kept her present in their lives.
When a child in the family dies of cancer, a theme arose where the remaining siblings find it important to keep their sister’s memory alive as they continue through life. This happens largely through communication about the child who died and through keeping the deceased child’s pictures and cherished possessions.

**The deceased child’s positive influence on his or her siblings.** In the families where the child with cancer died, his or her siblings presently report a theme that the deceased child has a positive influence on how they live their lives. The participants talked about making daily decisions that would make the deceased sibling happy or proud. One participant describes her deceased sister as the person who has the most influence on her life presently:

She’s the most important part of my life. She probably has the most influence on my life. The, like the things, a lot of things that I do like, I think, I hope, I hope she knows I’m doing it, I hope she’s proud. (Family 3, Participant 2)

When the child with cancer dies, it appears that some siblings use this individual’s memory almost as an extension of their conscience- they make ‘better’ decisions for themselves because they want to make the deceased individual happy and proud and because they would not want to disappoint the deceased sibling. Another participant shares this sentiment when she explains:

A lot of the times the decisions that I make in my head are asking her what she thinks, or thinking in my head how [my sister] would be happy with me for doing this decision, or what she would have wanted me to do. I am in constant dialogue with her. (Family 3, Participant 1)

The child who died from cancer has a long-lasting positive impact on the lives of his or her siblings (for the participants in the present study, at least ten years have passed since the death).
The participants whose sibling died from cancer are constantly trying to make better decisions so that their deceased sibling is happy with the choices they are making.

Future

Across participants’ descriptions of their expectations for their future experiences, there are shared similarities among the dyads consisting of two siblings from the same family. These similarities include the anticipation that the sibling who had cancer will continue to impact their lives in the future, the expectation that family relationships will stay the same or improve in the future, and the expectation that difficult emotions will continue in the future. Although all participants expect their emotions to continue into the future, the female participants’ expectations for their future emotions differ based on the survival status of the child with cancer. All participants (not just the females), anticipate differences for their future experiences based on the survival status of the child with cancer and their ordinal positions. There were no differences between sibling’s expectations for the future based on the participant’s ages.

Shared Similarities. When anticipating how their sibling’s battle with cancer will affect their futures, all of the participants reported several things: they anticipate that their sibling will play a role in their future, regardless of the child with cancer’s survival status; they expect their familial relationships to remain the same or improve; and they expect to a continuation of the experience of difficult emotions in the future.

Anticipation that the sibling who had cancer will impact their future. Regardless of the survival status of the child with cancer, a theme arose where participants expected that their sibling will play a role in their future. Each individual expected their sibling to play a different role, which exemplifies that each person has a different relationship with their sibling. One
participant described how she expects to become the caregiver for her brother if he becomes ill again:

I think that [my brother]'s illness will probably have a larger impact on my future than it currently does. I do plan on taking over his primary care, and whether that is taking him out for groceries for his apartment once a week, to having him live in my house, this will definitely affect my daily living. (Family 1, Participant 1)

For this participant, she expects that her brother will have an increased impact on her life than it does now. The opposite is true for her sister, who expects to be impacted less by her brother’s illness in the future. She describes how moving out for university will lessen her brother’s impact on her life:

I don’t think it will impact me as much because I think, um, I think by [the time I move out] I’ll have the space that I need, that I’m not living with him on a daily basis. So I’m not dealing with those daily frustrations, but when I see him I’m really happy to see him. (Family 1, Participant 2)

For this participant, she expects that she will be happier with the impact her brother has on her future because she will experience fewer daily frustrations and she will just be happy when she visits him. Other participants expect their siblings to have different impacts on their future, such as motivating them to continue working hard, to continue helping them make decisions in life, and helping them to appreciate things in life. One participant talked about how his sister’s death helps him appreciate his son more: “I think that I appreciate him more in certain ways than some people do” (Family 2, Participant 1). This participant said that he knows what it’s like to lose someone so he values what he has more than some people. Each sibling anticipated that the child
who had cancer will continue to impact their futures, although each individual expressed that their sibling would have a different impact on their future.

**Expectation that family relationships will remain the same or improve in the future.** All of the participants expressed a shared theme of optimism that their relationships with family members will remain the same or improve in the future. None of the participants expect to drift apart from family members or for their relationships to worsen in other ways, even if their past experiences are of family members drifting apart. In one participant’s family drawings, she identified that she had a strained relationship with her sister in the past as well as presently, however by the future she expected to have a very close relationship with her sister. When she talked about her future relationship with this sister, she explained how her sister has been struggling with an emotional issue but that her sister is seeking help to alleviate some of the stress associated with her emotional issue. The participant explained: “I think that um, she’s putting a lot of work into having a better relationship with everybody, so I think that hopefully things will calm down ... so we’ll have a better relationship” (Family 1, Participant 1). When she refers to things calming down, the participant is describing the stress associated with her sister’s emotional issue. This participant expects that her relationship with her sister will improve as her sister’s emotional issue becomes managed more appropriately.

All of the other participants talked about a theme of stability in their familial relationships as they moved into the future. For example, if an individual is presently close to their mother, they expected to be close to their mother in the future. This was true for siblings, fathers, and spouses as well. It appears that these individuals do not expect anything negative to happen that may cause their familial relationships to deteriorate. One participant talked about his relationship with his wife and how he thinks that they should be able to ‘make it’ through anything. He
explained that his parents were able to stay together through the loss of a child, so he thinks that he has great role models for a spousal relationship:

I often think that there’s no reason why my wife and I shouldn’t be able to live the rest of our lives together, you know, in that sense as a role model, like I, I look at that and I think, they went through probably something that’s probably as hard as anybody can ever go through in a relationship, and they came out of it. (Family 2, Participant 1)

This participant expects that he and his wife will continue to have a close relationship in the future and that they can make it through anything together. When describing their expectations for future relationships, the siblings of children who survived or died from cancer anticipate that their familial relationships will improve or remain the same.

**Expectation of continuity of difficult emotions in the future.** All of the participants expressed theme where they expect to continue to experience the same difficult emotions in the future as they experience presently. Participants expressed that enough time had passed (on average 16 years) since their sibling’s illness, so their emotional experience had become consistent. The participants expect this to continue into the future. One participant explained this:

I think the first initial part was when like, how she, like how her death impacted me fluctuated a lot, but now I’m kindof in that steady zone where her death impacts me the same now every day, uh I’d anticipate it being the same going forward. (Family 3, Participant 1)

Although each participant expected their emotional experience to remain the same, the emotions that participants expected to experience were different. For instance, the male participant expected to continue to experience guilt that he was not a good brother to his siblings. For a
description of the female participants’ expectations regarding their emotions, please refer to the following section.

**Females’ expectations for future emotional experiences differ by the survival status of the child who had cancer.** The emotional difficulties that females expect to experience in the future differ based on the survival status of the child with cancer. All females expect to experience fear in the future, however the *reasons* they think they will experience fear in the future differs based on the survival status of the child who had cancer. As well, the experience of sadness differs based on the survival status of the child with cancer.

In the families where the child died from cancer, the siblings reported that they were afraid that they would experience the death of another loved one. One participant expressed “my biggest fear in life is that someone close to me, someone that I love will pass away” (Family 3, Participant 1). For these individuals, there is a lot of fear associated with the possibility that someone close to them may die. These individuals dread the thought of re-experiencing the emotional difficulties of losing a loved one. One participant explained why she fears that another family member may die:

> Mainly because that will hurt. It will be so sad and also because I don’t wanna, I’m happy right now. I don’t want, I don’t wanna, I don’t want that to go away. I don’t, like my family’s in a good place. I don’t, like if God forbid anything happened, like I, I know that I would fall into a deeper slump. (Family 3, Participant 2)

For the participants whose sibling died from cancer, death is a very real threat. These people know how hard it is to experience the death of a loved one and they do not want to re-live such an experience.
For the participants in the family where the child survived cancer, they both anticipate that they will continue to experience worry that the illness will return or that the side effects from treatment will worsen. Furthermore, these participants expressed that they will experience sadness if these things occur. One participant expressed: “I don’t believe that my emotional state will change in the future, as long as [my brother]'s health remains the same. If he was to become sick again, then I might find myself with a lot of grief” (Family 1, Participant 1). This participant is worried that her brother will develop another tumour or that the side effects of his treatments will worsen. She expects to experience grief, “sadness,” and “disappointment” if he does become ill again or if the side effects of his treatment worsen. Their sister also worries about cancer returning or side effects getting worse: “there’s always that worry that it might come back ... [and] a worry that maybe he’ll become completely blind from the seizures” (Family 1, Participant 2). She continued to explain how she worries that his brain will start to deteriorate more and he will lose the functioning that he has now:

Recently it’s been like maybe the last two months and he’s been getting worse. But um, sometimes he gets better, but we think now that he’s like, this is like, this is it, he’s starting to just get worse. (Interviewer: okay, and do you think it’s going to stay like that then, for indefinitely, or just for-) I think so, cause I think that my parents said that uh, that the doctor said that this would happen, that eventually like, it starts to wear down and like the holes start to like really appear. (Family 1, Participant 2)

It seems like the siblings of a child who survived cancer worry that the illness might return in the future and that the side effects from the illness and treatment may get worse in the future. They also anticipate that they will be sad in the event that the illness returns or the side effects worsen.
When the sibling died from cancer, female participants expected to experience sadness for a different reason. The individuals whose brother or sister died from cancer expressed that they would be sad because their sibling was going to miss major life events and because people who become important to them in the future will never be able to meet the deceased sibling. One participant explains:

I know when I get married ... it’s going to break my heart that [my sister] can’t be one of my maid of honour or bridesmaids. When I have my first kid, it’s going to break my heart that I can just tell them about how wonderful their aunt was, but they can’t actually ever meet her. But other than that, I mean it, I think the upsetting thing going forward is just going to be, people that are important in my life um, who are new, who weren’t there in the past, won’t have known her. (Family 3, Participant 1)

For the participants whose brother or sister died from cancer, they expect to be sad because the deceased sibling will not be physically present in the future. These participants want their siblings there for important life events and to meet people who are important to them. As described in an earlier section, the participants made plans for ways to include their deceased sibling in future major life events, such as when one participant plans to dedicate a table at her wedding to her deceased sister. It appears that the participants made these plans so that they would feel less sadness when the deceased sibling was not present physically during major life events because the deceased sibling could be present spiritually. It appears that the siblings of a child who died from cancer experience sadness for a very long time because they miss the deceased sibling. However, they eventually learn ways to cope with the loss, often by creating ways to feel like their sibling is still alive and present in their lives.
Differences in anticipations about the future based on the survival status of the child with cancer. When the participants whose brother or sister died from cancer talked about their present experiences, they highlighted the importance of keeping their deceased sibling’s spirit alive. As they talked about doing this presently, the participants started to mention their plans for continuing to ensure that the sibling who died was present in different ways in the future. One individual described that her family is planning on selling her childhood home soon. She explained that she was worried until she realized that she “can make [new] memories and feelings of her [deceased sibling] in [her] new house.” Another participant explained how, at her wedding, she plans to “dedicate an entire table to her [deceased sibling] with all these pictures” (Family 3, Participant 1). By doing this, she will be able to feel like her sister is there in spirit, even though she cannot be there physically. A theme that arose was that the individuals whose sibling died from cancer were particularly concerned that their siblings would not be present during major life events, such as weddings and child births. By planning ways to keep the deceased sibling present at these events, the participants were able to alleviate some of their distress. Another participant explained how “even though they won’t have met her, I think my husband and my children are going to know that like they had an aunt [deceased sibling’s name] and like I want them to feel close with her” (Family 3, Participant 2). She plans to tell stories, show pictures, and share old home videos with her future husband and children so that they are able to feel connected to her. Evidently it is important to these individuals that the child who died is kept alive and present in their lives in the future. The participants whose sibling survived cancer clearly did not have to go through such efforts to keep their sibling involved in their lives in the future because the sibling who had cancer is physically present.
Differences in expectations about the future based on ordinal position. When the participants described how being the sibling of a child who survived or died from cancer will likely affect them in the future, the eldest children in the family were once again different from their later-born siblings. Only the eldest child in each family talked about how the experience will affect their child rearing practices and/or their plans for child rearing. This theme of the experience affecting their plans or child rearing occurred regardless of age, as the younger children in some families were older than the eldest children in others and still only eldest children talked about the cancer experiences affects on child rearing. This also happened regardless of whether the participant had children or not, as only one individual in the study had a child.

One participant explained how he and his younger brother had very different childhoods because his sister’s illness and death changed his parents. By comparing his childhood to his brother’s upbringing, the participant was able to make decisions about how he wants to raise his son and other future children. While the participant was in his ‘formative years,’ his parents were available, but his younger brother’s formative years occurred after their sister’s death when his parents were less available. Years later this individual is able to see the impact of their different upbringings and he thinks his brother had the worse experience. He described how they were raised differently:

But I think that [my brother] got screwed in the deal, for lack of better terms, you know what I mean? Because of what happened, and the age that he was. Those three or four years that followed, when I had certain advantages, he never got them I think. You know. And because I was that much older, but as a twelve, thirteen, fourteen year old kid, I don’t, I don’t think I appreciated it then. It’s something that I realized when I was twenty,
twenty-five, that you know, we had a very different childhood growing up. You know, which I think has a lot to do with why we’re different people now. You know, I, I do most of the same things my dad does. I’m a musician, umm, construction work, all those type of things that my dad taught me. Because when I was three, four, five, six, I was walking behind him with a hammer. I was, you know, [my brother] didn’t get that same stuff, you know, so I think that you know, and [my brother] doesn’t do that sort of stuff now either, the things that are very different for us. (Family 2, Participant 1)

Later in the interview he explained how observing these differences in childhood affects how he wants to be a father:

I think that I have a different appreciation, and I, and I think that because of what happened to [my brother], compared to me and our relationship, it will have a lot to do with how I want to be a father. You know, and it, and it’s like I said, it’s not to knock my dad, but when I look at the relationship I had with my dad, compared to the one [my brother] would have, I think that if, if we talked about you know, what his relationship was like, I know what I want to be like, and I’m sure that because of [my deceased sister] I saw both sides. You know, I may have never known the difference, or, or noticed it otherwise, but now I certainly see a big difference. (Family 2, Participant 1)

The participant wants to raise his child and future children similarly to how he was raised, as opposed to how his brother was raised. He attributes his knowledge about some of the different ways he could raise his children to the experiences he and his siblings had due to his sister’s cancer.

In another family, the eldest child talks about wanting to raise her future children the same way she was raised. She described about how her parents raised her and her siblings to be
empathic and optimistic and that she wants to instil the same values in her future children. When asked how the experience will impact her, the participant expressed:

I think that it’d really impact how I would raise children and who I would want them to be. Um, (Interviewer: Yes. How do you think it would be an impact?) I would want them to have a lot of empathy for people with special needs and be very open to it. And I want them to be very caring. And want them to have the strength and the optimism that we have. I wouldn’t wish any of this on them in any way, but I don’t think that I would be afraid of it if it happened. (Family 1, Participant 1)

This individual is using her parents as role models for how she wants to be a parent in the future. The eldest children in these families focused on how their past experiences as the sibling of a child with cancer will impact the way they raise children. None of the younger siblings in any of the families talked about the experience impacting the way they will raise children, even though the youngest child in one family is 11 years older than the eldest child in another family.

**Discussion**

The objective of this research project was to learn about the similarities and differences in the experiences of two siblings from the same family in the event that a third sibling diagnosed with pediatric cancer. From this research, many similarities and differences in siblings from the same family were discussed. Across all of the dyads, the most salient and overarching findings were that 1) the siblings of children who had cancer experience long-term effects, 2) siblings from the same family have more differences than similarities in their experiences, and 3) there appears to be continuity of the emotions that each individual experiences. Each of these findings will be discussed below followed by an explanation of the clinical importance of what was learned. Next, the limitations of the present study will be identified and discussed. Following
this, the findings about specific subsets of the sample (such as older siblings or female participants) will be discussed and the implications of these findings for families, researchers, and practitioners will be identified. Finally, suggestions will be made for future research.

**Overall findings**

**Experience of long-term effects.** In this study, dyads consisting of two siblings from the same family were interviewed an average of 16 years after the cancer diagnosis. When talking about their present experiences, all of the participants discussed several ways that the experience of being the sibling of a child with cancer still affects them. Furthermore, when speculating about their future experiences, the participants expect that they will continue to be affected by their past experiences as the sibling of a child with cancer. The results of this study suggest that there are long-term impacts of being the sibling of a child who survived or died from cancer. Although the experience of long-term impacts was common among the siblings in the study, each sibling experienced a different set of long-term effects. For example, some individuals were more emotionally impacted presently than others, reporting more numerous and intense difficult emotions. Evidently the experience of long-term effects is common, however the intensity, type, and number of effects experienced on a long-term basis differs.

Based on the results from this study, it is important for practitioners and families working with the siblings of children with cancer to realize that care and support may be required on a long term basis for some siblings. Being the sibling of a child with cancer appears to be a life-altering experience that impacts these siblings for an extended period of time. Some of these individuals may continue to need support for years after the experience, while other individuals may not. The siblings of children who had cancer would likely benefit from practitioners and families understanding that they may be affected in different ways for long periods of time. By
understanding the possibility for long-term effects, families and practitioners can create a safe space for these siblings to experience and cope with these long-term effects.

**Siblings from the same family tend to have different experiences.** In this study, the researchers were interested not only in similarities of experiences, but also differences of experiences of siblings. The results of this study display that the siblings of a child with cancer overall experience different events and interpret the same events differently. In all three time periods, the siblings in each dyad reported more differences than similarities. This was partially because many of the similarities in experiences between siblings also constituted differences. For example, although most siblings expect to experience sadness and fear in the future, the reasons they anticipate these emotional experiences differ. Another example of one situation being both a similarity and difference in siblings is how all of the participants expect the child who survived or died from cancer to continue to impact their lives in the future, however the way they anticipate their sibling being involved in their futures differs. Ordinal position, the integration of age and ordinal position, and survival status were the most common reasons for differences between siblings. Age alone was not found to be a source of differences between two siblings from the same family in any of the three time periods.

The results of the study demonstrate that two siblings from the same family have different experiences and require different supports. Even when describing the same event, two siblings from the same family focused on different aspects of the situation. This differential focus seems to be linked to different emotional reactions to similar events. Sometimes these differences were drastic, with one sibling remaining optimistic while the other felt intense difficult emotions. Clearly in these situations the children require different a type and/or amount of support. As evidenced by the results of this study, researchers, families, and practitioners
working with the siblings of children with cancer should focus on the individual needs of each child, not only on strengthening family-based protective factors.

Based on the results of this study, researchers, families, and practitioners working with the siblings of children with cancer are encouraged to view siblings from the same family as individuals who have different experiences. People working with families of children with cancer need to learn about the specific needs of each sibling in the family so that they can cater services and care to the needs of each individual sibling.

**Continuity of emotional experiences.** The results of this study suggest that there is a strong connection between the emotions each sibling experienced during the past to the emotions he or she is experiencing presently and to the emotions he or she expects to experience in the future. Sadness, fear, and anger were the most common emotions experienced by participants presently. Each participant who reported these emotions had experienced them in the past and anticipated that they will also experience them in the future. Because of this continuity in emotional experiences, it is important to attempt to assist the siblings of children with cancer emotionally as early as possible. Based on the results of this study, it seems likely that successfully supporting a more positive emotional experience for the sibling during the illness would also create more positive emotional experiences years later. Emotional support can come in at least three forms: trying to alleviate negative emotions, trying to bolster positive emotions, or attempting to do both. It is likely that the third option would be more successful overall, however as this study demonstrates, each child is different and one approach would probably not suit all of the siblings of children with cancer. It is critical to realize that although early intervention is likely optimal, this does not mean that later interventions would not be successful. It is possible that supporting a shift toward positive emotional experience for these siblings at
any time during or after the cancer experience could be related to the experience of positive emotions later in life. Using a longitudinal study, future researchers should investigate the long-term implications of various programs geared at supporting the emotional experiences of the siblings of children with cancer.

This research did not investigate different ways to support the siblings of children with cancer emotionally; however some participants mentioned techniques that they employed to remain in a more positive emotional state. Such techniques included keeping busy, focusing on positive events, and talking about their experiences. Perhaps interventions and services geared towards enhancing siblings’ emotional experiences indirectly would be effective for some siblings of children with cancer. For example, one portion of an intervention could be to encourage families to do activities together so that the siblings are busy and also have a chance to talk about their experiences. Such interventions are not directly working on improving siblings’ emotional experiences. Instead the services are supporting activities that may in effect help improve the emotional experience of siblings of children with cancer. Alternatively, cognitive treatments may be successful, where children could be taught about different, more positive ways to think about their experiences. There are also many other types of treatments that may be effective in supporting positive emotional experiences in the siblings of children with cancer. More research is required to understand which interventions would be successful for these children. Furthermore, not all interventions would be successful with all children. More research is required so that practitioners can predict which treatments would be effective for specific children. Although the present study does not indicate how to support the siblings of pediatric cancer patients emotionally, the results of this study do emphasize the importance of such support.
Limitations

Although this research was theoretically and methodologically sound, there were several limitations that need to be addressed. First, the sample was relatively small and heterogeneous with only one male participant. Second, much of the results were based on individual’s recollections of the past, which may not be entirely accurate. Finally, because of the exploratory nature of the study, the questions were open ended to allow the participants to identify the important aspects of their experiences. In some cases, participants did not mention things that were important to other individuals and it is difficult to determine whether these omissions were due to a lack of importance for the individual.

The sample size for the present study was fairly small, with six participants totalling three dyads. With a small sample size, it can be difficult to ensure that saturation was achieved. The interviews with the final dyad were repetitious in many ways of the interviews with the first two dyads, however new situations were still discussed. It is possible that a fourth dyad may have added experiences that were not discussed by the present sample. The researcher felt that it was more important to become fully immersed in the experiences of the present sample than to increase the sample size and use a more surface-level analysis with more individuals. The sample was fairly heterogeneous, with individuals who ranged from one to sixteen years old at the time of diagnosis, the length of treatment ranging from 2 months to ten years, and some of the children with cancer survived while others died from the illness. Because of the heterogeneous sample, the population of individuals covered in the study could not be narrowed. In phenomenological studies, it is ideal to have small homogenous samples in order to explore the experiences of a small, select set of individuals. Because of the exploratory nature of the study, a heterogeneous sample is acceptable, if not ideal. Finally, with only one male participant
in the study, gender was not as well represented. The one male participant may have had very
different experiences than other males who were the brother or sister of a child with cancer. For
this reason, gender differences could not be analyzed. Although the sample was not ideal, the
results are still valid and important because the study was designed to determine if differences
existed between two siblings from the same family and then to inform future research. It was
very clear, even based on the small sample, that differences did occur between siblings from the
same family. As well, differences were observed between siblings from the same family based
on several factors. These results can be used to inform future researchers about which factors
need to be studied more in depth. For example, a future study could use quantitative methods to
determine if significant differences can be observed between siblings from the same family
based on the factors identified in the present study.

The second limitation of the present study is that the results about participant’s
experiences during their sibling’s cancer were based on recollections. The participants were
interviewed an average of sixteen years after the diagnosis, which gives participants a long time
to forget the details of their experience. The best way to eliminate error based on participant’s
memory is to perform a longitudinal study, where data is gathered at several time periods. A
longitudinal design would have also allowed for the examination of changes in participants ideas
as they age. For the present study, a longitudinal study was neither possible nor was it preferred.
Although the participants may have forgotten some of the details surrounding their past
experiences, it is their memories that the participants make meaning from. When participants
recall their experiences, it is what they can remember that has an impact on them presently. For
example, if an individual recalls that they were not as helpful as they could have been but forgets
that they were scared during the experience, the experience will likely represent a time of guilt as
opposed to a time of fear. This will change the meaning of the experience for the individual—he or she has focused on a different element of the experience from which to derive meaning. Accordingly, participant’s recollections, regardless of their accuracy, are the critical elements of meaning making. For this reason, the accuracy of participant’s recollections is a minor limitation.

The third limitation in this study is that questions were open ended and participants sometimes talked about different things, making it difficult to determine if omissions were due to a lack of importance. The only way to overcome this issue is to include specific questions about each individual item of interest. This can be limiting for an exploratory study because participants may be less likely to identify other experiences that were significant to them. For example, participants were asked to describe their emotional experiences, instead of being asked about each possible emotion in turn. Sometimes participants talked about different emotions, and this is where it is difficult to see if an omission meant a lack of experience of an emotion. The choice to remain open ended was informed in this case, as participants were able to explain their experience of different emotions and to talk about the emotions that they felt were most salient to their experience. Open ended questions allow participants to provide more explanation and qualifications to their descriptions; however these questions are less specific than closed questions, which can allow participants to forget important experiences. Balancing the information received and acknowledging the limitations based the type of questions is important so that false conclusions are not drawn. Accordingly, the results where participants did not mention a specific item were identified and these results must be interpreted with caution.

Specific Findings

Despite the limitations of the present study, the findings of the present study are still valid and important. Prior to interviewing the participants for the study, it was hypothesized that age,
ordinal position, gender, and the survival status of the child with cancer would all account for differences between siblings. Due to difficulties recruiting male participants, gender could not be considered in this study. Alternatively, the experiences of the female siblings of children who had cancer were described. This section will consist of discussions of the experiences of the different subsets of the participants in this study, such as the experiences of female participants or first-born siblings. The first finding that will be discussed is the continuity of females reporting emotional distress. Following this, the second finding that will be discussed is that the female participants all expect to experience fear in the future, however the reason that they expect to experience fear differs based on the survival status of the child who had cancer. The third finding that will be discussed is how, in the families where the child with cancer died, the siblings take measure to ‘keep him or her alive’ presently and plan to continue doing so in the future. Following this, the fourth finding to be discussed will be how the eldest child in the families with young children acted as caregivers for their younger siblings, but being the caregiver had different meanings for these individuals and corresponding differences in their present experiences. The fifth finding discussed will be how age alone was not found to explain differences in siblings at any time period.

**Females experience of difficult emotions.** The results of this study suggest that female siblings of children with cancer have highly emotional experiences, both at the time of the illness as well as years later. Although the emotions that females reported were mostly difficult emotions, these women experienced positive emotions too. Each individual woman described a different set of emotions as well as different priorities of emotions: for example, one woman mentioned that she felt predominantly sad during her sister’s illness but she also experienced fear and anxiety. For other individuals the experience of optimism, fear, or anger was more
prominent. Evidently the emotional experience of each woman differs, but overall female siblings of children who had cancer experience a multitude of difficult emotions. These differences in emotional experiences can explain some of the differences in these women’s overall experiences. For the women who felt predominantly difficult emotions during the illness, that part of their life was remembered as a negative time. Conversely, the one woman who felt more optimism in the past seemed to remember this time more positively.

As mentioned in an earlier section, there is continuity across time in the emotions that the siblings of children with cancer experience: those individuals who experienced numerous difficult emotions in the past are likely to experience numerous difficult emotions presently and to anticipate these emotions continuing into the future. As the results of this study suggest, the female siblings of children with cancer tend to have a highly emotional experience. When these two findings are considered together, emotional support for female siblings at the time of the illness is incredibly important. Early emotional interventions for these female siblings may help in creating a more positive experience, which would likely relate to long-term changes towards positive emotions.

**Females’ expectation of the experience of fear in the future.** Although all of the female participants expect to experience fear in the future, the reasons that they expect to be afraid differs based on the survival status of the child with cancer. In the event that the child survived cancer, his or her sister(s) expect to experience fear in the future that the illness will return or that the side effects will worsen. The results of this study suggest that, for those individuals whose sibling survived cancer, their expectation to experience fear is centralized around the health of the child who survived cancer as well as their own experiences. These individuals do not want their sibling to suffer, but they also worry that they will be affected
negatively by a relapse or increase in the severity of the side effects from their brother or sister’s treatment.

When the child died from cancer, his or her sister(s) fear that someone else they are close to will die. The results of the study suggest that these individuals expect to experience fear in the future because the experience of being the sibling of a child who died from cancer was so traumatic and they do not want to experience anything like that again; just thinking about the possibility that someone they love may die induces fear. These people know how hard it is to experience the death of a loved one and they do not want to re-live such an experience. The results of this study suggest that when the child survived cancer, his or her sister(s)’ fear is centralized around their own personal experience: they are scared about what they may go through in the future.

It is interesting that the siblings of the children who died from cancer did not report that they expect to experience fear for the health and well-being of their loved ones: they only reported an expectation of fear for their own reaction to the death of someone they care about. It is possible that these individuals do not expect to be fearful about their loved ones’ health and well-being because they may not have a specific individual to focus on who is likely to become ill. For the individuals whose brother or sister survived cancer, they worry specifically about that brother or sister’s health and well-being; they are not worried about the health and well-being of all of their loved ones.

Another interesting finding is that although the sisters of children who had cancer expect to fear different things based on the survival status of the child who had cancer, one of the reasons that they expect to be afraid is similar: they fear that they will experience illness and/or death again in the future. Many people feel that bad things will not happen to them and they feel
a sense of invincibility. The results of this study suggest that this feeling is not present for the siblings of children who survived or died from cancer; they expect to experience fear in the future because they realize the possibility that someone they love may become sick and/or die.

**Keeping the deceased sibling alive presently and in the future.** The siblings who lost a brother or sister to pediatric cancer reported that it was important to them that the deceased child is kept alive in their present and future lives. Based on the results of this study, keeping the deceased sibling alive acted as a coping mechanism for the siblings of children who died from cancer by decreasing the sense of loss associated with the death. When the child who died was kept alive and present in their lives, siblings seemed to feel like the death was not a complete loss of the child. Instead, the results of the study suggest that these siblings felt that the death constituted a loss of the child’s physical body, but that some part of the child lived on. This was evidenced by the behaviours the siblings reported performing, such as continuing to talk to the deceased child, choosing behaviours that would make the deceased child proud, and creating new memories of the deceased child. These behaviours necessitate a belief that some part of the child who died from cancer lives on, otherwise there would be no one to talk to, make proud or make new memories with. These are important findings, which should be used to inform individuals who design and implement programs for the siblings of children with cancer. In families where a child has died from cancer, the siblings may benefit from learning about ways to keep the deceased sibling alive and present in their lives.

The results of this study also suggest that siblings wanted to maintain a relationship with the deceased child so that they would never forget him or her. Siblings were able to remember the child who died by performing rituals, talking to the deceased child, keeping the deceased child’s possessions, and writing down memories of the deceased child. Some participants
expressed that remembering the deceased child was important because they felt a sense of duty to the deceased child. These individuals explained that they would not want to be forgotten, so they made efforts to ensure the deceased child is not forgotten. Other individuals wanted to remember the deceased child so that they could continue to value the time they spent with him or her. For these individuals, the time they had with the child before he or she died is precious and the memories of this time need to be retained.

**Different meanings of acting as a caregiver for younger siblings.** The results of this study suggest that the eldest child in the family acted as a caregiver for his or her younger siblings. Although this was a theme across families, the meaning of acting as a caregiver differed. For one individual, acting as a caregiver for her younger siblings was internalized into her description of herself as a caring person as evidenced by her continual description of herself a caring individual presently and in the future. Becoming the caregiver for her younger siblings during her brother’s illness holds a positive meaning for this individual. For another individual, he perceived his actions as a caregiver for his younger siblings as not being ‘enough’ and he has internalized this perceived shortfall into a lasting sense of guilt. Interestingly, his younger sibling disagrees with his perception that he was not a good enough caregiver.

One possible explanation for the differences in meaning associated with being the caregiver for younger siblings is the difference in their interpretations of the quality of care they were able to provide. One participant felt she provided adequate care while another did not. The important factor here is that these are individual’s interpretations of their own behaviors- not other people’s perspectives. This may mean that an individual who provides high levels of care and support to his or her siblings may still perceive that they did not do enough. Conversely, an individual can provide very little care but still feel that their support was adequate. The results
from the present study suggest that different perspectives on the amount and quality of care provided is associated with individuals deriving different meaning from their experiences as caregivers for younger siblings. From this study, the perception that one provided adequate care was related to a sense of self as a caring individual while the perception that one did not provide adequate care was related to feelings of guilt.

**Age alone did not explain differences in siblings.** Differences in participants’ ages alone were not found to explain differences in experiences of the siblings of children with cancer. The only time that age seemed to influence differences in siblings from the same family was when age was combined with ordinal position in the past. Age differences did not influence differences in sibling experiences in any way presently or in participants’ expectations for the future. As a matter of fact, a theme from participants’ present experiences was that age differences impacted sibling relationships less as time passed. Ordinal position and age were combined together in the past to explain the closeness of sibling relationships, where, for example, first born children felt closest to second born children because they were closest in age. In participants’ descriptions of the present and anticipations for the future, differences in age were described as less drastic by the siblings. Because age differences seemed smaller, the closeness of sibling relationships were not based on similarities between ages any more. In the present and anticipated future, differences in age did not explain differences in siblings’ experiences.

When participants talked about having different experiences than their siblings in the past, they often said it was because they were ‘older’ or ‘younger’ than their sibling(s). This inherently combines age and ordinal position together. When analyzing these differences, it became clear that some differences could be attributed to differences in birth order (such as when
eldest siblings became caregivers for younger siblings, regardless of age) and some seemed to be a combination of birth order and age (such as where elder siblings experienced a sense of growing up quickly if they were not yet adolescents at the time of diagnosis). However, none of the differences could be explained by age differences alone.

The finding where age does not explain differences in sibling experiences is very important for practitioners working with the siblings of children with cancer. For instance, oftentimes support groups are created to assist the siblings of children with cancer. Based on the results of this study, it may not make sense to divide children into different support groups based on age alone. Instead, the results of this study suggest that it would make sense to have adolescents in different groups than children and then to divide both adolescents and children into smaller groups based on birth order. Specifically, first-born siblings seem to have different experiences than their later-born siblings. Another situation that impacted differences in sibling experiences in the past was differences in the closeness of relationship to the child with cancer. Perhaps dividing children into different groups based on birth order and/or closeness of relationship to the child with cancer would allow practitioners to better support the needs of each group of siblings.

**Suggestions for Future Research**

This research helped us learn more about the similarities and differences in the experiences of two siblings from the same family when a third child in the family is diagnosed with cancer. The results of this research suggest that siblings from the same family often have different experiences and interpret the same experiences differently. Although it has now been demonstrated that siblings have qualitatively different experiences, more research is required to determine if the differences observed between siblings from the same family are significant.
quantitatively. This could be done by administering questionnaires to two or more siblings from the same family when another child is diagnosed with cancer and then comparing the results. The questionnaires would need to be developed using a thorough literature review to determine the important experiences to cover in the questions. Important topics would include, but are not limited to emotional experiences, relationships, changes in daily life, information received about cancer, and supports required and received.

In many situations in the present study, participants would talk about their sibling’s experiences. However, these descriptions did not always align with the sibling’s description of their own experience. For this reason, future research is required to determine how accurately siblings assess each other’s experiences and opinions. An interesting extension of research on the accuracy of siblings’ assessment of each other’s experiences would be examining the impacts of correct and incorrect assessments of siblings’ experiences. In the present study, one sibling felt guilty that he did not support his younger siblings enough; however his younger sibling reported that she received adequate support from him. The elder sibling in this case was affected negatively (by experiencing guilt) by a misunderstanding of his sibling’s experience. More research is needed to understand the implications of correct and incorrect assessments of sibling experiences.

In the present study, elder siblings reported becoming the caregiver for younger siblings during their brother or sister’s treatment for cancer. Being the caregiver had different meanings for these individuals. Further research is required to determine if other things are involved in the meaning making process of the care giving role for eldest siblings when a child is diagnosed with cancer. As well, if different processes and factors are involved when eldest siblings make meaning of being the caregiver for younger siblings, perhaps different meaning will be derived.
More research is required to learn if being the caregiver for younger siblings when a child in the family is diagnosed with cancer means different things to other individuals.

The results of the present study suggest that during the treatment phased of cancer, some siblings were able to adjust to lower parental attention better than others. For example, in the family with all adolescent children, the siblings reported being fairly capable of dealing with less parental attention. It is difficult to determine if this was because these individuals were older and more autonomous, or if these individuals had more adaptive personalities. Future research should measure adaptiveness as a temperament trait and determine if it correlates with outcome measures such as the experience of difficult emotions. This research could help answer questions such as ‘When a child is diagnosed with cancer, do highly adaptive siblings experience less loneliness than siblings who are less adaptive?’

All of the families in this study were nuclear families and the parents stayed together throughout and after the illness. Future research should include families with different family configurations. An interesting research question would be if, in separated families, the siblings of children who died from cancer have different memories, rituals, and possessions of the deceased child at different households. If so, do the siblings of children who died from cancer assimilate these representations of the deceased child together or keep several separate images of the deceased child? Research that includes families with different configurations can examine if siblings from, for example, blended families have different experiences when a child is diagnosed with cancer than children from nuclear families or children from single-parent families. Also, when blended families are included in the research, the experiences of step-siblings of the child with cancer could also be examined.
The present study only contained one male participant. Future research should include more male participants so that their experiences can be better understood. Furthermore, with more male participants, gender comparisons could be performed to examine the similarities and dissimilarities of siblings of children with cancer.

**Conclusion**

Although there are similarities in the experiences of two siblings who had a third sibling undergo treatment for cancer during childhood or adolescence, these siblings often have different experiences and react differently to the same experience. Two siblings from the same family were interviewed an average of 16 years after a third sibling was diagnosed with cancer. Participants reflected on their past, present, and anticipated future experiences. Across all three time periods, more differences than similarities between siblings within the same family were discussed. The objective of this research was to learn about the similarities and differences between two siblings from the same family when a third sibling is diagnosed with cancer. It was hypothesized that four things would be useful in explaining the differences in siblings of children with cancer: age, ordinal position, gender, and the survival status of the child who had cancer. With only one male participant gender differences could not be considered.

When talking about their past experiences, two similarities between siblings in the same family were shared across all of the dyads: participants’ mothers were absent during the treatment phase of cancer and the routines in the family changed. All of the participants discussed difficulties associated with these changes in the family. However, some siblings had more adverse reactions to their mothers’ absence and changes in the family routines. In the past, ordinal position, the combination of age and ordinal position, and the survival status of the child with cancer could all be used to explain differences in the experiences of siblings of children.
with cancer. Age alone was not found to explain differences in the experiences of siblings from the same family. Four unanticipated situations were also found that helped the researcher understand the differences between sibling experiences in the past: siblings were sometimes in different locations during cancer treatment, siblings experienced different situations and events, siblings appraised similar situations and events differently, and siblings had different relationships.

When discussing their present experiences as the siblings of children who survived or died from cancer, three similarities arose: they were experiencing long-term emotional difficulties, they felt that age was less important in the closeness of sibling relationships, and their past experiences as the sibling of a child with cancer influenced their career choices and plans. Many differences between siblings’ experiences were also observed when participants talked about their present experiences. These differences could be explained by the gender of the child who had cancer and the survival status of the child who had cancer. Neither age nor ordinal position explained differences in the present experiences of siblings of children who were diagnosed with cancer an average of 16-years ago.

Three similarities were noticed when the siblings of children who survived or died from cancer speculated about their future experiences: they anticipate that their sibling will play a role in their future, they think their familial relationships will stay the same or improve in the future, and they expect to continue experiencing the emotions they presently experience. Although the participants expect to continue experiencing the same emotions that they presently experience, the participants differed on the emotions they expect to experience. The female siblings of a child who survived cancer talked about different expectations for their future emotional experiences than the female siblings of a child who died from cancer. Siblings (male and female)
also had different expectations for their future experiences based on the survival status of the child with cancer and ordinal position.

From this research, it has become clear that two siblings from the same family have both similar and different experiences when a third child in the family is diagnosed with cancer. Siblings of children with cancer have distinctive experiences and unique service needs. It is important for researchers, families, and practitioners working with the siblings of children with cancer to treat each child in the family like a unique individual and to try to understand his or her unique experiences.
References


Appendix A

Recruitment poster (on 8.5x 14 paper)

Participate in a Study: The Experiences of Siblings of Children with Cancer

- This research project will focus on the experiences of two siblings who had a third sibling undergo treatment for cancer during childhood or adolescence.

- Participants are required to have gone through this experience at least one year ago, therefore having had the chance to reflect on the situation. This means that the sibling with cancer would either have been in remission for at least one year or would have passed away at least one year ago.

- We hope to discover more about the stories and experiences of siblings' family relationships when a child in the family is diagnosed with cancer.

Participant Requirements

Participants are asked to meet with Ms. Laura Gillies, the research student, to engage in a private interview with her regarding their experience with their sibling's childhood cancer treatment.

- Participants must be 18 years of age or older.

- Participants have gone through this experience a minimum of one year ago.

- Participants must have been old enough at the time of the brother's or sister's diagnosis to remember their experience.

- Two siblings from the same family who had a third sibling undergo treatment for cancer must both be willing to participate.

University of Guelph
Department of Family Relations

Ms. Laura Gillies
Research Assistant
Department of Family Relations
(519) 824-4841
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Dr. Susan Stirling
Department of Family Relations
(519) 824-4829 x 65003
stirling@uoguelph.ca

This research has received ethical clearance from the University of Guelph Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS2) at the Research Administration Office (RAO).
Appendix B

Classroom Presentation Script

(The poster will be put up on an overhead or as a slide)

Hello everyone, my name is Laura Calvert and I am a Master’s student in the Family Relations and Human Development program. I am currently looking for people to participate in my study on the experiences of two siblings who had a third sibling undergo treatment for cancer during childhood or adolescence. I am looking to find dyads consisting of two siblings from the same family who are both at least 18, remember their sibling’s illness, and went through this experience at least one year ago. Participants will be asked to partake in an interview with me, which will take approximately an hour. Your sibling will be asked to participate in a separate interview with me, which will also take approximately an hour. If you and your sibling have experienced having a third sibling with cancer during childhood or adolescence and you are both willing to participate in my study, please contact me at lcalvert@uoguelph.ca. Thank you so much for your time. I will leave some posters at the front for anyone who is interested in my study.
Appendix C

Recruitment Letter: To be Distributed via Organizations

Dear Sir and Madam,

We at [organization] are forwarding this letter on behalf of Ms. Laura Calvert, a student working on her MSc. in Family Relations and Human Development at the University of Guelph, and her supervisor, Dr. Susan Lollis, from the Department of Family Relations and Applied Nutrition at the University of Guelph. Her research for her thesis is on the experiences of two siblings who have had a third sibling undergo treatment for cancer during childhood or adolescence. From this research, Ms. Calvert hopes to learn more about the types of experiences that children or adolescents have when a sibling is diagnosed with cancer. This information will be helpful for families, practitioners, teachers, and other individuals working to support the siblings of children and adolescents who are living with cancer. Furthermore, Ms. Calvert hopes to learn about the long term supports that siblings of children or adolescents with cancer identify wanting and/or needing.

Participants in Ms. Calvert's research need to be two siblings from the same family who are both at least 18, remember their sibling’s illness, and went through this experience at least one year ago. For Ms. Calvert's research, it is important that the participants would have experienced their sibling’s remission or death one year ago or more so that we may learn about the long-term implications of being the sibling of a child or adolescent with cancer. Each sibling will be interviewed separately and each interview will last approximately an hour. The attached research poster contains more detailed information on the study.

If you or someone in your family is interested in participating in or has questions about Ms. Calvert’s study, please contact her directly by email at lcalvert@uoguelph.ca or by phone at (519) 835-8453.

Your decision regarding participation in the study will have no effect on the provision of services with [organization]. Furthermore, Ms. Calvert will not inform [organization] of the identity of the individuals who choose to participate in the study.

This research has received clearance from the University of Guelph Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant you can contact the REB administration by email at reb@uoguelph.ca or by phone at (519) 824-4120, ext. 56606.

Ms. Calvert thanks you in advance for your time and consideration.
Appendix D

Consent Form

Participant initials ____

(On University of Guelph Letterhead)

CONSENT TO PARTICIPATE IN RESEARCH

THE SIBLING EXPERIENCE OF CHILDHOOD AND ADOLESCENT CANCER

You and your brother or sister are asked to participate in a research study by Ms. Laura Calvert, Dr. Susan Lollis from the Department of Family Relations and Applied Nutrition at the University of Guelph, and Dr. Susan Cadell from the Faculty of Social Work at Wilfrid Laurier University. The results will contribute to Ms. Calvert’s master’s thesis project.

PURPOSE OF THE STUDY

The purpose of this research project is to develop an understanding of individuals who had a brother or sister undergo treatment for cancer during their childhood or adolescence. In researching the stories of two siblings from the same family, we hope to learn about what it was like to grow up in a family with a child who was treated for cancer. We hope to learn more about the common experiences, themes, and emotions felt by most siblings in this type of situation. In interviewing and studying the experiences of siblings of children and adolescents who had cancer, more can be understood about how to help children in the future who experience a similar situation.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

Interviews

You are asked to meet with Ms. Calvert on one occasion at a comfortable location of your choice to engage in an in-depth, audio-recorded interview about your experiences as the sibling of a child or adolescent who underwent treatment for cancer. Ms. Calvert is passionate about the experiences of siblings of children and adolescents with cancer. You will be dealing with an individual who is sensitive to your experiences. Dr. Susan Lollis is a Registered Psychologist with the College of Psychologists in Ontario and can be contacted if you need to discuss the research study any further.

Your brother or sister who did not have cancer will be asked to participate in a separate in depth, tape-recorded interview about his or her experiences.
Duration

Interviews will last between 60 and 90 minutes in duration and will be scheduled at a time that is most convenient for you. Due to the sensitive nature of the topic and the length of the first interview, a second interview may be scheduled.

Research Findings

Research findings will be available to you upon completion of the thesis project in September of 2011, if so requested. All of your information will be kept confidential.

POTENTIAL RISKS AND DISCOMFORTS

The information covered in the interviews is of a personal and emotional nature and because of this you may experience some emotional or psychological distress. You have the right to leave any questions unanswered or withdraw from the study at any time if you do not feel completely comfortable participating.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR SOCIETY

As a participant, you may benefit from your involvement in this research study by having your voice heard and knowing that in sharing your experiences you are helping the social science community to better understand the needs of other children in these types of situations.

With more research in this area, we can better understand what children and adolescents are going through when they have a sibling experience cancer, as well as ways to assist them and the entire family through this process.

CONFIDENTIALITY

The data collected in this research is strictly confidential and will only be available to Ms. Laura Calvert, the research student, and her advisor Dr. Susan Lollis, and Dr. Susan Cadell who is a member of Ms. Calvert’s research committee. Audiotapes will be transcribed by Ms. Calvert or a research assistant who will maintain the strictest confidentiality. Each interview will be identified by a participant number. Names and all identifying information will be kept separate from the interview transcriptions. Both transcriptions and demographic surveys will be kept in separate locked filing cabinets and participant numbers will be used to ensure that personal information cannot be traced back to the transcribed interview. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants. All audiotapes and transcripts will be kept until publication of the research.
Participant initials _____

The three exceptions to confidentiality are as follows:

1. If information is disclosed by the participant indicating a clear risk of harm to self or others, people, services, or authorities may need to be contacted in order to protect the safety of relevant parties.
2. If there is a disclosure of child abuse, and this is clear and present threat to the safety of children, people, services, or authorities may need to be contacted in order to protect the safety of children.
3. If information regarding ongoing or past maltreatment by a professional (such as a doctor or psychologist) is disclosed, it may need to be reported in accordance with the Health Protection Act.

CONTACTS

This research has received clearance from the University of Guelph Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant you can contact the REB administration by email at reb@uoguelph.ca or by phone at (519) 824-4120, ext. 56606.

This research has also received clearance from the Wilfrid Laurier Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant, you can contact the REB Chair, Dr. R. Basso, by email at rbasso@wlu.ca or by phone at (519) 884-0710, ext. 5225.

If you have any questions or concerns about the research, please feel free to contact the research student: Ms. Laura Calvert at lcalvert@uoguelph.ca or her Faulty Advisor Dr. Susan Lollis at (519) 824-4120 ext, 53003 or slollis@uoguelph.ca

I have read the above description or have had it read to me. I am satisfied that I know the purpose of this research and the nature of my participation. I agree to participate in this study.

________________________________________   __________________________
Name (please print)     Witness (please print)

________________________________________
Signature

________________________________________
Witness Signature

__________   _________
Date       Date
DIRECT QUOTATIONS

The results of this study will be reported using quotations directly from the interview transcripts. This is done to ensure that each participant’s description of his or her experiences is portrayed in the most accurate way possible. Audio-taped interviews will be transcribed by Ms. Calvert and all identifying information will be replaced at this time with pseudonyms and code numbers. Each participant’s interview will receive a code number to identify it. Names and all identifying information will be kept separate from the interview transcriptions. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants.

I have read the above description regarding the use of direct quotations or it has been read to me. I am satisfied that my identity will remain confidential. I agree to allow Ms. Calvert to use direct quotations from my interview (You may still participate in the study if you do not allow the use of direct quotations).

______________________________  ___________________ ___________
Name (please print)     Witness (please print)

______________________________  ___________________ ___________
Signature      Witness Signature

______________________________  ___________________ ___________
Date       Date

If you would like a summary of the findings of this research when it is completed please provide your contact information below.

Mailing address:

    OR

Email Address:
Appendix E

Assent Form

(On University of Guelph Letterhead)

ASSENT TO PARTICIPATE IN RESEARCH

THE SIBLING EXPERIENCE OF CHILDHOOD AND ADOLESCENT CANCER

You and your brother or sister are asked to participate in a research study by Ms. Laura Calvert, Dr. Susan Lollis from the Department of Family Relations and Applied Nutrition at the University of Guelph, and Dr. Susan Cadell from the Faculty of Social Work at Wilfrid Laurier University. The results will contribute to Ms. Calvert’s master’s thesis project.

PURPOSE OF THE STUDY

The purpose of this research project is to develop an understanding of individuals who had a brother or sister undergo treatment for cancer during their childhood or adolescence. In researching the stories of two siblings from the same family, we hope to learn about what it was like to grow up in a family with a child who was treated for cancer. We hope to learn more about the common experiences, themes, and emotions felt by most siblings in this type of situation. In interviewing and studying the experiences of siblings of children and adolescents who had cancer, more can be understood about how to help children in the future who experience a similar situation.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

Interviews

You are asked to meet with Ms. Calvert on one occasion at a comfortable location of your choice to engage in an in-depth, audio-recorded interview about your experiences as the sibling of a child or adolescent who underwent treatment for cancer. Ms. Calvert is passionate about the experiences of siblings of children and adolescents with cancer. You will be dealing with an individual who is sensitive to your experiences. Dr. Susan Lollis is a Registered Psychologist with the College of Psychologists in Ontario and can be contacted if you need to discuss the research study any further.

Your brother or sister who did not have cancer will be asked to participate in a separate in-depth, tape-recorded interview about his or her experiences.
Duration

Interviews will last between 60 and 90 minutes in duration and will be scheduled at a time that is most convenient for you. Due to the sensitive nature of the topic and the length of the first interview, a second interview may be scheduled.

Research Findings

Research findings will be available to you upon completion of the thesis project in September of 2011, if so requested. All of your information will be kept confidential.

POTENTIAL RISKS AND DISCOMFORTS

The information covered in the interviews is of a personal and emotional nature and because of this you may experience some emotional or psychological distress. You have the right to leave any questions unanswered or withdraw from the study at any time if you do not feel completely comfortable participating.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR SOCIETY

As a participant, you may benefit from your involvement in this research study by having your voice heard and knowing that in sharing your experiences you are helping the social science community to better understand the needs of other children in these types of situations.

With more research in this area, we can better understand what children and adolescents are going through when they have a sibling experience cancer, as well as ways to assist them and the entire family through this process.

CONFIDENTIALITY

The data collected in this research is strictly confidential and will only be available to Ms. Laura Calvert, the research student, and her advisor Dr. Susan Lollis, and Dr. Susan Cadell who is a member of Ms. Calvert’s research committee. Audiotapes will be transcribed by Ms. Calvert or a research assistant who will maintain the strictest confidentiality. Each interview will be identified by a participant number. Names and all identifying information will be kept separate from the interview transcriptions. Both transcriptions and demographic surveys will be kept in separate locked filing cabinets and participant numbers will be used to ensure that personal information cannot be traced back to the transcribed interview. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants. All audiotapes and transcripts will be kept until publication of the research.
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1. If information is disclosed by the participant indicating a clear risk of harm to self or others, people, services, or authorities may need to be contacted in order to protect the safety of relevant parties.

2. If there is a disclosure of child abuse, and this is clear and present threat to the safety of children, people, services, or authorities may need to be contacted in order to protect the safety of children.

3. If information regarding ongoing or past maltreatment by a professional (such as a doctor or psychologist) is disclosed, it may need to be reported in accordance with the Health Protection Act.

CONTACTS

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This research has also received clearance from the Wilfrid Laurier Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant, you can contact the REB Chair, Dr. R. Basso, by email at rbasso@wlu.ca or by phone at (519) 884-0710, ext. 5225.

If you have any questions or concerns about the research, please feel free to contact the research student: Ms. Laura Calvert at lcalvert@uoguelph.ca or her Faculty Advisor Dr. Susan Lollis at (519) 824-4120 ext, 53003 or slollis@uoguelph.ca

I have read the above description or have had it read to me. I am satisfied that I know the purpose of this research and the nature of my participation. I agree to participate in this study.

______________________________  ___________________ ___________
Name (please print)     Witness (please print)

______________________________  ___________________ ___________
Signature      Witness Signature

_____________________________   ___________________ ___________
Date       Date
DIRECT QUOTATIONS

The results of this study will be reported using quotations directly from the interview transcripts. This is done to ensure that each participant’s description of his or her experiences is portrayed in the most accurate way possible. Audio-taped interviews will be transcribed by Ms. Calvert and all identifying information will be replaced at this time with pseudonyms and code numbers. Each participant’s interview will receive a code number to identify it. Names and all identifying information will be kept separate from the interview transcriptions. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants.

I have read the above description regarding the use of direct quotations or it has been read to me. I am satisfied that my identity will remain confidential. I agree to allow Ms. Calvert to use direct quotations from my interview (You may still participate in the study if you do not allow the use of direct quotations).

______________________________  ___________________ ___________
Name (please print)     Witness (please print)

______________________________  ___________________ ___________
Signature      Witness Signature

_____________________________   ___________________ ___________
Date       Date

If you would like a summary of the findings of this research when it is completed please provide your contact information below.

Mailing address:

OR

Email Address:
Appendix F

Parental Consent Form

Participant initials _____

(On University of Guelph Letterhead)

PARENTAL CONSENT FOR ADOLESCENT TO PARTICIPATE IN RESEARCH

THE SIBLING EXPERIENCE OF CHILDHOOD AND ADOLESCENT CANCER

Your adolescent and his or her brother or sister are asked to participate in a research study by Ms. Laura Calvert, Dr. Susan Lollis from the Department of Family Relations and Applied Nutrition at the University of Guelph, and Dr. Susan Cadell from the Faculty of Social Work at Wilfrid Laurier University. The results will contribute to Ms. Calvert’s master’s thesis project.

PURPOSE OF THE STUDY

The purpose of this research project is to develop an understanding of individuals who had a brother or sister undergo treatment for cancer during their childhood or adolescence. In researching the stories of two siblings from the same family, we hope to learn about what it was like to grow up in a family with a child who was treated for cancer. We hope to learn more about the common experiences, themes, and emotions felt by most siblings in this type of situation. In interviewing and studying the experiences of siblings of children and adolescents who had cancer, more can be understood about how to help children in the future who experience a similar situation.

PROCEDURES

If your adolescent volunteers to participate in this study, we would ask him or her to do the following things:

Interviews

Your adolescent is asked to meet with Ms. Calvert on one occasion at a comfortable location of his or her choice to engage in an in-depth, audio-recorded interview about his or her experiences as the sibling of a child or adolescent who underwent treatment for cancer. Ms. Calvert is passionate about the experiences of siblings of children and adolescents with cancer. Your adolescent will be dealing with an individual who is sensitive to your experiences. Dr. Susan Lollis is a Registered Psychologist with the College of Psychologists in Ontario and can be contacted if you need to discuss the research study any further.
Your adolescent’s brother or sister who did not have cancer will be asked to participate in a separate in depth, tape-recorded interview about his or her experiences.

**Duration**

Interviews will last between 60 and 90 minutes in duration and will be scheduled at a time that is most convenient for your son or daughter. Due to the sensitive nature of the topic and the length of the first interview, a second interview may be scheduled.

**Research Findings**

Research findings will be available to your adolescent upon completion of the thesis project in September of 2011, if so requested. All of your adolescent's information will be kept confidential.

**POTENTIAL RISKS AND DISCOMFORTS**

The information covered in the interviews is of a personal and emotional nature and because of this your son or daughter may experience some emotional or psychological distress. Your adolescent has the right to leave any questions unanswered or withdraw from the study at any time if he or she does not feel completely comfortable participating.

**POTENTIAL BENEFITS TO PARTICIPANTS AND/OR SOCIETY**

As a participant, your adolescent may benefit from your involvement in this research study by having his or her voice heard and knowing that in sharing his or her experiences, he or she is helping the social science community to better understand the needs of other children in these types of situations.

With more research in this area, we can better understand what children and adolescents are going through when they have a sibling experience cancer, as well as ways to assist them and the entire family through this process.

**CONFIDENTIALITY**

The data collected in this research is strictly confidential and will only be available to Ms. Laura Calvert, the research student, and her advisor Dr. Susan Lollis, and Dr. Susan Cadell who is a member of Ms. Calvert’s research committee. Audiotapes will be transcribed by Ms. Calvert or a research assistant who will maintain the strictest confidentiality. Each interview will be identified by a participant number. Names and all identifying information will be kept separate from the interview transcriptions. Both transcriptions and demographic surveys will be kept in separate locked filing cabinets and participant numbers will be used to ensure that personal...
information cannot be traced back to the transcribed interview. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants. All audiotapes and transcripts will be kept until publication of the research.

The three exceptions to confidentiality are as follows:

1. If information is disclosed by the participant indicating a clear risk of harm to self or others, people, services, or authorities may need to be contacted in order to protect the safety of relevant parties.
2. If there is a disclosure of child abuse, and this is clear and present threat to the safety of children, people, services, or authorities may need to be contacted in order to protect the safety of children.
3. If information regarding ongoing or past maltreatment by a professional (such as a doctor or psychologist) is disclosed, it may need to be reported in accordance with the Health Protection Act.

CONTACTS

This research has received clearance from the University of Guelph Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant you can contact the REB administration by email at reb@uoguelph.ca or by phone at (519) 824-4120, ext. 56606.

This research has also received clearance from the Wilfrid Laurier Research Ethics Board as consistent with the standards of the Tri-Council Policy Statement for Research Involving Humans (TCPS). If you have any questions regarding your rights as a participant, you can contact the REB Chair, Dr. R. Basso, by email at rbasso@wlu.ca or by phone at (519) 884-0710, ext. 5225.

If you have any questions or concerns about the research, please feel free to contact the research student: Ms. Laura Calvert at lcalvert@uoguelph.ca or her Faulty Advisor Dr. Susan Lollis at (519) 824-4120 ext, 53003 or slollis@uoguelph.ca

I have read the above description or have had it read to me. I am satisfied that I know the purpose of this research and the nature of my adolescent son’s or daughter’s participation. I agree that my adolescent son or daughter can participate in this study.

______________________________  ___________________ ___________  
Name (please print)     Witness (please print)
DIRECT QUOTATIONS

The results of this study will be reported using quotations directly from the interview transcripts. This is done to ensure that each participant’s description of his or her experiences is portrayed in the most accurate way possible. Audio-taped interviews will be transcribed by Ms. Calvert and all identifying information will be replaced at this time with pseudonyms and code numbers. Each participant’s interview will receive a code number to identify it. Names and all identifying information will be kept separate from the interview transcriptions. All portions of the transcript that Ms. Calvert will use in her thesis or future presentations or publications will use code numbers or pseudonyms, to ensure confidentiality of all participants.

I have read the above description regarding the use of direct quotations or it has been read to me. I am satisfied that my adolescent’s identity will remain confidential. I agree to allow Ms. Calvert to use direct quotations from my adolescent’s interview (Your son or daughter may still participate in the study if you do not allow the use of direct quotations).

______________________________  ___________________ ___________
Name (please print)     Witness (please print)

______________________________  ___________________ ___________
Signature                  Witness Signature

______________________________  ___________________ ___________
Date                      Date
Appendix G

Demographic Information

Information about your sibling’s cancer
Sibling Name:_________________  DOB:_________
Gender:_______________________
Age at time of cancer experience: ________________
Months/Years of cancer treatment: ________________
Did you sibling die of cancer?_____________________
Date of sibling’s death:___________________________
This sibling is my:_______________________________ sibling (please circle one)
Biological      Non-biological (please specify)________

Information about sibling’s cancer:
Type(s) of Cancer:
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________

Type(s) of Treatment:
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________

Length of Treatment:
(from diagnosis to death, diagnosis to cure, diagnosis to remission, remission to re-diagnosis, etc.)
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________

Information about Hospital and Location:
Hospital Name, Location:
__________________________________________________

Proximity of Hospital to Family Home:
__________________________________________________
Appendix H

**Family Tree and Social Supports Legend**

- Male
- Female
- Deceased Male
- Deceased Female
- Relationship
- Very Close Relationship
- Divorce
- “Rocky” Relationship (tension, fights, arguments, etc)
- Distant Relationship (existent relationship but less supportive/close)

Ideas for whom to include:

<table>
<thead>
<tr>
<th>Parents</th>
<th>Parents of your friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult friends of the family</td>
<td>Other siblings</td>
</tr>
<tr>
<td>Extended Family</td>
<td>Hospital Staff</td>
</tr>
<tr>
<td>Teachers</td>
<td>Counselor/Therapist</td>
</tr>
<tr>
<td>Child Life Specialist</td>
<td>Other</td>
</tr>
</tbody>
</table>

Appendix I
Legend:
Black = Family Members
Blue = Non-relative individuals
Appendix J

**Interview Guide**

Step 1: Consent

Step 2: Demographic information

Step 3: “When you think back to before [insert name] was diagnosed, what was your family like?”

Probes:
- Relationships
- Support
- Feelings/emotions
- Day-to-day life description

Step 4: Family and social support in **PAST** diagram

Step 5: “When you think back to when [insert name] had cancer, how do you feel it affected your life?”

Probes:
- Positive experiences  **What do you think your sibling experienced?**
- Negative experiences
- Support received
- More support needed
- Feelings/emotions
- Relationships from family diagram
- Day-to-day life description
- Siblings involvement in care

Step 6: “We are going to change our focus to what your life is like now.” Family and social support diagram for **PRESENT**

Step 7: “From you present outlook, and where you currently are in your life, how do you feel being the sibling of a child or adolescent who had cancer affects you now?”

Probes:
- Positive experiences  **What do you think your sibling experienced?**
- Negative experiences
- Counseling
• Other supports
• Feelings/emotions
• Relationships in diagram
• Changes in the diagrams from Past to Present
• Daily life effects
• Present communication

Step 8: “We are going to change our focus again, this time to what you think your life will be like in the future.” Family and social support diagram for FUTURE

Step 9: “Do you think the experience you had with your siblings’ cancer will continue to influence your life in the future and if so, in what ways?”

Probes:
• Positive experiences
• Negative experiences
• Counseling
• Other supports
• Feelings/emotions
• Relationships in diagram
• Changes in the diagrams from Past to Future, Present to Future
• Daily life effects
• future communication

Step 10: “Is there anything else you would like to tell me about your experiences as the sibling of a child who was diagnosed with cancer?”

Step 11: “Are there any issues that you feel have been overlooked during this interview?”

Step 12: “Do you have any questions before we finish?”

Step 13: “Thank-you for your time and for telling your story of being the sibling of a child who was diagnosed with cancer.”

Step 14: Resource Handout
Appendix K

Resources Handout

Thank you very much for your time. If you would like to speak to someone about this project specifically, please contact me, Laura Calvert at lcalvert@uoguelph.ca. You can also contact my thesis advisor, Dr. Susan Lollis at (519) 824-4120 ext. 53003 or by email at slollis@uoguelph.ca.

We understand that this interview could have been of a sensitive nature. If, after having completed the interview, you feel the need to discuss your experiences further with someone, the following resources are available:

**Counseling Services, University of Guelph**
Phone: (519) 824-4120 ext. 53244  
Address: 3rd Floor of the South end of the University Centre, University of Guelph  
Available Services: Counseling with professionals, by appointment; group therapy and workshops; walk in services

**McNally House**
Phone: (519) 824-4120 ext. 55002  
Address: Gordon Street, across from Axelrod, University of Guelph  
Available Services: Peer counseling over the phone or one-on-one, drop in centre: hours are Monday to Friday, from 12:00 noon until 10:00pm

**Counseling Services, Wilfrid Laurier University**
Phone: (519) 884-0170 ext. 2338  
Address: 2nd floor, Student Services Building, Wilfrid Laurier University  
Available Services: Counseling with professionals, by appointment; Crisis/Urgent appointments with professionals available; Self-help resources

**Peer Help Line, Wilfrid Laurier University**
Phone: (519) 884-7337  
Available Services: Line is staffed by student volunteers and is a support service for students, available from 7 pm to 3 am. Callers may remain anonymous

**Canadian Cancer Society- Kitchener**
Phone: (519) 886-8888  
E-mail: waterloo@ontario.cancer.ca  
Address: 241 Duke St. West, Kitchener, Ontario, N2H 3X5  
Available Services: One-on-one peer support, Peer support groups, Information services, Resources

**Canadian Cancer Society**
Phone: (519) 824-4261  
Email: wellington@ontario.cancer.ca  
Address: 214 Speedvale Ave. W, suite 4A, Guelph, Ontario  
Available Services: one-on-one peer support, peer support groups, information services
Canadian Cancer Society Support Line
Phone: 1-800-263-6750
Hours: Monday to Friday, 9:00am-5:00pm
Available Services: talk to a cancer survivor. Support available in multiple languages
Appendix L

Table L1 (Page 1)

A sample of Themes from Family 3, Participant 2

<table>
<thead>
<tr>
<th>At the beginning of the illness she held in her feelings to help her family</th>
<th>Cancer is a family diagnosis</th>
<th>Experience of frustration</th>
<th>Experience of sadness</th>
<th>Experience of happiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>She held her feelings in because she didn’t want to burden her already stressed out parents</td>
<td>Cancer is a family diagnosis</td>
<td>When she was not busy in the past she was scared, sad, and frustrated</td>
<td>After her sister died, it was confusing, sad, and hard</td>
<td>Presently is happy that they had her sister for almost 16 years</td>
</tr>
</tbody>
</table>

| At first she held in her feelings because she thought it was more important to be positive for her sister | It was a big change when her sister was diagnosed with cancer | Experienced frustration when people told her that ‘time will heal’ her pain | She misses her sister every day | She is able to be happy now because she knows her sister would want her to live a good life |

| While at Camp Trillium’s family camp, it felt like she had a normal family again (family was not normal other times) | After her sister died she was angry and frustrated when people tried to talk to her | Has learned to live with the sadness of missing her sister | Presently feels lucky to have a good support system of friends |

| The kids spent a lot of time visiting or calling their sister in the hospital | She was frustrated because the illness kept getting worse and it wasn’t fair | It was so sad seeing her sister die that it doesn’t even seem real | Presently there are more good days than bad days |

| | | Expects to miss her sister every single day because she will never ‘get over it’ | Thinks she will continue to have more good days in the future but that there will always be bad days |

<p>| | | She is proud of herself for learning to be happy again | |</p>
<table>
<thead>
<tr>
<th>Experience of emotional difficulties after her sister died</th>
<th>Experience of fear</th>
<th>It was upsetting to see her sister in pain and to watch her body deteriorate</th>
</tr>
</thead>
<tbody>
<tr>
<td>It took 4 years after her sister died for her to be happy again</td>
<td>She was scared in the past that her sister would be in pain or would be upset</td>
<td>She was scared in the past that her sister would be in pain or would be upset</td>
</tr>
<tr>
<td>After her sister died, it was confusing, sad, and hard</td>
<td>In the past she was afraid that if she talked to her mom, she would find out something bad about her sister</td>
<td>Wished their family could split up the burden of cancer so her sister didn’t have all the pain</td>
</tr>
<tr>
<td>After her sister died she was angry and frustrated when people tried to talk to her</td>
<td>Was and is still scared that she will start forgetting things about her sister</td>
<td>She was scared of how her sister would feel during the treatment</td>
</tr>
<tr>
<td>After her sister died it has hard to figure out how to live without her</td>
<td>Was scared of how much worse things might get during the illness</td>
<td>She was frustrated because the illness kept getting worse and it wasn’t fair</td>
</tr>
<tr>
<td>After her sister died she distanced herself from her family</td>
<td>She was scared of how her sister would feel during the treatment</td>
<td>It was upsetting to see her sister in pain</td>
</tr>
<tr>
<td>After her sister died she didn’t want to do the things she used to do with her sister</td>
<td>When she was not busy in the past she was scared, sad, and frustrated</td>
<td>It was upsetting seeing/hearing her sister be sick</td>
</tr>
<tr>
<td>It seemed unnatural to live without her sister</td>
<td>Her biggest fear about the future is that she will lose someone else that she loves</td>
<td>It was hard to see her sister weak</td>
</tr>
<tr>
<td>Experienced frustration when people told her that ‘time will heal’ her pain</td>
<td>Thinks she will continue to fear losing another loved one</td>
<td>It was hard to see her sister’s body deteriorate</td>
</tr>
<tr>
<td>It was upsetting to her that her sister won’t be there for her major life events (like her wedding)</td>
<td>She was left alone with her sister once and it scared her because she didn’t know what to do</td>
<td></td>
</tr>
<tr>
<td>In the past she thought she should be miserable after what happened</td>
<td>Cancer was a scary word in the past</td>
<td></td>
</tr>
</tbody>
</table>
Table L2

A Sample of the Cluster of Themes from Family 3, Participant 2

<table>
<thead>
<tr>
<th>Experience of emotional difficulties</th>
<th>Considers her sister a cancer survivor because she never let the illness change her personality</th>
<th>Continuity of closeness of relationships</th>
<th>Became closer to peers who had also lost someone to cancer</th>
<th>Received a lot of support from family and extra-familial sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>At the beginning of the illness, she held in her feelings to help her family</td>
<td>The sister who had cancer did not let cancer change her personality</td>
<td>The family was close before her sister got sick</td>
<td>Friendships changed when her sister was diagnosed</td>
<td>Received support from extra-familial sources</td>
</tr>
<tr>
<td>It was upsetting to see her sister in pain and to watch her body deteriorate</td>
<td>Considers her deceased sister a cancer survivor</td>
<td>Was closest to the sister who got cancer in the past</td>
<td>Became close to her sister’s friends during the illness</td>
<td>Received high levels of support from her family during the illness</td>
</tr>
<tr>
<td>It was hard to deal with the changes in family structure when her sister died</td>
<td>Relationships within the family stayed the same when her sister got sick</td>
<td>close to people who have also experienced cancer</td>
<td>Going to Camp Trillium was a positive experience</td>
<td></td>
</tr>
<tr>
<td>Experience of emotional difficulties after her sister died</td>
<td>Continuity of closeness with parents</td>
<td>She will always have the friends she made during her sister’s illness</td>
<td>Acting like a kid at Camp Trillium and Sick Kids Hospital made things feel more normal</td>
<td></td>
</tr>
<tr>
<td>Cancer is such a negative experience that no one should have to go through it</td>
<td>Continuity of closeness with the sister who had cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of frustration</td>
<td>Continuity of closeness with sister</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of sadness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of fear</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>