WHICH SIBLINGS OF CHILDREN WITH CANCER ARE BEST HELPED BY PARTICIPATING IN A SPECIALIZED INTERVENTION PROGRAM?

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
Graduate Department of Institute of Medical Science
University of Toronto

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Abstract

To understand why some SCC experience psychological distress while others do not, researchers have turned their attention to potential protective factors that may influence the ability of SCC to cope with the cancer experience. Provision of protective/buffering factors specifically to less-resilient siblings (defined as those with higher initial depression and anxiety symptom scores) in the form of a structured program has not been previously attempted. The objective of this study was to explore outcomes of a specialized 8 week, intervention program for SCC. SCC and one parent completed standardized questionnaires exploring symptoms of depression and anxiety pre and post intervention. Results showed that the gender of the SCC, and the specific diagnosis of the child with cancer were factors significantly associated with the degree of reported symptoms of anxiety and depression respectively. Looking at significant interactions, we found that girls whose siblings had brain tumours improved less than other subgroups
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CHAPTER 1

Introduction
Childhood cancer is the second leading cause of death in North American children, second only to accidents (Canadian Cancer Society, 2009). Children who are diagnosed with cancer face many stressors and demands, such as repeated hospitalization, and painful treatments (Houtzager, Grootenhuis, & Last, 1999). Considering the fact that these children do not live in a vacuum, the diagnosis of childhood cancer is a devastating experience for all members of a family (Dolgin et al., 1997). Siblings are particularly vulnerable, especially as some professionals have suggested they are the most emotionally disregarded and distressed of all family members (Chesler & Barbarin, 1991; Heffernan & Zanelli, 1997; Murray, 1995, 1998, 2000; Spinetta, 1981). This claim has been supported by numerous reviews and a meta-analysis examining the psychological distress experienced by siblings of children with cancer. These concluded that although most siblings of children with cancer do not suffer from severe psychopathology, some experience significant psychological distress (Barlow & Ellard, 2006; Houtzager et al., 1999; Sharpe & Rossiter, 2002; Williams, 1997).

Psychological distress can be defined as an upsetting or aversive feeling, with symptoms of depression and/or anxiety that do not meet criteria for psychopathology as defined by the Diagnostic and Statistical Manual of Mental Disorders-Fourth edition (DSM-IV-TR)(American Psychiatric Association [DSM-IV-TR], 2000). Researchers postulate symptoms of anxiety and depression to be the most disruptive and longest lasting emotional responses to the cancer experience (Carpenter & Sahler, 1991; Barbarin, Sargent, Sahler, & Carpenter, 1995). Thus, for the purpose of this study, psychological distress was defined as symptoms of anxiety and depression and these symptoms served as outcome variables for this study.
Anxiety and Depression

Prevalence of Symptoms of Anxiety and Depression in Siblings as Compared to the General Population

Kovacs and Spielberger reported that approximately 7% of children and adolescents in the general population experience clinically significant levels of depression or anxiety. In contrast, Kovacs (1992) and Spielberger (1983) reported that 8% and 15% of siblings of children with cancer (SCC) experienced clinically significant levels of depression and anxiety, respectively. These results indicate that compared to the general population, SCC experience equivalent levels of depression, but more symptoms of anxiety. These outcomes are based on self-report measures by SCC. Achenbach (1991) found that when parents were the informants for reporting symptoms of depression and anxiety, 30% of parents reported that their sons/daughters experienced borderline or clinical levels of internalizing behavior problems such as symptoms of anxiety and depression. Out of the 30% of parents, 19% reported that the symptoms were clinically significant. This is significant although it is important to understand that clinical pathology will not be the focus of this study.

Symptoms of Anxiety in the General Population

Anxiety in children and adolescents has been defined as the presentation of symptoms of irrational fear and worry that is out of proportion to threats from the environment, and is usually associated with the anticipation of future events (Roth & Argyle, 1998). High levels of anxiety may be incapacitating because they disrupt concentration and performance, and can interfere with every aspect of life.

1) Siblings of children with cancer
Not only do children and adolescents with symptoms of anxiety have difficulties concentrating, but their cognitive process can be overwhelmed with pervasive negative thoughts such as, “what if something bad happens to me at school today?” (Roth & Argyle, 1998). These consistent negative thought and excessive worrying can be truly debilitating (Roth & Argyle, 1998)

Anxiety disorder can manifest in a number of ways. Excessive worrying, a common symptom, has been described as an uncontrollable sequence of pessimistic and negative thoughts associated with future perceived threats and harm (DSM-IV-TR, 2000). Anxiety can manifest as post traumatic stress – a stress reaction to an upsetting event that may be out of proportion to the severity of the event. Anxiety can manifest as phobia. Phobias are irrational narrowly defined fears associated with specific objects or situations which one tries to avoid (DSM-IV-TR, 2000). A child or adolescent with a phobia tends to avoid contact with the source of the fear in the hope of preventing intense anxiety. Children can suffer from generalized anxiety disorder, which according to DSM-IV-TR, includes “free floating anxiety” plus at least one of the following: 1) restlessness, 2) easy fatigue, 3) difficulty concentrating, 4) irritability, 5) muscle tension, 6) sleep disturbance (DSM-IV-TR, 2000). It should be mentioned that these symptoms may overlap with one another and not present individually.

Many factors can lead to the manifestation of symptoms of anxiety; however, a stressful life event appears to play a major role in the onset of such symptoms (Roth & Argyle, 1998). Since cancer in the family is, by definition, a stressful life event, it was explored as the potential anxiety provoking factor in this study.
Symptoms of Anxiety in Siblings of Children with Cancer

Murray’s (2000) literature review described childhood cancer as a stressful life event that escalates feelings of anxiety in siblings of children with cancer (SCC). Feelings of anxiety expressed by SCC may manifest as phobias associated with the cancer experience. It is very common for SCC to form the belief that cancer is contagious; this is especially true for younger siblings (<11 years of age) (Murray, 2000). Such children are afraid of catching the disease and being infected and so avoid all contact in the hope of preventing contamination. Feelings of anxiety in SCC may be expressed as excessive worrying. The unpredictability of the disease, treatment and prognosis creates great concern for these children, and, as a result, SCC worry excessively about their ill brother or sister’s condition (Murray, 2000). Many worry that their brother/sister will deteriorate and express fears about the possibility of their brother/sister dying (Murray, 2000). Moreover, it is extremely difficult for SCC to stand by and watch as their brother/sister is being treated at the hospital. Such passive observance tends to escalate their worries (Murray, 2000). This may be the reason why some parents refuse to take their healthy children to the hospital and, instead, opt to shelter them from the realities of the cancer experience (Murray, 2000). However, not taking the sibling to the hospital may be worse as children have vivid imaginations and can manufacture unrealistic stories of what is happening at the hospital. These inaccurate thoughts may be strengthened when they see their brother/sister looking ill (Murray, 2000). Seeing their bother/sister sick and not understanding why confirms their assumption that awful things happen at the hospital. This not only escalates their worries but may even lead to phobias associated with the hospital and healthcare professionals (Murray, 2000). Such stressors faced by SCC may
enhance whatever vulnerability they have to symptoms of anxiety. Because they are common, symptoms of anxiety was chosen as one of the primary outcome measures for this study and was measured using the State Trait Anxiety Inventory for Children (STAIC).

**Depression in the General Population**

Many children and adolescents with anxieties also feel depressed and, similarly, many who feel depressed are also anxious (Monroe & Simons, 1991). Depression is defined by emotional, cognitive, and behavioural symptoms. Symptoms of depression usually encompass feelings of profound sadness, fatigue, loss of energy, difficulty sleeping and changes in appetite (DSM-IV-TR, 2000). Depression also involves other cognitive and behavioral symptoms such as extreme guilt, feelings of worthlessness, concentration problems and even thoughts of suicide, or attempts at suicide (DSM-IV-TR, 2000). Although many kinds of stressful events can lead to the onset of depression, it is loss events (of significant people or roles) which seem to play the greatest role in precipitating depressive symptoms (Monroe & Simons, 1991). In summary, symptoms of depression may be emotional, cognitive or behavioural and are usually precipitated by a stressful event. Given that the experience of cancer in the family is considered to be a stressful life event and may include losses, I will now explore symptoms of depression in SCC.

**Symptoms of Depression in Siblings of Children with Cancer**

The cancer experience may be extremely stressful for siblings. A major reoccurring concern for SCC is the reduction of parental attention (Bendor, 1990; Chelsey, Allesewede, & Barbarin, 1991; Sargent, Sahler, Roghmann, & Mulhern, 1995; Shapiro &
Brack, 1994; Sloper, 2000). During this difficult time, the parents’ attention is mainly focused on the ill brother/sister, creating an imbalance of parental attention (Dolgin, et al., 1997). This imbalance of attention may place SCC at risk for symptoms of depression, as SCC’s emotional and social needs may not be fully addressed by their parents at this time (Dolgin et al., 1997). Moreover, SCC may spend more time with parental substitutes such as grandparents and neighbours (Freeman, O’Dell & Meola, 2000; Iles, 1979; Kramer, 1984). Due to changes in caretakers and reduced attention, many siblings have reported feeling like the “forgotten ones” (Spinetta, 1981; Chesler, Allswede & Barbarin, 1991). SCC have often also reported missing their parents, and some have even believed that their parents no longer love them as they experience the lack of attention, favoritism towards the ill child and (Haverman & Eiser, 1994) and decreased tolerance on the part of parents (Kramer, 1984).

Although some siblings may understand why their ill brother/sister is overindulged with gifts and attention, a sense of jealousy may be difficult to deny and suppress (Chesler, et. al., 1991; Haverman & Eiser, 1994). Consequently, SCC have often been reported to present with feelings of anger (Dolgin, et al., 1997), teasing, and clowning (Barrera, Chung, Greenberg, & Fleming, 2002) and somatic complaints (Carpenter & LeVent, 1994; Haffernan & Zanelli, 1997). These behaviours may be rooted in reduced parental attention and have been classified as attention seeking behaviour (Sindu, et al., 2006).

SCC encounter other changes in addition to lack of parental attention which may make this experience even more difficult. Very often SCC have to sacrifice social programs in order to accommodate the ill child and many miss the life they used to have
before the diagnosis (Houtzager et al., 2004). Family outings often decrease after a cancer diagnosis, further compounding feelings of loneliness and isolation (Madan-Sawin, Sexson, Brown, & Ragab, 1993). SCC’s feelings of loneliness, sadness, isolation and unimportance have been reported in several studies (Chesler, et al., 1991; Sloper, 2000) and these feelings have been linked to low self-esteem and internalized hostility sometimes manifesting as depression (Bendor, 1990).

Not only do SCC perceive themselves as unimportant, they also have to endure extended separations from their ill brother/sister. This separation is very difficult as they have often been reported to miss their playmate and companion (Sloper, 2000). In addition, SCC also worry that their brother/sister could die, further compounding their symptoms of depression (Nolbris, 2007). Nolbris discovered that siblings experience anticipatory grief as soon as the diagnosis is made (2007). In addition to feeling anticipatory grief, depending on their age, some siblings may even believe they were the cause of the illness and, as a result, feel great guilt (Bendor, 1990). Given that some of SCC perceive themselves to be alone and have no one to talk to about their feelings, coping with the situation becomes even more difficult (Murray, 1998). This lack of expression of feelings may potentially lead them to withdraw from others and become increasingly depressed (Bendor, 1990; Chesler, et al., 1991; Martinson, et al., 1990; Murray, 1998). In summary, there is evidence suggesting that some SCC experience symptoms of depression when dealing with their sibling’s cancer and, for this reason, symptoms of depression was chosen as one of the outcome variables for this study and was measured using the Children’s Depression Inventory (CDI).
**Changes over Time**

Most SCC have been reported to experience psychological distress during the first year after diagnosis (Sahler, Roghmann, Carpenter & Mulhern, 1994). For instance, a large collaborative study found that 63% of SCC experience psychological distress during the initial phases of the cancer diagnosis (Sahler, Roghmann, Carpenter, & Mulhern, 1994). However, another study reported that one-quarter of siblings exhibit psychological distress 6 months post diagnosis (Sloper & While, 1996). Again, a more recent study reported that symptoms of depression were evident in SCC years after their brother/sister had been successfully treated for cancer (Woodgate, 2001). This finding is congruent with Houtzager et al.’s study which found that a subgroup of SCC suffered from psychological distress two years after a brother or sister had been diagnosed with cancer. In addition to psychological distress, Houtzager et al., (2004) found that SCC reported lower quality of life (QoL) than their peer group. Quality of life is defined as one’s well-being across multiple life domains, such as physical, emotional, and social (O’Connor, 1993). The QoL finding emphasizes the global ramifications of the cancer experience (Houtzager, et al., 2004). In summary, the literature suggests that SCC psychological distress improves as time passes; however, there are also studies that demonstrate psychological distress two years after the sibling’s cancer has been treated. This inconsistency of findings about duration of symptoms warrants further investigation.

**Siblings Compared to the Ill Child**

Not only have SCC reported increased psychological distress when compared to the norm, but in some studies they have even reported more distress than the ill child
For example, siblings of children who had undergone aggressive and highly risky stem cell transplantation reported lower perceived quality of life and more internalizing problems than the ill child (Barrera & Atenafu, 2007). To further emphasize siblings’ vulnerability, Post Traumatic Syndrome (PTS) in siblings whose affected brother/sister had completed treatment over 5 years earlier was reported as moderate to severe in 32% of siblings, just below the reported rate for mothers (40%), but above the rates for survivors (14%) (Alderfer, et al., 2003). Furthermore, in an earlier study, Cairns and colleagues found siblings’ level of anxiety to be greater or similar to their ill brother’s/sister’s (Cairns, Clark, Smith & Lansky, 1979). In summary, these studies indicate that some SCC may even experience more psychological distress than the ill child. The reasons behind such findings need further exploration.

Positive Experiences and Outcomes

Although the literature shows that some SCC experience psychological distress, about 75% appear to cope well with the cancer experience (Taylor, 2001; Sloper & While, 1996) and some studies report no psychological difference between siblings and controls (Horwitz & Kazak, 1990). For instance, Horwitz and Kazak reported that SCC and controls do not differ on any measures of depressive or anxiety symptoms. (Horwitz & Kazak, 1990).

Some researchers have even pointed to positive outcomes from the sibling cancer experience. In an exploratory qualitative study, Kramer (1981) identified SCC with increased sensitivity and empathy for their brother/sister, and this increased empathy extended to others. This finding is congruent with that of other researchers who report
SCC’s increased compassion and empathy for both parents and ill siblings (Barbarin, et al., 1995). Kazak and Nachman found that SCC mature at a faster rate than controls, and perceive themselves as more independent (Kazak & Nachman, 1991). This independence and maturity may be a result of SCC receiving less parental attention, and in turn, becoming more self-sufficient. Alternatively, increased maturity may come from parents and families expecting and demanding that SCC perform more household tasks and be more involved in the caring of the ill sibling (Chelser, et al., 1991; Freeman, et al., 2000; Sloper, 2000).

Some improvements in family life have also been noted. In the midst of the turmoil, many siblings report a greater appreciation for their family and for the fragility of life (Haverman & Eiser, 1994). For instance, some SCC report greater family closeness and cohesion and an increase in the quality of time spent with their family (Chelser, et al., 1991; Kramer, 1984; Sloper, 2000).

Clearly, these findings indicate that there is considerable variability in SCC’s response to cancer. Factors that influence psychological distress in SCC need to be further researched. Cancer in a sibling may be best understood as a risk factor, one among many other personal, disease and family factors. For this reason, the next section will look at potential risk factors for psychological distress

**Risk Factors and Predictors for Psychological Distress**

In trying to understand why some SCC experience psychological distress while others do not, researchers have identified some factors of potential influence. Since SCC do not live in a vacuum, it is important not only to consider personal psychological factors but also socio-environmental factors such as family issues and disease-specific
and treatment-specific factors. In this study, the variables that were explored as correlates of SCC’s adaptation are: age and gender; family factors (birth order relative to the ill child) and the ill child’s clinical factors (type of cancer and time elapsed since diagnosis). These variables have been reported in the literature as risk factors or predictors of psychological distress e.g. symptoms of anxiety and depression. For this reason, they were further examined in this study.

**Individual Risk Factors for Psychological Distress**

SCC characteristics such as age and gender have been investigated as potential risk factors or as predictors of vulnerability for symptoms of anxiety and depression.

**SCC’s Age**

*Younger siblings and extended separation from parents*

Age appears to influence the onset of symptoms of depression and anxiety. As a child matures, his or her ability to cope with the experience of cancer in a sibling changes (Murray, 1995). Although findings have been inconclusive, in general, younger siblings (<11 years of age) may be the most affected. This is because they are ill-equipped to endure the extended separation from parents that is frequently necessary (Murray, 1995; Spinetta, 1981). To young SCC, extended separation from the primary caretaker is extremely anxiety-provoking because they lack the cognitive ability to understand why the separation is occurring. Their concept of time is not yet developed, and they may not understand that, though temporarily absent, their parent(s) will return (Murray, 2000). Young SCC may interpret such separation from parents as rejection (Sindu, et al., 2006).

Another factor that may make younger SCC more prone to psychological distress than older SCC is their almost total dependence on their parents for emotional and social
support (Hamama, et al., 2000). If parents are absent taking care of the ill child, their absence may be detrimental to the personal and social development of the SCC (Hamama, et al., 2000). Researchers believe that this absence may be the fundamental cause of symptoms of depression and may lead to impairment of attachment (Murray, 2000). In an attempt to regain parental attention, siblings 6-12 years of age have been reported to display externalizing behaviour problems as well as somatic complaints and anger (Bendor, 1990; Sahler, et al., 1994; Sargent, et al., 1995).

**Younger SCC and cancer-related knowledge**

Another reason why younger SCC may experience relatively greater psychological distress is their lack of cancer-related knowledge. For instance, some younger SCC believe they have caused the ill child to become sick (Binger, et al., 1969; Cain, Fast, & Erickson, 1964; Iles, 1979). Younger SCC lack a sense of causality and may think that their thoughts and wishes led to their sibling’s illness (Flavell, Miller & Miller, 1993). Not only do younger SCC lack knowledge about the cause of disease, they have also been reported to lack the cognitive skill to appreciate the prognosis of a cancer diagnosis (Houtzager, et al., 2001). For example, it has been reported that younger SCC come to their own conclusions about what is happening or what will happen in the future to their ill sibling. They may believe, erroneously, that their brother/sister will not survive (Sahler & Carpenter, 1991). Furthermore, SCC have been reported to nurse irrational fears about catching the illness (Houtzager, et al., 2001). Houtzager and colleagues suggest that these irrational fears and inaccurate conclusions may develop because they receive inaccurate or incomplete information about cancer (Houtzager, et al., 2001). These distorted and inaccurate ideas may cause a great burden of guilt, shame and other
internalized feelings, including symptoms of anxiety and depression (Sahler & Carpenter, 1991). In summary, younger SCC’s lack of cancer-related knowledge make them more prone than older SCC to psychological distress.

**Younger SCC and social and instrumental support**

With respect to social development, younger SCC are at a disadvantage. Changes in family dynamics and routines may limit younger SCC’s exposure to peers. Instead of interacting with their peers, these SCC may now be confined to the home, with limited socialization opportunities (Murray, 2000). This isolation can affect their sense of belonging, and in turn, intensify their symptoms of loneliness and lead to symptoms of anxiety and depression (Havermans & Eiser, 1994; Kramer, 1981; Murray, 2000). This possibility is exemplified in a study that reported that younger primary school aged SCC (7-11 years of age) exhibited greater state and trait anxiety than older school aged SCC (11-17 years) three months after cancer diagnosis (p=0.003) (Lähteenmäki, 2004). The author proposes that younger primary school age SCC increased symptoms of anxiety may stem from the lack of parental attention during the treatment period. In addition to social supports, younger SCC may also require greater instrumental supports than older SCC. These include help with daily activities such as feeding, bathing, and transport to and from school, as well as help with after school activities (Murray, 2002).

Thus, based on the aforementioned studies, young SCC (<11 years of age) may be more prone to psychological distress than older SCC due to lack of social and instrumental support.
Adolescent SCC

Adolescent SCC are likely to have enhanced coping skills and established peer groups, factors that may help them cope. By this stage in life, most adolescents have the cognitive ability to understand the meaning of a cancer diagnosis. They are better able to appreciate their ill brother’s/sister’s condition, the treatment, the prognosis and the effect on the family (Murray, 2000). Adolescents also have the ability to think abstractly and plan for the future (Houtzager, et al., 2004). This ability may allow them to understand the possible long-term implications of a cancer diagnosis (Houtzager, et al., 2004). For this reason, older SCC are usually more resilient to the experience of cancer in the family than younger SCC. For instance, adolescents reportedly display greater levels of empathy, maturity and self-esteem than younger children, possibly due to the increased trust and responsibility given to them by their parents (Chesler, et al., 1991; Sargent, et al., 1995).

Nevertheless, studies have shown that such traits do not rule out the emotional impact of cancer in a sibling and many adolescent SCC do experience psychological distress. One study reports that some adolescents deliberately choose to conceal psychological distress (Houtzager, et al., 2001). This finding is congruent with a recent study by our research team which found that SCC aged 11 to 18 years tend to ‘mask’ and deny their feelings (Barrera, et al., 2004). It has been reported that such behaviour may serve a function e.g. they may lessen the distress of parents (Bendor, 1990; Carpenter & Sahler, 1991). However, it has been suggested that this lack of openness about distress may increase the symptoms of anxiety and depression (Houtzager, et al., 2001).
In summary the literature suggests that younger age may be a risk factor for psychological distress in SCC. This statement is supported by Lähteenmäki’s, (2004) study which specifically looked at older vs. younger siblings and reported that younger SCC experience greater psychological distress. In consideration of this finding and other studies reported above, age was further explored in this study.

**SCC’s Gender**

Research has identified SCC gender as a crucial factor in influencing psychological adjustment. It has been demonstrated that females experience higher rates of psychological distress such as loneliness than do males (Woodgate, 2001). Recent results from our research team have confirmed this finding, indicating that adolescent female SCC are at greater risk for developing symptoms of depression, and anxiety than adolescent male SCC (p<0.05) (Barrera, Chung & Fleming, 2004). In general, adolescents go through many physical and emotional changes. Adolescent SCC females undergo the same physical and emotional changes as other females, but, are additionally burdened with cancer-related stressors (Sargent, et al., 1995). In the absence of their mother (mother is usually caring for the ill child), female SCC report increased household responsibilities and greater involvement in caring for other siblings, including the ill child (Sargent, et al., 1995). These stressors may further disrupt their everyday routine (Sargent et al., 1995) and may make them more susceptible to symptoms of depression and anxiety (Woodgate, 2001). To emphasize female siblings’ vulnerability, one study found female SCC to be more susceptible than male SCC to symptoms of post traumatic stress (PTS) (Alderfer, et al., 2003). Since female SCC reportedly tend to the ill child more than male SCC, this responsibility exposes them more directly to the trauma of having cancer,
placing them at relatively greater risk for the symptoms of PTS (Alderfer, et al., 2003). Moreover, males when compared to females are generally given more freedom to socialize, which may buffer against psychological distress as evidenced by anxiety and depression symptoms (Alderfer, et al., 2003).

In summary, the literature suggests that female SCC are more susceptible to developing psychological difficulties than male SCC. However, although studies have utilized large sample sizes and standardized questionnaires and found, in general, females experience more psychological distress, empirical findings are limited and somewhat contradictory. Thus, in this study, the effect of gender was further studied.

**Ill Sibling’s Clinical Risk Factors**

Clinical factors such as type of cancer and time elapsed since diagnosis has been investigated as factors influencing psychological distress in SCC.

**Type of Cancer Diagnosed**

There is evidence to suggest that SCC of children with brain tumours have greater difficulties adapting than SCC of children with other types of cancers (Houtzager, et al., 2001, Massie K & Barrera, M., 2010; Novakovic, 1994). These SCC express concerns about the late effects of invasive treatments for brain tumour on their brother’s/sister’s personality and behaviour. Such worries may increase their risk for symptoms of anxiety and depression (Houtzager, et al., 2001). Furthermore, well publicized survival rates may cause anxiety. The 5-year survival rate for brain tumours is known to be about 70%, whereas leukemia and lymphoma survival rates are 80% and 93% respectively (International Classification of Childhood Cancer, 2011). This means that SCC of siblings with brain tumours have to cope with the grim uncertainty about their sibling’s
survival (Novakovic, 1994). Their distress appears to be more deeply entrenched. Houtzager et al., (2001) found that anxiety in SCC of children with leukemia and lymphoma decreased significantly more after group participation when compared to siblings of children with brain tumours. This study demonstrates that the type of cancer diagnosed appears to have a significant effect on intervention effects as measured by differential anxiety scores.

In summary, based on the aforementioned studies, especially Houtzager’s (2004) study that reported siblings of children with brain tumours may be relatively more prone to psychological distress, this association was further examined in this study.

**Time since Diagnosis and Hospitalization Length**

Time since diagnosis is another clinical factor which may play a role in the psychological distress of SCC (Houtzager, 2004). In general, the psychosocial distress of SCC is more pronounced in earlier stages of cancer treatment than in later stages (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Hamama et al., 2000, Sharpe, 2002). In fact, emotional or behavioural problems among SCC rose from 7.7% to 18% shortly after diagnosis (Sahler, 1997). Later stages can be anxiety-provoking only if there are uncertainties related to extended treatments, if the sibling has relapsed, or if there are late or long-term side effects (Alderfer, et al., 2003; Lown, et al., 2008).

Another factor related to time since diagnosis is duration of hospitalization. It has been reported that the longer the sick child is hospitalized, the more disrupted family life becomes (Sloper & While, 1996). Parents understandably spend many hours in the hospital with the ill child. However, in most cases, one parent, most often the mother, stays at the hospital to care for the ill child. These frequent and prolonged stays interfere
with SCC’s contact with their mother leading to negative effects (Sloper & While, 1996). For instance, siblings report that their family is ‘disjointed’ because half of their family members are at the hospital and the other half are at home (Sloper & While, 1996). Furthermore, prolonged separations may create a shift in the family structure which necessitates a change in the roles and responsibilities of each member. Often SCC have to take on greater responsibilities within the household, including performing additional chores and becoming caregivers for younger children (Dolgin, et al., 1997; Nolbris, Enskar, & Hellstrom, 2007). These changes may be difficult for SCC, especially considering the fact that they are navigating through emotional waters. Some researchers postulate that this change experienced by SCC leads to symptoms of anxiety and depression which, in turn, cause SCC to further withdraw from family members and peers, again exacerbating their symptoms (Hamama, et al., 2000)

On the other hand, some researchers have examined the impact of the diagnosis and time since diagnosis of the child with cancer on sibling adjustment and found no significant difference when these factors were examined (Houtzager, et al., 1999). For example, diagnosis, and time since diagnosis were not associated with psychological distress in siblings, as reported by parents on standardized questionnaires (Sahler et al., 1994). Similarly, utilizing standardized questionnaires, Cohen and colleagues (1994), Hamama and colleagues (2000), and Sloper and While (1996) found no relationship between diagnosis and sibling’s level of psychological distress

In summary, the sick child’s clinical factors appear to be associated with SCC’s adjustment to their sibling’s cancer. However, literature pertaining to this relationship is varied and inconclusive. This may be because time since diagnosis varies between
studies and no standardized period is indentified. Moreover, some studies investigate psychological distress at only one point, usually after diagnosis, and researchers cannot determine whether adjustment difficulties remain constant or decrease over time. Since more research is needed to examine such factors, this study explores the association between psychological distress and time since diagnosis as well as type of cancer.

**Family Risk Factors**

There are many family factors that have been studied as potential correlates of adjustment problems in SCC such, parental education, number of siblings in the family and family income. However, for the purpose of this study, SCC birth order relative to the ill child was the only factor examined. Other family factors have not been consistently mentioned as risk factors in the existent literature.

**Birth Order**

SCC younger than the child with cancer are more prone to adjustment difficulties than SCC who are older than the ill child (Bucherbinder, Casillas, Krull, Goodman, & Leisenring, 2010). As already mentioned, younger SCC are more likely to be negatively affected by the cancer of their older sibling because their emotional, social, and instrumental needs may be unmet by distressed and often absent parents (Bucherbinder, et al., 2010). On the other hand, SCC who are older than the ill child exhibit more behavioural, social, and academic problems than earlier born SCC (Labay & Walco, 2004). Earlier born SCC can be prone to psychological distress because of the increase in responsibilities and expectations placed on them as parental attention shifts to the care of a younger child with cancer (Labay & Walco, 2004). Oftentimes these SCC are expected to perform caretaker tasks for their later-born siblings, such as cooking for them (Dolgin
et al., 1997; Nolbris, Enskar, & Hellstrom, 2007), or other chores and household tasks (Barrera et al., 2002; Houtzager, et al., 2004; Labay & Walco, 2004).

Birth order interacts with gender. For instance, female SCC who are younger than the ill child reported higher rates of loneliness than female SCC older than the ill child. (Sahler, et al., 1994). Older females tend to be given more responsibilities in caring for the sick child, and in the discharge of other family duties than younger females. This can be protective in that it allows older female SCC greater involvement with family affairs thus, decreasing their sense of loneliness (Houtzager et al., 2004).

In summary, the aforementioned studies suggest that female SCC who are younger than the ill child may be more prone than those who are older to psychological distress. Because of the lack of consistency and shortage of studies in this area, however, the association between SCC’s birth order relative to the ill child and SCC’s adjustment to the cancer experience was explored in this study.

**Group Intervention Programs**

In order to prevent psychological distress in SCC, many attempts have been made to design intervention programs to meet the needs of this population. These intervention programs vary in setting (group sessions, summer camps), and duration (five, six and eight weeks), (Heiney, et al., 1990; Dolgin, et. al., 1997; Houtzager, et al., 2001; Adams-Greenly, et al., 1987). However, many of these programs have not been evaluated with standardized measures or validated in other groups. Many studies have been qualitative, descriptive and correlational using anecdotal data (Prchal & Landolt, 2009). As reported in a 2009 systematic review, 62% of psychological interventions for SCC had to be excluded from consideration because outcome measures were not standardized and
validated (Prchal & Landolt, 2009). Moreover, none of the studies utilized structured sessions developed in accordance with the recommendations of the American Psychological Association (APA), nor did they meet criteria for empirically supported interventions as per the Chambless & Holland guidelines (1998). Chambless & Holland posit that an empirically supported intervention program should be manualized and structured to ensure fidelity and replicability (Chambless & Holland, 1998). Two family cancer interventions, Williams (2003) and Kazak (2005) attempted to address this gap but neither of these programs was designed exclusively for SCC.

Although Kazak’s intervention followed a structured manual, it was a weekend program designed for all family members of cancer victims. SCC were included but the program was not designed exclusively for them (Kazak, et al., 2005). On the other hand, Williams’ intervention program was a summer camp for siblings of children with a variety of chronic condition including cancer (Williams, et al., 2003). Consequently, the effectiveness of such programs for SCC remains unclear.

Preliminary Studies by our Research Team

To address the gap in the intervention field, Dr. Barrera, my supervisor, and her team developed an evidence-based manualized intervention exclusively for SCC, entitled Siblings Coping Together (SibCT) designed in accordance with the American Psychological Association guidelines for psychological interventions (Chung, Miranda, Fleming & Barrera, 2004).
Theoretical Framework for SibCT:

The theoretical framework for SibCT includes the following components: Cognitive Behavioural Therapy (CBT), family systems, expressive therapy and child development theory. The theoretical framework for this group intervention program was mostly based on Cognitive Behavioural Therapy (CBT). CBT was used to modify and correct distorted and inappropriate thoughts and behaviours identified during group sessions (Chung, et al., 2004). Important components were cognitive reconstructing (e.g. does parental absence mean lack of love), problem solving skills (identifying a specific problem and generating solutions to it), and assertiveness training (expressing one’s needs frankly and assertively). SCC were taught to question unrealistic assumptions, evaluations, and beliefs that provoked distress; and replace such thinking and the resultant behaviour with thoughts and actions likely to lead to less distress.

In addition to CBT principles, concepts from Family Systems Theory were integrated into the intervention program. Family System Theory posits that family members are interdependent and that the behaviour of each member impacts the other members (Kazak et al., 1997). When one family member is stressed, there is a cascading effect on other family members, and this can lead to a break in family unity (Kazak, 1997). Thus, in this intervention program, all family members’ concerns and worries were addressed, allowing SCC to feel compassion and empathy for other family members.

Another component in this intervention program was expressive therapy such as drama, art, music, and play. These therapeutic methods allowed SCC to explore and
express their feelings through a medium in which they felt comfortable, allowing them to address and resolve unsettled concerns.

Furthermore, to ensure that the activities were developmentally appropriate, a collection of activities designed for different developmental levels was included within the intervention manual. Child development principles were used to determine age appropriate activities. Children’s maturity, capability and preferences were also considered. For instance, for younger SCC, intervention activities were concrete such as painting and drawing. On the other hand, for older SCC, activities were more abstract such as journaling experiences or feelings. Developmentally appropriate activities were essential to the success of the program because they ensured that SCC were exposed to suitable information and material (Chung, et al., 2004).

**Pilot Studies**

To assess intervention effects, the Barrera research team conducted two pilot studies to evaluate the feasibility and outcomes of this intervention program. In the first pilot study, seventeen SCC participated in the group intervention. A pre-post design with standardized measures of SCC’s symptoms of depression and anxiety and behaviour problems was used to test intervention effects. Disease-related changes in communication and relationships, fear of disease and other worries were assessed, using a questionnaire developed for SCC (Barrera, et al., 2002). Although acceptability was achieved, there were some recruitment and retention problems related to openness of the inclusion criteria (e.g. including siblings of children who were in palliative care). Regarding outcomes, pre- post-intervention data was available for 12 SCC. Compared to pre-intervention scores, at the end of the program SCC reported a reductions in symptoms of
depression (p < .05), anxiety (p < 0.01), and fear of the disease (p < 0.05) (Barrera, et al., 2002). There were also improvements in disease-related communication (p < 0.05) based on parental report (Barrera et al., 2002). In the second study, recruitment and retention were improved and attrition reduced. The sample was larger (42 siblings) and participants reported significant improvements on self-reported symptoms of depression (p = 0.007) and anxiety (p = 0.007) at the end of the intervention and 6 months later (Barrera, et al., 2004). This study also identified age and gender as important variables in the efficacy of intervention, indicating that younger boys were more receptive to intervention than female children and adolescent females. The greatest reduction of symptoms was noted in younger male SCC.

**Significance of the Current Study**

Considering several studies have shown that most SCC do not experience severe psychopathology but instead suffer significant psychological distress our focus should not be directed only on identifying and helping SCC who are experiencing psychopathology, but also those experiencing psychological distress (Bendor, 1990; Houtzager, et al., 2004). Nevertheless, most studies to date focus only on SCC’s level of psychopathology and less attention is paid to their level of psychological distress. (Prchal & Landolt, 2009). In an effort to account for this methodological shortcoming, our primary focus was to assess the effects of a specialized intervention designed to enhance resiliency by examining the effects on less-resilient SCC, those who were experiencing psychopathology, as well as, those who were experiencing psychological distress. Less-resilient SCC were identified using their baseline depression and anxiety scores. Furthermore, symptoms of depression and anxiety were assessed as outcome measures.
because out of 11 sibling intervention studies mentioned in Prchal & Landolt’s systematic review on psychological intervention for SCC, only three, two of which were our preliminary studies looked at symptoms of depression, and, the effect size ranged from 0.31 to 0.47 indicating a small beneficial effect (2009). Furthermore, symptoms of anxiety was assessed in ten of those studies, and six out of the ten, which included one randomized control study found significant difference following intervention and four studies which included one randomized control study found no difference (Prchal & Landolt, 2009). Such findings warrant further investigation of the benefits of sibling intervention and for such reasons symptoms of anxiety and depression were assessed in this study. Lastly, seven of the 11 interventions mentioned in the systematic review examined predictors of intervention effects (Prchal & Landolt, 2009). However, the only factors investigated were age, gender, diagnosis, bereavement and number of camp attendance, as such Prchal and Landolt noted in their review a shortage of studies looking at predictors of intervention effects (2009). Thus, the key purpose of the current study was to assess sibling’s individual factors (age and gender), ill child’s clinical factors (diagnosis and time since diagnosis) and family factors (birth order relative to the ill child) on intervention outcomes assessed using pre and post anxiety and depression scores. Therefore, this research attempts to identify those siblings who would benefit most from a sibling intervention program and highlights those who may not benefit as much and draws attention to factors that must be targeted through intervention support before embarking on a full randomized control study.
More-Resilient and Less-resilient SCC – Risk Protective Model

Resiliency is the quality of being able to overcome challenge and adversity through personal and environmental factors (Masten & Powell 2003). Resiliency in SCC is the ability to adapt to the cancer of one’s sibling (Packman, et al., 2006). In trying to understand why some SCC are more resilient while others are less so, the risk-protective model (Garmezy, 1984) is helpful. Protective factors are those associated with positive outcomes in SCC and that help to shield these children from distress and lessen the severity of symptoms (Murray, 2000; Sloper, 2000). Risk factors on the other hand are defined as personal and environmental factors that heighten vulnerability and are associated with undesirable outcomes (Masten & Powell, 2003). Thus, the risk-protective model proposes that exposures to risk factors may be neutralized by protective factors (Garmezy, 1984). Thus, risk and protective factors are key to understanding resilience (Masten & Powell, 2003). Individuals with few protective factors experience lesser adaptation to stressful events than individuals with many. At the same time, those with fewer risk factors experience greater adaptation (Masten & Powell, 2003). According to Newman and Blackburn (2002), resiliency is influenced by internal risk/protective factors (e.g. emotional stability, cognitive, coping skills and problem solving skills) and external risk/protective factors (e.g. social support, instrumental support, family cohesion) (Newman & Blackburn, 2002). Thus, based on this model, it is hypothesized that SCC who are more resilient have the ability to bounce back from the cancer experience without manifesting high levels of psychological distress, because they have access to
protective factors such as educational, therapeutic and social support and these compensate for any extra risks they run in the form of being female, being young, having a sibling with a brain tumour, being in the early post diagnosis stage, and being younger than the ill sibling. Considering that risk and protective factors are cumulative, that is, the more protective factors one has in relation to risk factors, the greater the probability one has in adapting well, and since resilience is not conceptualized as a fixed trait but rather as a fluctuating process, then resiliency can be increased or enhanced by protective interventions (Fergus & Zimmerman, 2005; Masten & Powell, 2003).

**Stressor and Resiliency**

Some children faced with a stressful life experiences develop psychological difficulties, while others function well. Children in the latter group, commonly labeled "resilient," defy expectation by developing into well-adapted individuals (Masten & Powell, 2003). Two approaches have generally been used in operationalizing the magnitude of stress. One is to add up potentially stressful life events – i.e. the cumulative method (Garmezy & Telegen, 1984). The other is to focus on one major event that is inherently stressful such as war, parental divorce, poverty or illness (Walierstein, 1983). The second approach to stress was used in this study, since cancer in a sibling is seen as a major disruptive occurrence causing distress. Distress in children is usually expressed by internalizing symptoms such as depression and anxiety although it can also be expressed in externalizing symptoms such as hyperactivity (Zigler & Glick, 1986). Resilient children have relatively lower levels of distress in the face of a stressor compared to less
resilient peers. Symptoms of depression and anxiety were thus used as a measure of resilience.

Rationale for Thinking that a CBT-based Program Would Reduce Symptoms of Depression and Anxiety

Given the potentially debilitating effects of symptoms of anxiety and depression in children, effective treatment and early intervention is important (Barrett, Lock & Ferrell, 2001). Treatment studies have demonstrated that cognitive-behavioural interventions for children can successfully lessen such symptoms. Barrett, Lock and Ferrell (2001) compared the effects of a universal school-based preventive intervention for child anxiety at two developmental stages. Six hundred and ninety-two participants enrolled in grade 6 \( (n = 293) \), aged between 9 and 10 years, and grade 9 \( (n = 399) \), aged between 14 and 16 years, were allocated to either a school-based cognitive-behaviour intervention or to a monitoring group. Participants completed the Spence Anxiety Scale (SCAS) and the Child Depression Inventory (CDI) and were stratified into low, moderate and high-risk groups based on their anxiety scores at pre-intervention. The effects of the prevention program were evaluated at post-intervention and 12-month follow-up intervals. The preliminary results of this study were very promising. As a group, children who received the intervention reported lower rates of self-reported anxiety, as measured by the SCAS, post-intervention, compared with those who were in the wait-list control group. In regards to self-reported depression, as a group there was no significant effect at post-intervention. Furthermore, the effectiveness of this program for those children reporting clinical levels of anxiety at pre-intervention, were even more pronounced.
Notably, 75.3% of children in the intervention group who were at risk at pre-intervention showed significant benefits by being involved in the intervention program and no longer reported symptoms of anxiety within the clinical range at post-intervention. Conversely, more than half (54.8%) of the children in the comparison group who were at risk at pre-intervention remained at risk, scoring above the clinical cut-off on the SCAS. Also, when only clinically anxious children were used, as measured by pre-intervention SCAS scores, a significant reduction in self-reported symptoms of depression was also evident from pre-to- post-intervention for the intervention group only when compared to the control group. Overall such findings suggest cognitive-behavioural prevention intervention is potentially successful in reducing symptoms of anxiety and depression in high risk children. Hence, our study investigated the effects of SibCT, a cognitive-behavioural prevention program designed for siblings of children with cancer.

**Rationale for Using Symptoms of Anxiety and Depression as a Proxy Measure for Resiliency**

In deciding which instruments best assess resiliency, it has been argued that "resilient" children's reactions to their stressful life experiences are primarily internalizing in nature. This argument is based on two empirically based findings. First, children identified as resilient are generally at high developmental levels, as reflected by their greater intellectual maturity (Pellegrini, 1980). Second, at higher levels of development, distress tends to be expressed more often in internalizing symptoms such as, depression and anxiety than in externalizing ones such as, hyperactivity (Zigler & Glick, 1986). Given these findings, for this study less-resilient children were determined based on elevated levels of symptoms of depression and anxiety pre-intervention.
Thus, based on aforementioned concepts and studies, the theory was that by participating in SibCT initially less-resilient SCC may become more resilient. This is because SibCT provides protective factors ² such as, educational, therapeutic and social support which aids SCC in coping with the cancer experience. The protective factors provided through SibCT are described below.

**Protective Factors Provided Through SibCT.**

SibCT provides three main forms of aid that are protective of resiliency - educational, therapeutic and social.

1) *Educational Support*

There is tentative evidence that gaining information about cancer is beneficial for SCC. This evidence suggests that when SCC are provided with age appropriate information about cancer, their level of fear and disease-associated anxiety is reduced (Barrera et al., 2004; Carpenter, Sahler, & Davis, 1990; Dolgin, et al., 1997; Evans, Stevens, Cushway, & Houghton, 1992; Houtzager et al., 2001; Lobato & Kao, 2002; Roeyers & Mycke, 1995; Sahler & Carpenter, 1989; Sidhu et al., 2006; Williams et al., 2003). In addition, in response to being more knowledgeable SCC may develop an enhanced feeling of control which allows them to feel less anxious (Houtzager et al., 2001). As described earlier, SCC who are not medically informed about cancer may believe it to be contagious and may develop fearful thoughts of contracting the disease, thus increasing their anxiety (Murray, 2000). An intervention program that can provide medical information and rectify distorted beliefs by replacing them with accurate facts may in this way reduce symptoms of anxiety and depression.

2) *Protective factors* are variables that buffer SCC from psychological distress associated with the cancer experience: enhance resiliency
In the SibCT intervention program, SCC were provided with accurate and age appropriate medical information about cancer and about cancer’s effect on the family.

2) Therapeutic Support

Many SCC believe that they need to shield and mask their feelings for fear of either upsetting their parents (this is seen in adolescents) or of not expressing socially expected feelings (this is reported in younger SCC) (Barrera, et al., 2004). Thus, an intervention program which allows for open expression of feelings and thoughts in a safe environment would be theoretically beneficial. SibCT does not only allow open expression of feelings and thoughts but, as a second therapeutic technique, SCC are taught effective coping and problem-solving strategies, empathy, and optimism to help them manage cancer related stressors. The development of empathy has been reported as an important protective factor for SCC, since studies have demonstrated that siblings with greater empathic abilities experienced less psychological distress (Packman, et al., 2006). Researchers postulate that more empathetic SCC are capable of perceiving the difficulties that their ill brother/sister and other family members are experiencing, and they may have a greater understanding and appreciation for the imbalance of attention and resources, experiencing less psychological distress. Optimism is also another important protective factor noted in the literature. When SCC are more optimistic during the cancer experience they have been reported to experience less psychological distress (Houtzager, et al., 2004). Psychological distress also appears to be influenced by subjective appraisal of the cancer experience. When SCC believe the cancer experience is less threatening they are
more capable of employing actions to manage the stress, and in essence reduce 
psychological distress (Folkman, et al., 1986). Thus, these aforementioned therapeutic 
factors were targeted through the SibCT intervention.

3) Social Support

Meeting and interacting with other SCC who may be having similar experiences 
to their own is theorized as exerting a positive effect on psychological well-being. Due to 
their interrupted social life, these SCC may lack the opportunity to develop essential peer 
relationships (Barrera, et al., 2004). By participating in the group, SCC develop and 
practice appropriate peer relationships, in this way enhancing their social supports. This 
is essential because when SCC sense greater social support they are less likely to report 
symptoms of depression, and anxiety (Barrera, et al., 2004). Moreover, the SibCT 
intervention aims to enhance the bond between SCC and their parents. Studies have 
reported that when parents are able to provide emotional support to SCC they experience 
less psychological distress (Sloper, 2000). Thus, such opportunities were provided 
through the intervention in hope of reducing psychological distress associated with the 
cancer experience.

In summary, the literature suggests that SCC experience numerous stressors and 
disruptions in their daily lives and in general, are at risk for psychological distress that 
may or may not reach pathological levels. Moreover, many studies suggest that specific 
risk factors such as personal characteristics (age, gender), family factors (birth order 
relative to the ill child), and disease factors (particular cancer diagnosis and time since 
diagnosis) may play a role in influencing SCC’s adjustment to the cancer experience and 
may explain why some SCC are more vulnerable than others to psychological distress.
However, not all SCC with these risk factors are susceptible to distress. In fact, some are remarkably more resilient. Based on this observation, it is hypothesized that SCC who are more resilient may be so because they are protected by factors such as social, educational and therapeutic support. Thus, it may be possible that vulnerable SCC who were provided with the same protection through a specialized intervention may too become more resilient to psychological distress.

**Objectives**

The aim of this study was to better understand the effects of intervention with a specific manualized form of group therapy on psychological distress symptoms of children whose siblings have been diagnosed with cancer. Outcomes of more-resilient and less-resilient SCC were compared. Mediating factors such as age, gender, time elapsed since diagnosis, type of cancer and birth orders were taken into account.

1) Primary objective: The primary objective of this study was to investigate intervention outcomes of more-resilient and less-resilient SCC. Determination of resiliency was based on psychological distress scores prior to intervention. Less-resilient SCC were defined as scoring one standard deviation above the mean for one of three scales (CDI= ≥ T-score 60 (Kovacs, 1992), STAIC parent and child versions = ≥ T-score 34 (Spielberg, 1983). More-resilient SCC were those scoring within the normal range or below the normal range on all the scales.

2) Secondary/exploratory objectives: In addition to examining the effects of individual resilience, this study will explore the effects of individual (age and gender), family (birth order with respect to ill sibling) and clinical factors (time
since diagnosis and type of cancer) on intervention effects and interaction of these factors. 

**Hypotheses**

1) Compared to more-resilient SCC, less-resilient SCC will show greater improvement on symptoms of anxiety and depression pre to post intervention.

2) Compared to less-resilient older SCC, less-resilient younger SCC will show greater improvement pre to post intervention. Older SCC are defined as ≥ 11 years old and younger SCC as <11 years old.

3) Compared to less-resilient female SCC, less-resilient male SCC will show greater improvement pre to post intervention.

4) Compared to less-resilient SCC of children with a later diagnosis, less-resilient SCC of children with an earlier diagnosis will show greater improvement pre to post intervention.

5) Compared to less-resilient SCC of children with other cancers, less-resilient SCC of children with brain tumours will show greater improvement pre to post intervention.

6) Compared to less-resilient SCC of children who are older in age relative to the child with cancer, less-resilient SCC of children who are younger in age to relative to the child with cancer will show greater improvement pre to post intervention.
CHAPTER 2

Method
The present study aimed to evaluate the outcome of Siblings Coping Together (SibCT), a manualized 8-week group intervention for siblings of children with cancer (SCC). The evaluation was based on a decline in psychological distress scores as measured by three standardized instruments. On the basis of the pre-intervention scores, SCC were dichotomized into ‘more-resilient’ and ‘less-resilient,’ with the prediction that the intervention would be particularly useful to the less-resilient participants, those with the higher pre-intervention distress scores. It was recognized that several other factors would probably influence outcome and these were also taken into account, such as, the SCC’s age and gender, birth order with respect to ill sibling and the ill sibling’s clinical factors: time since diagnosis and type of cancer.

**Sample Size Estimation**

The sample size required for this study was calculated using the minimum clinically important difference (MCID) in improvement from pre-intervention to post-intervention, and the standard deviation for Children’s Depression Inventory (CDI), one of the three outcome measures used in this study. Based on a previous study by our research team, the MCID was found to be 4.5, with a standard deviation of 7.8 (Barrera et.al., 2002). To achieve 80% power (the probability of correctly rejecting a false null hypothesis (Cohen, 1988) at a significance level (alpha) of 0.05) it was estimated that 52 participants for each group (more-resilient and less-resilient) were required for the study. This sample size is also adequate for the analysis of anxiety scores, measured by the State Trait Anxiety Inventory for Children scale. Moreover, for regression equations using six or more predictors, an absolute minimum of 10 participants per predictor variable is
appropriate, since 5 predictors variables were examined, 50 participants were needed (Greens, 1991)

Based on our available sample size of participants for this study, 57 less-resilient siblings and 54 more-resilient siblings, the minimum sample size requirement was satisfied. This is reassurance that there is a low probability of making a Type II error, or incorrectly failing to reject a false null hypothesis, that is, failing to observe a difference when in fact a difference exists.

Design and Procedure

The data for this study were part of a larger study ongoing since the year of 2002 at two hospitals: SickKids and BC Children and Women’s’ Hospital (BCCWH). A convenience (non-random) sampling strategy was used to recruit siblings of children with cancer (SCC). SCC for the study were either referred to the group by their clinical team or invited to participate if the family had a child with cancer. A combined sample of 151 SCC participated in this study: 23 from BCCWH and 128 from SickKids. The total number 128 siblings from SickKids include: 12 SCC who had participated in a preliminary study (Barrera et al., 2002), 42 from a second preliminary study (Barrera et al., 2004) and 74 newer recruits.

Following Research and Ethics Committee approval, SCC were either referred to the group by staff (i.e., nurses, physicians, social workers) in the Haematology/Oncology (H/O) Department due to parental concerns of behavioural and emotional difficulties, or were invited to participate. Potential participants were screened for inclusion/exclusion criteria by H/O staff and then by a graduate student or research assistant who contacted the family by phone or in person.
The nature and purpose of the study was explained to families who fulfilled the inclusion criteria. After verbally agreeing to participate, SCC and one parent were invited for an initial assessment at SickKids or BBCWH hospital, depending on the SCC location. During this visit, potential participants were told that taking part in the study was completely voluntary and they were free to withdraw from the study at any point without jeopardizing their treatment at the hospital. Parents who consented to participation were asked to sign consent forms and to complete the pre-intervention parent questionnaires as well as a demographic questionnaire attached in appendix. The SCC was asked to sign assent or consent forms (based on age/competence as determined by a health care provider in the research team during the initial screening) and to complete the pre-intervention child questionnaires (described below). A copy of the consent/assent forms are attached in the Appendices. Questionnaires were read out loud for those children who had poor reading skills. The same questionnaires were completed again post intervention, 8 weeks later.

**Participants**

Participants in the group intervention met the following inclusion criteria:

1. Had a sibling who was or had been treated for cancer at SickKids hospital, or British Columbia’s Children's and Women’s Hospital and was at least three months post diagnosis.

2. Was able to read and speak English.

3. 8-17 years of age
4. Was able to commit verbally to stay in the group for the duration of the study (5 out of 8 intervention sessions must have been attended for data to be used in this study)

The exclusion criteria were:

1) Participants diagnosed with a developmental or psychiatric disorder such as, autism, conduct disorder that would prevent them from participating in the group actively and pro-socially.

2) Participants who were actively receiving psychological treatment elsewhere.

3) Participants whose brother’s/sister’s treatment for curative purpose had been discontinued, i.e. who was receiving palliative care only and was not expected to live more than 6 months, or who had died.

**The Intervention Program**

**Goals.** The intervention program had three main goals:

1. Social- SCC were given the opportunity to meet others undergoing a similar experience and to participate in group activities

2. Educational- SCC were provided with age-appropriate medical information about cancer and cancer’s effect on the family

3. Therapeutic- SCC were given the opportunity to express their feelings and thoughts in an open environment, with other SCC and trained counselors, and to hear about and practice effective coping strategies
SibCT Format

The SibCT intervention program consisted of eight two-hour group sessions, held once a week for eight weeks in a children’s play area within the hospitals. Each session focused on a particular theme: Session 1 addressed group rapport and rules (e.g. respecting each other and being on time). Age-appropriate medical information about cancer was the focus of session 2; this information was taught by a guest nurse who used visually-enhanced handouts and medical props to engage the SCC. Sessions 3-6 were psychosocial in nature; topics discussed during these sessions were: the family context (e.g. how each family member is affected by cancer), SCC issues and feelings (resentment towards parents and the ill child), relationship between siblings (e.g. jealousy and guilt) and problems in the school context (e.g. harassment by peers). Session 7 focused on generating hope for SCC’s future. Lastly, to put closure to the intervention, session 8 was a graduation ceremony where parents and friends were invited and certificates were given out to SCC to recognize their accomplishments (Chung, et.al, 2003: Manual for SibCT).

Structure of Each Session

Each session had a specific structure including: a) Pre-Activity, which served to occupy participants who came early, as well as to provide the opportunity for SCC to engage in informal conversations with facilitators and fellow participants. Pre-activities consisted of tasks such as drawing or making a name tag; b) Review, which took up the “fun work” (homework) assigned during the previous session and re-involved SCC who had been absent during the last session. It refreshed concepts discussed during the last session; c) Mental Set Activity, which served to prepare SCC for the main activity by
helping them be emotionally and mentally ready for a more engaging and potentially difficult task. This included activities such as brain-storming feelings associated with the cancer experience; d) Main Activity, designed to be a more involved and engaging activity such as discussing difficult feelings, experiences or problems through storytelling or games; e) Snack period. This allowed for spontaneous socialization among SCC. During this time, siblings mingled and had open unstructured interaction with one another; f) homework (fun work) served two purposes: it allowed SCC to maximize the therapeutic effects of the intervention by applying strategies learned during the session at home, in their natural environment. Secondly, it kept parents involved in the activities, potentially increasing support (Chung, et.al, 2003).

**Activity and Group Selection**

The activity for each session was carefully chosen by facilitators as well as the supervising psychologist. In selecting the appropriate activity, many factors were considered such as, the age, gender, maturation and developmental level of the SCC as well as their interests and hobbies. This ensured that all SCC who participated in the intervention program were fully engaged. To further ensure engagement of SCC, group facilitators participated in every activity and were able to assist SCC who needed extra help or who had difficulty understanding the task.

To assure cohesiveness and compatibility, the membership of each group was carefully selected. Based on availability, SCC were grouped by age and maturity level. For instance, if a younger SCC was mature and was developmentally above their age group, they were placed in a group with older siblings because this assured a better fit. Great attention was also taken to balance groups by gender. It was considered important
to have approximately equal numbers of females and males in a group, so one gender did not overpower the other.

**Group Facilitators**

All group facilitators were clinically trained graduate students and/or clinical assistants with Master level training in clinical psychology. Training for the facilitators consisted of reading and studying the manual, observing group sessions through a one-way mirror prior to participation (5 observed sessions), and, finally, participating as a group facilitator assistant.

Facilitators were supervised by a registered psychologist who oversaw the execution of the intervention program. Weekly meetings were held during which facilitators and the psychologist debriefed the previous session and planned for the next week’s activities.

**Measures**

To assess the effects of intervention, anxiety and depression symptoms were used as the outcome measures for this study. It is important to emphasize that symptoms of anxiety and depression were used to measure psychological distress (not diagnostic categories).

**The Children’s Depression Inventory (CDI)**

In this study the Children’s Depression inventory (CDI) was used to measure symptoms of depression in SCC (Kovacs, 1992). This self-rated, 27-item scale was designed for children between the ages of 7-17. Items range from “I cry all the time, I cry sometimes or I never cry”. Alpha coefficient for the CDI ranges between 0.71 to 0.89 (Kovacs, 1992) and was 0.68 in our previous study (Barrera et al., 2004). The total
standardized T-score was used for analysis, with higher scores indicating more symptoms of depression. Based on the CDI manual, the mean T-score is 50, and a T-score of 65 is the cut off score for clinical depression in children (Kovacs, 1992). The author of the manual suggests that the cut off score be used as a guideline only and not as an absolute rule (Kovacs, 1992)

*The State Anxiety subscale of the State Trait Anxiety Scale for Children (STAIC)*

The State Anxiety subscale of the State Trait Anxiety Scale for Children (STAIC) was used to measure symptoms of anxiety in SCC (Spielberger, 1983). The child version of the STAIC consists of 20 items that measure state and trait anxiety. Question range from “I feel…very sad, sad, or not sad.” Adequate reliability and validity have been reported with an alpha coefficient of 0.65 (Spielberger, 1983). The STAIC-Parent Form was adapted from Spielberger’s child version by our research group to be identical in form and content to the STAIC. For this version, the child’s parent was asked 20 questions about their children feelings. The internal consistency of this adapted version was tested by our research team in the first pilot study and found to have an alpha coefficient of 0.93 (Barrera et al., 2002). Additionally, recently the STAIC was tested for its internal consistency with a new sample of 16 parents yielding an alpha coefficient of 0.91.

In investigating SibCT effect on promoting resilience, SCC were identified as less-resilient or high risk, at baseline using The Children Depression inventory (CDI), and, the State Trait Anxiety Scale for Children as well as the parent form (STAIC) prior to intervention. For this study, high risk, less-resilient siblings were defined as scoring
one standard deviation below the clinical range for one of the three aforementioned scales (CDI= ≥ T-score 60 (Kovacs, 1992), STAIC (parent and child versions) = ≥T-score 34 (Spielberg, 1983). More-resilient siblings were identified as scoring within the normal range on all the aforementioned scales. The clinical range was not used because the focus of the study was on SCC who are at risk for psychological distress as opposed to those who might qualify for a psychiatric diagnosis.

**Addressing risks**

Other than initial discomfort at joining a new program, the intervention was considered low risk. Session 1 included activities designed to reduce the initial unease and permit SCC to develop trust and comfort. No adverse events were recorded in the groups.

**Privacy**

The information obtained for this study was kept confidential and the only individuals who had access to the information were the two psychologists, Drs. Barrera, and Chung, and their research team. To further ensure that the identity of the participants was kept confidential, ID numbers were assigned to each participant. All the documents were stored in a locked filing cabinet where access was permitted only to the psychologists and the research team involved in the study. Moreover, any data saved on the computer was password-protected. The privacy of the data was not breached during the period of study.

**Method Used to Analyze the Results**

Data for this study were entered and processed using the Statistical Analysis Software (SAS), English Version 9.3. First, descriptive statistical analyses such as means, standard
deviations, and proportions were performed. Subsequently, three separate repeated measure ANOVA tests were conducted to investigate hypothesis 1 by examining the difference in depression and anxiety using pre and post intervention scores between more-resilient and less-resilient SCC. Third, an overall MANOVA was conducted to determine if the effects would change when all the dependent variables were included in the model. Fourth, a multiple linear regression was conducted to address hypotheses 2-6, by determining which variables and interactions among variables (gender, age, type of cancer diagnosed, time since diagnosis and birth order relative to the ill child) were predictors for intervention effects, as measured by differences between symptoms of anxiety and depression pre and post. All statistical tests were 2 sided, and a p-value < 0.05 was considered significant.

**Preliminary analyses**

**Preparation of the data**

**Accuracy of data entry and managing missing data**

Prior to statistical comparisons of pre and post intervention scores, the data were examined thoroughly by a research assistant for accuracy of entry. As in most similar studies, some pre and post intervention CDI and STAIC child and parent scores were missing due to attrition or joining the group after the initial assessment period. Table 1 displays the number of missing pre & post outcome scores. Moreover, if two or more of the pre or/and post intervention outcome scores were missing these individuals were
excluded from analysis (22-More-resilient group and 16- Less-resilient, leaving 54 less-resilient and 57 more-resilient siblings) (Tabachnick & Fidell, 2001)

**Table 1**

Number of Missing Pre, Post & Difference between Post and Pre Outcome Scores

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCC reported depression (CDI)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>More-resilient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less-resilient *</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>SCC reported anxiety (STAIC)</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>More-resilient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less-resilient</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Parent proxy anxiety (STAICP)</td>
<td>6</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>More-resilient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less-resilient</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* Defined by pre-intervention scores: CDI= ≥ T-score 60 (Kovacs, 1992), STAIC parent and child versions = ≥ T-score 34 (Spielberg, 1983).

**Categorizing data**

For the purpose of analyses, each continuous independent variable such as age and time since diagnosis was dichotomized by assigning a numerical value to each subgroup. SCC age was collapsed and categorized into: 1=below or equal to 11 years and 2= greater than 11 years. The age cut-off was in accordance to our two preliminary studies
(Barrera, et al., 2002, 2004). Furthermore, this cut-off was also used in Dolgin’s study (1997) which looked at intervention effects in siblings of children with cancer, in this study he used 7-11 years as the cut-off to define younger siblings and 12-17 years as the cut-off to define older sibling. Time since diagnosis was also categorized, 1 was assigned if the ill child was diagnosed fewer than 365 days before SCC entry into the group and 2 if diagnosis had been made more than 365 days prior.

Subsequently, categorical variables, including gender, type of cancer and SCC age relative to the ill child were also dichotomized to 1 and 2. SCC’s gender was dichotomized to 1= male and 2 = female. Type of cancer was also dummy coded to 1=other cancers (leukemia, lymphoma, other blood disorders, and other tumours) and 2=brain tumour. Lastly, SCC age relative to the ill child’s age was also dichotomized. SCC younger than the sick child were assigned a 1; SCC older than the sick child or equal in age were assigned a 2. (See Table 2 for the breakdown of the categories)

Table 2

Categorization of Variables

<table>
<thead>
<tr>
<th>Age</th>
<th>1=below or equal to 11 years</th>
<th>2=greater than 11 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>1= male</td>
<td>2 = female</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>1= ill child was diagnosed fewer than 365 days</td>
<td>1= ill child was diagnosed more than 365 days</td>
</tr>
<tr>
<td>Type of cancer diagnosed</td>
<td>1=other cancers (leukemia, lymphoma, other blood disorders, and other tumours)</td>
<td>2=brain tumour.</td>
</tr>
<tr>
<td>SCC age relative to the ill child’s age</td>
<td>1=SCC younger than the sick child</td>
<td>2=SCC older than the sick child or equal in age were assigned</td>
</tr>
</tbody>
</table>
Preparing Data Based on Outcome Variables

To evaluate improvement, difference scores were calculated by subtracting post scores from pre scores for more-resilient and less-resilient SCC, this was done for each outcome variable. Determination of resiliency was based on psychological distress scores prior to intervention. Less- resilient SCC were defined as scoring one standard deviation above the mean for one of three scales (CDI= ≥ T-score 60 (Kovacs, 1992), STAIC parent and child versions = ≥ T-score 34 (Spielberg, 1983). More-resilient SCC were those scoring within the normal range or below the normal range on all the scales.

Since not all SCC reported improvement post intervention (some in fact, reported increased symptoms of depression and anxiety) there were some negative values. Table 3 shows the number of negative difference scores.

Table 3

Number of SCC with a Negative Difference between Post and Pre Scores

<table>
<thead>
<tr>
<th>Measure</th>
<th># of Negative Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCC reported depression (CDI)</td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>12</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>12</td>
</tr>
<tr>
<td>SCC reported anxiety (STAIC)</td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>16</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>16</td>
</tr>
<tr>
<td>Parent proxy anxiety (STAICP)</td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>11</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>6</td>
</tr>
</tbody>
</table>
**Descriptive Statistics**

Preliminary statistical analyses were performed to determine the frequency, means, standard deviations, maximum and minimum for each outcome variable as shown in Tables 4-7.

**Table 4**

More-resilient and Less-resilient SCC

<table>
<thead>
<tr>
<th>Resilient Status</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less-resilient</td>
<td>57</td>
<td>51</td>
</tr>
<tr>
<td>More-resilient</td>
<td>54</td>
<td>49</td>
</tr>
</tbody>
</table>

**Table 5**

Descriptive Statistics for Less-resilient SCC

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger</td>
<td>42</td>
<td>73</td>
</tr>
<tr>
<td>Older</td>
<td>15</td>
<td>27</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>31</td>
<td>54</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>46</td>
</tr>
<tr>
<td>Type of Cancer Diagnosed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain tumour</td>
<td>21</td>
<td>37</td>
</tr>
<tr>
<td>Non-brain tumour</td>
<td>36</td>
<td>63</td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 365 days</td>
<td>29</td>
<td>51</td>
</tr>
<tr>
<td>&lt; 365 days</td>
<td>28</td>
<td>49</td>
</tr>
<tr>
<td>Birth Order Relative to the Child with Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than</td>
<td>37</td>
<td>65</td>
</tr>
<tr>
<td>Older than</td>
<td>20</td>
<td>35</td>
</tr>
</tbody>
</table>

*Defined as equal to 11 years or younger
**Homogeneity and Normality**

Prior to running a parametric test, data for each dependent variable were analyzed to determine whether the statistical assumptions for these tests were satisfied. The first assumption, assumption of normality (i.e. Shapiro-Wilk, Kolmogorov-Smirnov), which states that the sample was drawn from a population whose distribution was normal was tested for each outcome variable for the More-resilient and less-resilient group. Next, the second assumption of the parametric statistical test model, assumption of homogeneity of variance (i.e. Levene’s test), which states that populations have equal variances, was also tested for each outcome variable.

**Homogeneity and normality test for the Children’s Depression Inventory (CDI) scores**

To test for equal variance, a Levene test was conducted for both groups, more-resilient and less-resilient SCC. Following analysis, a non-significant Levene’s test ($p=0.062$) was found, indicating that homogeneity of variance assumption was not significantly violated.

To examine the normality assumption, skewness, which is a measure of the symmetry of the distribution, and kurtosis, which is a measure of the peakedness, were examined for each sample distribution (Howell, 1997). The Shapiro-Wilk value, which was used to determine assumptions of normality, turned out to be significant for both the more-resilient and less-resilient group ($p=0.01$) and ($p=0.01$) respectively, suggesting that scores for each group cannot be assumed to be drawn from a normally distributed population. When this assumption is violated, there is an increased Type 1 error rate and an inflated alpha level (Tabachnick & Fidell, 2001). One strategy recommended for managing this violation is to exclude extreme cases (if only few such cases exist) until
normality is achieved (transforming the data). This strategy was not employed here because the extreme cases reflect a true clinical population. Artificially normalizing the sample by excluding important clinical data would distort these real differences (Tabachnick & Fidell, 2001). Different transformation techniques were tried, but could not produce data that could reasonably be assumed to be normally distributed.

Given that the CDI data were skewed, a decision had to be made regarding whether to proceed with parametric or non-parametric analyses. Non-parametric tests such as the Wilcoxon Sum Ranks test involve ranking scores and are not as greatly impacted by extreme scores as parametric tests are. The main advantage of using non-parametric tests is that they do not rely heavily on assumptions concerning the shape of the curve. Parametric tests, on the other hand, are potentially less powerful when extreme scores are involved (Siegel, 1956). Nevertheless, most researchers agree that substantial departures from the normal distribution have little effect on the results of statistical tests (e.g. Keppel, 1982) and that, when a sample of participants is large (sample size greater than 30, \( n > 30 \) ), this degree of skewness is unlikely to make a substantive difference to the analysis. This proposal is supported by the well-known theory called Central Limit Theorem (Tabachnick & Fidell, 2001). Furthermore, parametric tests are known to be quite robust in the face of moderate violations of normality. However, to be cautious, a non-parametric test, the Wilcoxon Sum Ranks test, was also conducted and similar conclusions were reached on both parametric and non-parametric analysis. Since no difference in outcomes were found based on the parametric and non-parametric tests, only outcomes based on parametric tests are reported for CDI scores.
**Homogeneity and normality test for state trait anxiety inventory for children (STAIC) scores**

A non-significant p value ($p=0.08$) on Levene’s Test of Equality of Variance was found, suggesting that the equal variance assumption had not been significantly violated. Further tests revealed that requisite assumptions were also not violated, based on a non-significant Shapiro-Wilk p-value ($p=0.348$) for the more-resilient and ($p=0.20$) for the less-resilient group. These results indicate that normality assumptions were met.

**Homogeneity and normality test for state trait anxiety inventory for children parent proxy (STAIC scores for parent proxy) scores**

Following examination of assumption of normality, it was found that parent proxy STAIC scores for the more-resilient group were not normally distributed, as assessed by the significant Shapiro-Wilk test ($p=0.05$). They were, however, normally distributed for the less-resilient group, as determined by the non-significant Shapiro-Wilk test ($p=0.06$). On the other hand, homogeneity of variance was not violated between more-resilient and less-resilient groups as assessed by Levene's test for equality of error variances ($p=0.06$). Again, the Wilcoxon Sum Ranks test was performed to examine whether a difference existed between the parametric and non-parametric tests. Since no difference in outcomes were found based on parametric and non-parametric tests, only outcomes based on parametric tests are reported for STAICP scores.
CHAPTER 3

Results
Statistical Analyses

Aim 1: to investigate intervention outcomes in more- resilient and less-resilient SCC (resilience determined prior to intervention) based on pre and post scores of psychological distress, as measured by CDI and STAIC

Hypothesis 1: Less-resilient SCC will report greater improvement on symptoms of anxiety and depression following intervention than more- resilient SCC, as measured by CDI, STAIC and parent proxy STAIC pre and post scores.

To evaluate aim 1, three separate repeated measures ANOVA tests were conducted to explore if significant differences between less-resilient and more-resilient SCC CDI, STAIC and STAIC pre and post scores existed. The results indicated that less-resilient SCC significantly differed when compared to less-resilient SCC based CDI pre and post scores ($F(1, 109) = 20.21, p<0.0001$). Further examination into groups of siblings illustrated that less-resilient SCC also had significantly lower STAIC pre and post scores than more-resilient SCC ($F(1, 109) = 25.42, p<0.0001$). Moreover, less-resilient SCC were also found to have lower anxiety scores based on STAIC parent proxy scores than more-resilient SCC ($F(1, 103) = 38.66, p<0.0001$). Next, to include all of the dependent variables into one model a two-way MANOVA test was used. Given that the three dependent variables are likely to be correlated; this test is the most appropriate analysis. The Hotelling-Lawery Trace report was found to be significant ($F(3, 96) = 10.23, p<0.0001$). This indicates a time (pre-post) x group (more/less resiliency) interaction Thus, these results show that the less-resilient SCC reported greater post intervention improvement of anxiety and depression symptoms as measured by the CDI, STAIC and parent proxy STAIC scores. Therefore, the hypothesis that less-resilient SCC
will report greater improvement on symptoms of anxiety and depression post intervention compared to more-resilient SCC was supported. Table 7 displays the means and standard deviations of each outcome variable. Considering the same measures were used for group separation and for outcome measures, there may be a danger of regression towards the mean.

**Table 6**

Descriptive Statistics for Pre & Post Outcome Variables for More-resilient and Less-Resilient SCC

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M(^1)</td>
</tr>
<tr>
<td>SCC reported depression (CDI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>54</td>
<td>43.35</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>57</td>
<td>52.67</td>
</tr>
<tr>
<td>SCC reported anxiety (STAIC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>50</td>
<td>27.62</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>57</td>
<td>34.03</td>
</tr>
<tr>
<td>Parent proxy anxiety (STAICP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>45</td>
<td>29.48</td>
</tr>
<tr>
<td>Less-Resilient</td>
<td>57</td>
<td>37.87</td>
</tr>
</tbody>
</table>

1. Mean
Table 7

Descriptive Statistics for Difference between Post and Pre on Outcome Variables for More-resilient and Less-resilient SCC

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCC reported depression (CDI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>54</td>
<td>0.68</td>
<td>6.97</td>
<td>-22</td>
<td>22</td>
</tr>
<tr>
<td>Less-resilient</td>
<td>57</td>
<td>6.31</td>
<td>10.92</td>
<td>-19</td>
<td>50</td>
</tr>
<tr>
<td>SCC reported anxiety (STAIC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More-resilient</td>
<td>50</td>
<td>1.44</td>
<td>5.36</td>
<td>-12</td>
<td>11</td>
</tr>
<tr>
<td>Less-resilient</td>
<td>57</td>
<td>4.10</td>
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<tr>
<td>More-resilient</td>
<td>45</td>
<td>1.07</td>
<td>4.33</td>
<td>-13</td>
<td>10</td>
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<tr>
<td>Less-resilient</td>
<td>57</td>
<td>6.37</td>
<td>6.26</td>
<td>-9</td>
<td>23</td>
</tr>
</tbody>
</table>

Note. The higher the score, the greater the reduction in symptoms post group participation

Aim 2: to understand the effect on the intervention of specific contributory factors: time since diagnosis; diagnosis; SCC age and gender; and SCC birth order relative to the ill child by focusing on only less--resilient SCC.

Prior to running the regression model, the statistical assumptions (homogeneity and normality) for parametric tests were examined for age, gender, ill child’s diagnosis, time since diagnosis and SCC’s birth order relative to the ill child. The results of homogeneity and normality for each variable are displayed in Tables 13 & 14 respectively. To explore the simultaneous contributions of multiple predictors on an outcome, the data was analyzed using a multiple regression model with built in interactions using SAS. We used a multiple regression model because we wanted to reach the correct conclusions not only about which predictors are important but also whether the multiple predictors that influence an outcome do so independently or whether
they interact. A series of simple regressions cannot accomplish these tasks; if we want to examine the simultaneous effects of multiple predictors on an outcome, we must use a method that treats them accordingly. Conducting a series of simple regression analyses may lead to erroneous conclusions about the contribution of each predictor variable because this approach does not account for their simultaneous contributions (Baron & Kenny, 1986). As a result, a predictor may be deemed important when it is not, or, conversely, a predictor may appear unrelated to the outcome when it is. When all the predictors were included into our three separate multiple regression models investigating the non-resilient group data, only gender was found to significantly predict STAIC (anxiety) scores and diagnosis was the only variable found to significantly predict CDI (depression) scores and no significant predictor(s) was found for STAIC parent proxy scores. For depression scores diagnosis explained 15% of the variance ($R^2=0.15$, $F(5, 56) =5.77$, $p=0.02$). Moreover, gender significantly predicted 15% of the variance for anxiety scores ($R^2=0.15$, $F(5, 56) =7.92$, $p=0.007$).

**Interactions**

In building our model using SAS we considered including the predictor if the bivariate, t-test test had a p-value of 0.2 - 0.25 or less (Hosmer & Lemeshow, 1989). We used this elimination scheme because all the predictors in the data set are variables that could be relevant to the model. According to Hosmer and Lemeshow if the predictor has a p-value greater than 0.25 in a bivariate analysis, it is highly unlikely that it will contribute anything to a model which includes other predictors (1989). Thus, the only variable found to be potential predictors, by showing a p-value of 0.2 or less, when CDI
differential scores were examined as an outcome measure of intervention effects, were
the ill child’s diagnosis ($p=0.009$), and SCC birth order relative to the ill child ($p=0.20$).
When the STAIC parent proxy differential scores were examined as an outcome measure
of intervention effects, gender ($p=0.28$) and the ill child’s diagnosis ($p=0.09$) were the
only factors found to have a $p$-value of 0.2 or less. Although, gender was found to have a
$p$-value slightly greater than 0.2, this factor was still included in our model because it is a
clinically important variable and as suggested by Hosmer and Lemeshow was included in
our model (1989). Lastly, when STAIC differential scores were analyzed, the only factor
found to have a $p$-value of 0.2 or less was gender ($p=0.006$). Moreover, clinically
important characteristics: age and gender were also incorporated in the regression model
to examine interaction of these factors

**Regression model including CDI including Diagnosis $\times$ Age; Diagnosis $\times$ Gender;
Diagnosis $\times$ Birth order as interactions**

To consider interactions, since we do not have any prior hypothesis of specific
interactions, we considered all the possible interactions between the potential predictors
(that is variables that when tested had a $p$-value <0.2). Results indicate that the interaction
of the ill child’s diagnosis $\times$ birth order was not significantly associated with differential
CDI scores ($F (1, 53) =0.51, p=0.47$). Next, we examined important clinical variables
including age and gender and a significant interaction was found between diagnosis $\times$
gender,($ F (1,52) = 5.21, p=0.026$) but not age $\times$ diagnosis, ($F (1,53)=3.72, p=0.06$) No
significant interaction was found between the effects of birth order $\times$ age ($F (1,53)=0.061, p=0.806$); birth order $\times$ gender ($F(1,52)=0.579, p=0.450$) on CDI
differential scores. Furthermore, there was no significant interaction between age $\times$
gender \((F (1, 52) = 0.508, p = 0.479)\) based on CDI differential scores. In summary, only one interaction, diagnosis \(\times\) gender was found, this indicates that the effects of these variables are not independent but instead, dependent on one another (Howell, 2002).

**Regression model including State Trait Anxiety Scale for Children (STAICP) Parent Proxy Differential Score by Gender \(\times\) Diagnosis; Age \(\times\) Gender; Age \(\times\) Diagnosis**

A regression test was conducted to ascertain whether an interaction existed between STAIC parent proxy differential scores by gender \(\times\) diagnosis. No significant interaction between the effects of gender \(\times\) diagnosis based on STAIC scores was found, \((F (1, 52) = 1.75, p = .191)\). Since age was noted to be a clinically important variable which may impact intervention effects, it was also examined. Interaction tests revealed no significant interaction of age \(\times\) gender \((F (1, 52) = 0.047, p = 0.828)\); age \(\times\) diagnosis \((F (1, 53) = 3.377, p = 0.072)\). Thus, no significant interaction was noted when STAIC parent proxy differential scores were examined.

**Regression model including State Trait Anxiety Scale for Children (STAIC) Differential Score by Gender \(\times\) Diagnosis**

A regression was conducted to assess whether an interaction existed between STAIC differential scores by gender \(\times\) age, two clinically important variables. No significant interaction between the effects of gender and age based on STAIC differential scores was found, \((F (1, 52) = 0.758, p = 0.388)\).
### Table 8

Pre and Post Outcome Measures for Less-resilient SCC Based on Age

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th>Post</th>
<th></th>
<th></th>
<th></th>
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<th></th>
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<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
<td>SD</td>
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<td>Min</td>
<td>N</td>
<td>M</td>
<td>SD</td>
<td>Max</td>
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<tr>
<td>SCC reported depression (CDI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Younger</td>
<td>42</td>
<td>51.05</td>
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<td>80</td>
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<td>15</td>
<td>49.00</td>
<td>10.39</td>
<td>76</td>
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<tr>
<td>SCC reported anxiety (STAIC)</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Younger</td>
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<td>8.73</td>
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<td>42</td>
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<td>7.94</td>
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### Table 9

Pre & Post Outcome Measures for Less-resilient SCC Based on Gender

<table>
<thead>
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<th>Measure</th>
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<th>Post</th>
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<td>N</td>
<td>M</td>
<td>SD</td>
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<td>Min</td>
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</table>
Table 10
Pre and Post Outcome Measures for less-Resilient SCC Based on Ill Child’s Diagnosis

<table>
<thead>
<tr>
<th>Measure</th>
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<th>Post</th>
</tr>
</thead>
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<tr>
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<tr>
<td>SCC reported depression (CDI)</td>
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<td>Other cancers</td>
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<td>53.61</td>
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<td>Brain tumours</td>
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<td>51.05</td>
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<td>Other cancers</td>
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<td>34.95</td>
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<td>Other cancers</td>
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<td>38.61</td>
</tr>
<tr>
<td>Brain tumours</td>
<td>21</td>
<td>36.62</td>
</tr>
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</table>

Table 11
Pre & Post Outcome Measures for Less-Resilient SCC Based on Time Since Diagnosis

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th>Post</th>
</tr>
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<tbody>
<tr>
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<td>N</td>
<td>M</td>
</tr>
<tr>
<td>SCC reported depression (CDI)</td>
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<tr>
<td>Under 365 days</td>
<td>29</td>
<td>52.62</td>
</tr>
<tr>
<td>Over 365 days</td>
<td>28</td>
<td>52.71</td>
</tr>
<tr>
<td>SCC reported anxiety (STAIC)</td>
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<tr>
<td>Under 365 days</td>
<td>29</td>
<td>33.28</td>
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<td>Over 365 days</td>
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<td>34.82</td>
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<td>Parent proxy anxiety (STAICP)</td>
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<tr>
<td>Under 365 days</td>
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<td>38.21</td>
</tr>
<tr>
<td>Over 365 days</td>
<td>28</td>
<td>37.54</td>
</tr>
</tbody>
</table>
### Table 12

Pre and Post Outcome measures for Less-Resilient SCC Based on Birth Order Relative to the Ill Child

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Post</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
<td>SD</td>
<td>Max</td>
<td>Min</td>
<td>N</td>
<td>M</td>
<td>SD</td>
<td>Max</td>
</tr>
<tr>
<td>SCC reported depression (CDI)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than ill child</td>
<td>37</td>
<td>54.19</td>
<td>13.36</td>
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<td>35</td>
<td>37</td>
<td>47.00</td>
<td>9.29</td>
<td>71</td>
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<tr>
<td>Older than ill child</td>
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<td>49.85</td>
<td>12.10</td>
<td>89</td>
<td>31</td>
<td>20</td>
<td>46.10</td>
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<td>SCC reported anxiety (STAIC)</td>
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<td></td>
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<tr>
<td>Younger than ill child</td>
<td>37</td>
<td>34.95</td>
<td>9.53</td>
<td>57</td>
<td>20</td>
<td>37</td>
<td>30.43</td>
<td>6.48</td>
<td>50</td>
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</tr>
<tr>
<td>Younger than ill child</td>
<td>37</td>
<td>37.92</td>
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<tr>
<td>Older than ill child</td>
<td>20</td>
<td>37.80</td>
<td>6.83</td>
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<td>20</td>
<td>31.40</td>
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</tbody>
</table>

### Table 13

Test for Violation of the Assumption of Homogeneity for Independent Variables

<table>
<thead>
<tr>
<th>Measure</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Time since Diagnosis</th>
<th>Birth order</th>
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<td>SCC reported depression (CDI)</td>
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<td>ns</td>
<td>ns</td>
<td>ns</td>
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<tr>
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<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Parent proxy anxiety (STAICP)</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

*Note.* ns = non-significant
In summary, the first hypothesis, which stated that less-resilient SCC would report greater improvement on symptoms of anxiety and depression post intervention than more-resilient SCC (as measured by CDI, STAIC and parent proxy STAIC pre and post scores) was supported. When investigating factors that could have contributed to this outcome, the only factor found to be significant when CDI differential scores were examined as an outcome measure of intervention effects, was the ill child’s diagnosis.

*Summary of results*

In summary, the first hypothesis, which stated that less-resilient SCC would report greater improvement on symptoms of anxiety and depression post intervention than more-resilient SCC (as measured by CDI, STAIC and parent proxy STAIC pre and post scores) was supported. When investigating factors that could have contributed to this outcome, the only factor found to be significant when CDI differential scores were examined as an outcome measure of intervention effects, was the ill child’s diagnosis.
When STAIC differential scores were analyzed, the only factor found to be significant was gender ($p=0.007$). However, when the STAIC parent proxy differential scores were examined, no factor was found to be significant. Lastly, when interactions of these factors (factors with a $p$-value $<0.2$) were examined, one significant interaction was found: diagnosis and gender ($p=0.026$).

To summarize, the results of this study show that the more distressed siblings of children with cancer are to begin with, the more the group intervention helps them, but this is less marked if the brother or sister of the SCC has a brain tumour than if the cancer is of any other type. Also, male siblings improved more when compared to female siblings based on STAIC differential scores. Furthermore, an interaction was found for gender and diagnosis on CDI differential scores. This signifies that male SCC with a brother/sister with other cancers (non-brain tumours) improved significantly more based on CDI differential scores as compared to female SCC with a brother/sister with brain tumours, male SCC with a brother/sister with brain tumours, as well as, male siblings with a brother/sister with other cancers. These results will be discussed in the next chapter and compared to the results found in the literature discussed in Chapter 1.
CHAPTER 4

Discussion
The current study was designed to assess the psychological distress in siblings of children with cancer (SCC) prior to intervention and following intervention. More resilient siblings N=54 (those who scored below the cutoff on one of the following three measures: CDI= ≤ T-score 60 (Kovacs, 1992), STAIC parent and child versions = ≤ T-score 34 (Spielberg, 1983) were compared to less-resilient siblings N=57 (those who scored above the cutoff) to determine which group would show the largest decreases in scores on anxiety and depression on the same measures. Previous research on psychological distress experienced by siblings of children with cancer has had mixed results (Cohen, et al., 1994). Horwitz & Kazak (1990) as well as Sloper (2000) have even asserted that the experience of having a sibling with cancer, although a challenge initially, may result in overall benefits, such as greater empathy, maturity and independence, as well as greater family cohesiveness. However, other research has reported psychological distress in the form of symptoms of anxiety and depression and behavioural problems (Barrera, et al., 2002; Houtzager, et al., 2004; Labay & Walco, 2004). This inconsistency in findings suggests that some SCC do better than others perhaps because they have more risk factors to begin with or, perhaps, because they have fewer protective factors. The risk-protection model proposes that vulnerability in SCC can be conferred by specific variables such as age, gender, birth order, and even the nature of the ill sibling’s disease, especially the impact of a particular diagnosis, and the SCC’s distance from the initial diagnosis in terms of elapsed time. At the same time, education, therapy, and social support can be conceptualized as protective factors that serve to reduce negative impacts. Thus, based on the concept of risk and protection, some SCC were expected to be more vulnerable than others. We hypothesized that the more
vulnerable ones could be made less vulnerable through specialized intervention. The more resilient ones, we thought, may benefit less from the intervention, not needing the same protection. Therefore, our first hypothesis anticipated that the more vulnerable or less-resilient SCC would report greater improvement on symptoms of depression and anxiety following intervention than the initially more-resilient SCC. We measured depression and anxiety by CDI and STAIC scales. As anticipated, the less-resilient SCC reported greater improvement on symptoms of anxiety and depression when compared to the more-resilient SCC. This finding supports the hypothesis that the intervention was more beneficial for less-resilient than more-resilient SCC. In the following section I will provide potential explanations for this finding. To date no other study has looked at more-resilient and less-resilient siblings of children with cancer in the context of intervention.

Reasonable explanations for our finding may stem from the fact that the intervention provided less-resilient SCC lacking protective factors with the necessary assets and resources to ameliorate their psychological distress in the form of therapeutic, educational and social support.

**Therapeutic Support**

An essential part of coping is being able to use appropriate and beneficial coping strategies. These strategies can aid in accurately appraising and processing the stressor before employing a suitable action, which can mitigate the effects of the stressor. From prior research, it appears that SCC’s ability to cope may be dependent on two factors: their past experiences and
their subjective appraisal of their sibling’s cancer (Barbarin, et al., 1995; Lazarus & Folkman, 1984; Sloper & While, 1996).

**Past Experience**

In the group intervention, SCC’s past experience was addressed by using principles from Cognitive Behavioral Therapy. SCC were encouraged to revisit their past by sharing and communicating their experience with the group. Group facilitators were then able to address and rectify unrealistic conceptions, assumptions, expectations, evaluations, and beliefs that were hindering the SCC’s ability to cope. For instance, if SCC expressed the belief that their mother stayed at the hospital so much because she loved their sibling more than she loved them, the belief was examined and alternate explanations were explored. It was important not to let the false belief linger because it could mar future subjective appraisals. Teaching SCC alternative methods of appraising the negative experience, such as focusing on the whole picture, was thought to play a part in improving their coping skills and ultimately reducing their symptoms of anxiety and depression. Other studies have found that, when SCC were able to embrace accurate views, their symptoms of anxiety and depression diminished (Houtzager, et al., 2004; Lobato & Kao, 2002). Furthermore, by participating in the intervention, SCC were given the opportunity to express their true feelings without being judged. This was probably also protective in that it allowed for deeper, more complicated, feelings to emerge, be shared and ultimately resolved. Thus, it is
hypothesized (although this was not directly tested in this study) that less-
resilient SCC who took part in SibCT had many more misconceptions and
unresolved feelings about the cancer experience than did the more-resilient
SCC. By participating in the group, such fallacies were addressed and, as a
result, less-resilient SCC were better able to cope, in that way diminishing
their symptoms of anxiety and depression. The more-resilient SCC may have
had fewer misconceptions to begin with.

**SCC’s Subjective Appraisal**

Through participating in the intervention, SCC were taught positive
cognitive appraisal. Positive cognitive appraisal is defined as the ability to
process the stressor as being controllable (Lazarus, 1984). Positive cognitive
appraisal is a protective factor that has been shown to enhance adjustment to
cancer in a sibling in several studies (Barrera, et al., 2004; Sahler, 1997). For
this reason, SCC were taught to reappraise difficult situations and take control
of the problem, instead of adopting an attitude of helplessness. Given that
positive cognitive appraisal has been shown to partially mediate the
relationship between adaptation and resilience (Wallander & Varni, 1992),
less-resilient SCC who were helped to accurately understand the implication
of the stressor were better prepared to implement an action that could resolve
their problem. As a result, they became more resilient. The more-resilient
SCC had presumably learned these lessons before attending group.
**Optimism**

Furthermore, SCC who took part in the intervention were also taught to be optimistic. Optimism is reported to be important protective factors when facing adversity (Packman, et al., 2006). SCC were taught to be optimistic by re-evaluating adverse events in a more positive light. For example, if SCC expressed the feeling that they missed their mother because she was at the hospital with their ill sibling, the group facilitators would reframe this negative feeling by suggesting that this was an opportunity to spend more time with their father, allowing them see the ‘silver lining’ behind their concern. Houtzager, et al., (2004) found that SCC who remained optimistic throughout the cancer experience tended to cope better.

Thus, it may be that encouraging both a sense of control and a sense of optimism helped less-resilient SCC to become better copers and reduced their symptoms of anxiety and depression following intervention. The already resilient SCC may already have felt optimistic and in control before starting the group so the effect for them was not as great.

**Empathy**

Empathy was also modeled and induced in the group so that SCC began to understand cancer’s psychological effect on the all members of the family. SCC who participated in SibCT were taught to empathize with family members feelings through fun activities and games. Research has shown that,
when SCC are able to empathize with other family members’ feelings, they tend to exhibit fewer symptoms of psychological distress (Labay & Walco, 2004). Labay and Walco (2004) states on the basis of empathy that children who are less effective at understanding the emotional states of others have difficulty communicating their own emotional needs and may, instead, resort to impulsive or aggressive means of expression. In their study, SCC who were informed through intervention about the impact of cancer on the whole family were better able to adapt to the cancer experience than SCC who were not (Labay & Walco, 2004). It may be that being informed allows SCC to understand differences in the allocation of family resources (e.g., parents’ time and attention, finances, privileges) that are common to the cancer experience. It is hypothesized (though not directly examined in this study) that the level of empathy may have increased by participating in the intervention and this led to reduced symptoms of anxiety and depression in less-resilient SCC. The already resilient SCC probably did not need their empathy raised.

**Educational Support**

Before SCC can fully appraise their family situation, they need to have all the necessary information pertaining to it, including some medical knowledge about cancer. Research (Evans C, Stevens M, Cushway D, et al., 1992; Kramer RF, Moore IM. 1983; Sourkes B, 1980) has shown that SCC with little medical knowledge have greater difficulty in adapting to the cancer
in the family than those more knowledgeable. SCC often witness their brother or sister enduring painful medical procedures, being sickened by medicines and gradually going bald, but many do not have sufficient medical knowledge to understand what is really happening to their sibling and some may not have access to resources that would help them find this information. In fact, some SCC believe that cancer is contagious, leading to unnecessary concerns and fears (Alderfer, et al., 2010). These unrealistic concerns and fears may develop into symptoms of anxiety which can be detrimental to the SCC’s well-being. Moreover, many parents themselves do not understand the disease and therefore do not have the necessary knowledge to be able to teach the SCC (Sahler, 1994). For this reason, SCC who participated in the intervention were provided with age appropriate medical information by a guest nurse. SCC were also given the opportunity to ask questions about cancer, treatments for cancer, and potential outcomes. It may be that less-resilient SCC lacked this knowledge prior to the intervention, although this was not directly tested. If that were so, the extra information may have played a role in reducing their psychological distress, whereas the more-resilient SCC may have had more knowledge to start with. Other studies have also found that psychological distress decreased when SCC were provided with medical information. For example, Sahler and Carpenter (1991) found that providing cancer-related knowledge reduced fear associated with cancer. Similar results were also found by other researchers (Barrera, et al., 2004; Dolgin, et al., 1997; Houtzager, et al., 2001; Lobato & Kao, 2002; Roeyers &
Mycke, 1995; Sahler & Carpenter, 1989; Sidhu, et al., 2006; Williams, et al., 2003) who have reported a positive relationship between SCC’s knowledge about cancer and their level of psychological distress, which has included anxiety, fear, depression and behavioural problems.

**Social support**

Social support from peers, family and other members of the community has been identified as an important protective factor that reduces risk and promotes coping (Barrera, et al., 2004; Carpenter & Sahler, 1991; Varni & Katz, 1997; Varni et al., 1994). SCC with higher perceived social support reported greater self-esteem, and higher self-esteem has been positively correlated with SCC’s level of psychological distress (Cohen, 1994). The turmoil introduced by a sibling’s cancer can make SCC lives overwhelming and hectic, and, as a result, limit their ability to maintain and utilize their social networks (Houtzager, et al., 2001). Furthermore, friends may be unable to relate to the problems of SCC since they have not experienced similar situations. As a result, many SCC may feel isolated and alone with their experience.
By participating in the group, SCC were exposed and introduced to other SCC with similar problems. This allowed them to understand that there are other children with similar experiences and concerns, that they are not alone. Many studies have shown that increased social support can enhance psychological well-being by allowing SCC to gain a sense of consistency and belonging (Barrera et al., 2004; Houtzager, 2001). Moreover, the group intervention gave SCC the chance to act like kids and to have fun with their peers. SCC were given the opportunity to participate in activities that interested them. This allowed them to maintain a sense of normalcy as well as giving them the chance to forget about their brother/sister’s illness, even if only for a while. Sloper (2000) found that, when SCC were asked what they do to cope, the most commonly listed coping mechanism was participating in extracurricular activities (Sloper, 2000). It was suggested by the author that when SCC participated in extracurricular and after-school activities, they were less isolated and felt less lonely. This intervention program was designed to be “fun,” and SCC saw it as entertaining and interactive.

In addition to peer social support, the literature has emphasized the support of mentors. These important people are also known as teachers, coaches, counselors, ministers, and neighbours. Children who are more resilient to adversity have been reported to have a caring adult other than their parents in their lives (Masten & Powell, 2003). Such adults tend to listen and
help SCC put their problems into a more constructive perspective (Masten & Powell, 2003). Studies have shown (Benoliel, 1970; Rollins, 1990) that SCC often reveal significant information to their mentors that may be unknown by family members. Without these invaluable individuals, SCC may have no one to turn to for help dealing with cancer in the family. SCC in the intervention had the opportunity to interact with facilitators and to even share concerns in private, if needed. Therefore, this intervention program had the potential to increase not only peer support but also to provide SCC with a mentor. This increased support, though it was not directly tested, may have played a role in reducing less-resilient SCC’s symptoms of depression and anxiety following intervention. More-resilient SCC may already have had sufficient social support.

**Parental Support**

The SCC-parent relationship is another important potentially protective factor identified in the literature. Masten and colleagues (2003) suggest that, by enhancing the quality of parenting, one can enhance competence and increase resilience. One way to enhance the benefits of parenting is through increased conversation about thoughts and feelings related to the cancer experience (Hamama, et al., 2000). This was shown by Waechter (1971, cited in Walker 1993), who reported that when SCC were not left in dark about their brother’s/sister’s prognosis and were able to openly talk to their parents about the disease, they experienced less anxiety than SCC who were
protected and had difficulties talking to their parents about the disease. In fact, Evans et al.’s (1992) estimate that only one in four SCC talk to their parents about cancer while approximately one third of SCC talk to no one. One possible explanation for this finding may be that SCC 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). For such reasons, SCC in the group were encouraged to have open communications with their parents and most homework which was assigned as part of the intervention ensured that such interaction occurred.

Another means of enhancing the benefit of parenting is by enhancing parent-SCC cohesion. This is supported by Kazak and her colleagues who reported that in families with greater cohesion, where parents are emotionally available, SCC adjust relatively better to their sibling’s cancer (Horwitz, & Kazak, 1990). SCC often perceive their parents to be emotionally unavailable even when they are in close physical proximity (Bendor, 1990). The decrease in attention that the SCC receives from a parent when their sibling is ill can have detrimental effects on the child. The SCC can feel unloved, unimportant, isolated, lonely, and/or insecure (Houtzager, et al., 2004; Terzo, 1999). Although this was not tested, SCC who participated in the group may have received extra individual attention from parents during the trips to and from the hospital. In fact, some SCC mentioned that after group sessions they spent
one-on-one time with their mother/father, something they had not done before.

It may be that SCC who were initially more-resilient were so because they received adequate support from their parents, which less-resilient SCC may have lacked. Increase social support through parental attention may have played a part in reducing reported psychological distress in the less-resilient SCC.

Hypothesis 1, that less-resilient SCC had a greater decrease in scores of psychological distress at the end of the intervention than did more-resilient SCC, thus appears valid because many aspects of the intervention addressed factors that were designed to increase resiliency. The more-resilient SCC, whose scores at the beginning of treatment were already low, may not have been able to benefit as significantly. For this reason, the intervention was expected to be beneficial to the less-resilient group. Moreover, since the more-resilient group did not benefit as much, we considered that group as the comparative group, since their average mean was similar to the normal population.

To further investigate which factors may have influenced intervention effects for the less-resilient SCC, certain factors such as age, gender, type of cancer diagnosed in the ill sibling, time since diagnosis, and birth order relative to the ill child were explored in this study. Only gender was found significant when STAIC differential scores were examined and the ill child’s diagnosis was significant when CDI differential scores were examined.
Age

Although multiple researchers have documented that age of the SCC at the time their sibling is diagnosed with cancer is a powerful determinant of distress in cross-sectional studies, this was not confirmed in this study (Barbarin, et al., 1995; Hamma, et al., 2000; Sargent, et al., 1995). The hypothesis that less-resilient SCC under age 11 would show greater improvement post intervention than less-resilient SCC over age 11 was not supported. This finding does not necessarily contradict conclusions reported in the literature. Young age may in fact be a contributing factor to distress, but the intervention may have addressed age differences and may, therefore, have cancelled out age effects. For instance, one factor that was addressed through the intervention was cancer-related knowledge. Studies have shown that older SCC tend to know medically related information about cancer that younger SCC lack (Houtzager, et al., 2004). As a result, young SCC experienced high levels of fear and worry that their brother/sister would not survive, that all members of the family would get ill, that the illness was contagious, and other irrational fears. Given that SCC in the intervention received accurate and complete information about cancer, delivered in an age appropriate way, such age-associated distress could have been obliterated.

Based on prior research, empathy was also found to correlate significantly with age (Labay & Walco, 2004), with older SCC having an increased ability to express empathy than younger SCC (Labay & Walco, 2004). Through the intervention, all SCC were taught to be empathetic to others and, perhaps, by
participating in the intervention, age difference in empathy (an important factor in distress, as explained above) was reduced.

Lastly, young SCC are more affected than older SCC by parental absence (Barbarin, et al., 1995). With the reduction in parental attention and opportunities to engage in after-school activities, this increased isolation and stress all lead to psychological distress, especially in the young (Sindu, et al., 2006). However, it may be that the intervention provided the young SCC with enough social support to decrease their sense of loneliness and, in turn, to cancel out the benefits of older age. Moreover, perhaps 11 years old was not the correct cut off and differences may be have been noticed if a different cut off was used

**Gender**

In this study, the hypothesis was that, among less-resilient SCC, girls would not respond as well to the intervention as boys. This hypothesis was partially supported as gender was associated with SCC reported symptoms of anxiety, with males experiencing fewer symptoms of anxiety based on the differential STAIC than females following intervention. However, the hypothesis was not supported when symptoms of depression or parent reported symptoms of anxiety were examined. Female SCC may have increased household responsibilities when a sibling is ill and may be more involved than male SCC are with their sibling’s illness. This may have been more disrupting to their daily lives and caused relatively greater stress, in part accounting for their elevated (compared to male SCC) symptoms of anxiety (Houtzager, et al., 2004) and this may have persisted
despite intervention. Another explanation for reports of greater anxiety by girls is that females in the North American culture are more open to expressing their feelings than boys (Hamana, Ronen, & Rahav, 2008). Female SCC’s higher rate of symptoms of anxiety may be due to the fact that they felt more comfortable than boys in reporting such symptoms. Perhaps, even though boys were taught to express their feelings during the group, this difference persisted and girls continued to freely express more anxiety. This conclusion is supported by the fact that, judging by parents’ reported symptoms of anxiety, there was no difference between boys and girls. It is possible, of course, that girls were more anxious but the parents were not attuned to the fact.

The finding that female SCC did not experience a lesser drop of symptoms of depression than male SCC has to be squared with previous research (e.g., Alderfer, et al., 2004; Hamama, et al., 2000), which suggests that females SCC experience more symptoms of depression in general than male SCC and symptoms of depression improve to a lesser degree following intervention (Barrera, et al., 2004). Gender differences may have also been equalized through intervention. Thompson & Gustafson (1996) found that female SCC receive less social support than males and that might have been well addressed by the group so that the drop in depression scores was the same for male and female initially less-resilient SCC.
**Time since Diagnosis**

The hypothesis proposed that less-resilient SCC of siblings with a recent diagnosis would report greater improvement on symptoms of anxiety and depression following intervention than less-resilient SCC of siblings with a diagnosis that had been made a longer time ago. This hypothesis was not supported. It was speculated that time since diagnosis might be related to distress because it influences how much time parents spend at home or in the hospital (Houtzager, et al., 2004; Terzo, 1999). The literature on this topic is mixed as some studies suggest that siblings of children newly diagnosed may experience greater distress and that, as time progresses, SCC have sufficient time to adjust, assimilate, and normalize their difficulties. Perhaps, given that participants in the intervention are provided with social, therapeutic and educational support, adjustment may have been enhanced and time since diagnosis may no longer have played an important part in the experience of distress. Moreover, there are also studies that suggest that SCC can experience psychological distress many months and years after diagnosis, that they don’t merely “get used” to the idea. Continuing difficulties reflect continuing stressors and uncertainties related to extended treatments, cancer relapse, late and/or long-term side effects (e.g., Alderfer, et al., 2003; Lown, et al., 2008). Whatever the reasons, SCC whose sibling had been recently diagnosed and SCC whose sibling had been diagnosed over a year prior to the start of group improved to the same extent after intervention. Moreover, although the literature suggests that SCCs’ psychological distress seems to be more pronounced in the
early stages from 6 to 12 months after diagnosis it may be that no difference was noticed because the 12 month cut off was used instead of the 6 month cut off.

Diagnosis

The diagnosis of the child with cancer was hypothesized to be an important determinant of extent of improvement from the intervention. Specifically, a diagnosis of brain tumour, with its devastating effects on the ill child was expected to predict lesser improvement in less-resilient SCC scores. Our results showed that this was true for SCC depression scores but not for anxiety scores.

Although this was not directly tested, brain tumours may have been perceived to carry more risk of complication and death than other cancers such as leukemia, lymphoma, and other tumours. SCC whose siblings are diagnosed with brain tumors may be required to cope with greater uncertainty about the survival of their brothers/sisters, pervasive late-effects, and possible behaviour changes post treatment (Houtzager, et al., 2001).

Moreover, in addition to their own worries, SCC whose siblings have brain tumours also witness the parallel emotional suffering of their parents. Such emotional state may be related to more reported symptoms of distress in parents of children with brain tumours (Fuemmeler, Mullins & Marx, 2001). Although the intervention attempted to address such concerns, it may be that these SCC require additional information or attention that, considering their unique needs, was not sufficiently provided. On the other hand, it may be that their symptoms of anxiety were addressed through intervention since their
symptoms may have been associated with excessive, unrealistic worry and fear about the disease. Such anticipation may have been addressed by the guest nurse who provided age appropriate medical information during intervention. Thus, such results suggest that these SCC may have been less preoccupied with fears such as heredity or contagion following intervention.

**Sibling’s Birth Order Relative to the Ill Child**

Presently, there is a lack of research evaluating the influence of birth order on SCC level of psychological distress although, intuitively, an SCC older than the ill sibling might feel more responsible and, therefore, more distressed. Accordingly, the present study hypothesized that less-resilient SCC younger than the ill child would experience greater improvement following intervention than less-resilient SCC older than the ill child, whose feeling of responsibility would be harder to assuage. No significant differences were found for either CDI differential scores or STAIC differential scores.

As a more exploratory step following the primary analyses, interactions were examined as possible predictors of improvement in psychological distress following intervention. Only significant interactions will be discussed in the following section.

**CDI differential score by diagnosis and age; gender and diagnosis**

When the interaction between diagnosis and age was examined, the results suggested that younger siblings (age 11 or under) of children with cancers other
than brain tumour improved significantly more following intervention compared to equally young SCC of children with brain tumours, and to all older SCC (over age 11). The interaction between diagnosis of the ill child and the age of the SCC may be due to differences in understanding the illness. For instance, younger SCC may not fully understand the long-term implications of cancer, and may not, therefore, be as affected by the ill child’s potential prognosis as older SCC. Brain tumours have a worse prognosis than other childhood cancers; even young SCC appear to appreciate this nuance (Houtzager, et al., 2001) and the group, perhaps, is less able to recognize or address the emotional distress of younger children than it can for older children dealing with the worry of brain tumour.

Research has posited age and gender as factors influencing adaptation to the cancer in the family experience (Hamama, et al., 2000; Houtzager, et al., 2004). Specific cancer diagnosis and gender however, have not received much coverage in the literature and for this reason this section may be more speculative than evidence based. Compared to children diagnosed with other cancers, children with brain tumours often need additional care, usually performed by female SCC (Houtzager, et al., 2004; Sahler, et al., 2004). This additional involvement may increase perceived stress. Moreover, such increased responsibilities may also cut into social contacts and activities with friends, reducing social support for female SCC of siblings with brain tumours. This extra demand may tax coping resources, potentially leading to psychological distress (Bearman Miller & La Greca, 2005; Houtzager, et al., 2004). The results of this study suggest that female SCC with a brother/sister with non-brain tumour cancers improved significantly more from the intervention than female SCC with a brother/sister with brain tumours, and more than all
male SCC. The results suggest that the resources provided through intervention to female siblings of children with brain tumours may not have addressed their unique and individual needs for managing the extra demands made on them. On the other hand, male SCC may not contribute as much to the household responsibilities, be as involved with the illness, are less restricted and hence experience fewer disruptions in their daily lives (Houtzager, et al., 2004). Thus, male SCC may be more disconnected from the ill child and stay emotionally at arm’s length and, as a result, may not be as affected by the cancer experience when compared to female siblings.

**Diagnosis and Birth order**

No interaction was noticed when diagnosis and birth order were examined as factors influencing CDI differential scores. However, a simple main effect was found for diagnosis that showed SCC of children with cancers other than brain tumours reported significantly greater improvement of symptoms of depression than SCC of siblings with brain tumours, independent of birth order. Again, the impact of brain tumour in the ill sibling appears to be of major importance.

In summary, the group intervention was successful in lowering the psychological distress on the initially less-resilient SCC through the provision of therapy, education, and social support. A relative lack of success on the part of the intervention was most evident in SCC, especially older SCC, who are dealing with the stress of brain tumour in a sibling. The only factor found to significantly influence STAIC differential scores (e.g. improvement in anxiety) was gender, boys improving more than girls. However, when CDI differential scores (e.g.
improvement in depression) was only influenced by the ill child’s specific diagnosis of brain tumour.

**Limitations**

There are several limitations that affect the generalization of this study. First, a major problem with the pre-post design is that it is difficult to attribute positive changes to the intervention since some may be due to the effects of time rather than to the intervention. This problem could be solved with the use of a two pre-tests that are 8 weeks apart and a post-test design to account for the effects of time. However, the ultimate design which would account for most threats to internal validity is a randomized control trial (RCT) design, which is considered the gold standard for intervention research. For instance, to assess the efficacy of the SibCT intervention program, an experimenter can compare the experimental group (EG) – receiving SibCT intervention group – and the attention control group (CG) – receiving an activity program following intervention, and potentially 3 months later to assess sustainability of intervention effects. The CG can be conceptualized as an alternative group intervention focused only on recreational activities, a sham group. Unlike the EG, sessions in the CG group will not be structured around the themes described in the SibCT manual but instead, will be recreational in nature without the therapeutic and educational aspects of SibCT. The CG can be designed to control for potential effects of attention (8 sessions), time (1.5 to 2 hours each) and the Hawthorne effect (parent and sibling bias of knowing that they are receiving group intervention), potential threats of experimental bias. However, if a RCT is not feasible, another form of control could be an eight week wait group to account for the effects of time.
A second limitation of this study is that the same instruments were used to separate participants into the two main groups (less-resilient and more-resilient) as were used to measure improvement. By definition, those in the less resilient group started off with a higher score and, therefore, had more scope to improve. Their greater improvement could, therefore, be a statistical illusion-regression towards the mean. (Barnett, Van der Pols & Dobson, 2005). Given that I did not design this study; potential design changes that could have controlled for regression towards the mean include having SCC randomly allocated to two interventions, sham and treatment. By using this design the responses from both groups should be equally affected by regression towards the mean. The mean change in the sham group will provide an estimate of the change caused by regression toward the mean (plus any sham effect). The difference between the mean change in the treatment group and the mean change in the sham group is then the estimate of the treatment effect after adjusting for regression towards the mean (Barnett, et al., 2005). If a RCT is not feasible, generally regression to the mean increases with larger measurement variability. To reduce such variability in future studies SCC with a high level of psychological distress could be selected using two or more baseline measurements. The selection criterion (i.e. a cut-off) can then be applied to either the mean of the multiple measurements, or the later measurement, this method assumes that the regression toward the mean effect has taken place between the initial and later measurements (Barnett, et al., 2005). This method of taking an extra outcome measure allows for a better estimate of each subject’s true mean before the intervention.

An alternative design that would control for regression towards the mean would be to divide the two groups using a different instrument to define resilience, one that is not
used as the outcome instrument. Considering I did not have input into what measures to use, different instruments could have been used pre, and post. For example an instrument that could have been used to categories more-resilient and less-resilient siblings at baseline would be the Resiliency Scale for Child and Adolescents (RSCA). The RSCA is composed of three stand-alone global scales of 20-24 questions each and ten subscales: Sense of Mastery Scale: optimism, self-efficacy, adaptability; Sense of Relatedness Scale: trust, support, comfort, tolerance; Emotional Reactivity Scale: sensitivity, recovery, impairment (Prince-Embury, 2008). This scale is relatively new and was not available to our research team when the data for this study was first collected. Furthermore, considering I was only adding a small sample to an already existing database I had to keep my instruments consistent. Nevertheless, future studies may want to consider using this scale as a screening tool in determining which children may most benefit from a psychosocial intervention program.

Third, there are also limitations related to the self-report instruments. Foremost, parental and sibling reports may not fully and accurately reflect the psychological distress associated with SCC experience. Some SCC may deny or fail to perceive and report psychological distress, due to social desirability (Barrera, et al., 2004; Fife, et al., 1987; Sharpe & Rossiter, 2002). On the other hand, parents may underreport or not accurately report psychological distress because they may be too busy attending to the ill child’s needs and thus unaware of the SCC’s concerns (Barrera, et al., 2004; Houtzager, et al., 1999). For instance, parental reports in other studies have been shown to underreport sibling psychological distress compared with what siblings themselves report (Murry, 1999). Some parents are not always able to detect problems in the sibling’s psychosocial
functioning (Houtzager, et al., 2004). Often, parents themselves are burdened and overwhelmed and therefore may be less capable to judge or detect changes in SCC’s emotions (Cohen, et al., 1994). Also, some SCC may conceal their emotions from their caregivers, in order to protect them from additional distress (Carpenter & Sahler, 1991). Moreover, parents mostly report psychological distress noticed at home. For such reasons, researchers should use multiple informants including, for example, teachers, in investigating the psychological distress of SCC and to understand SCC’s adjustment in other contexts such as the school environment.

Fourth, in consideration of the limited sample size it was necessary to decide which outcome measures best assessed intervention effects. Symptoms of anxiety and depression were used in this study because those were reported to be most common and longest lasting in SCC. Also, since all our preliminary studies included anxiety and depression scores as outcome measures it was most appropriate that we continue assessing anxiety and depression scores as outcome measures for this study since we were adding to a large dataset. Nevertheless, there are a few other standardized instruments that may be useful for assessing intervention effects. For example, quality of life instruments may be useful for looking at sibling adaptation to the cancer experience. These scales generally assess children’s daily functioning across physical, emotional, and social context. The Pediatric Quality of Life Inventory (PedsQL 4.0) is well established 23-item standardized generic measure of health related QOL with a self-report and a parent proxy version (Varni, Seid, & Rode, 1999). Both versions of this measure could be used in this study to assess the SCC overall adaption to the cancer experience, allowing researchers to assess the global impact of intervention effects
Furthermore, family variables such as maternal distress may also influence siblings’ psychological adjustment to the cancer experience (Cohen, et al., 1994). Within the family, emotional and behavioral difficulties are interrelated and can negatively impact all family members (Kazak, et al., 1997). Mothers who had a chronically ill child reported significantly higher depression levels than normative values (Prabucki, 1987). For example, Cohen et. al. reported that the greater the severity of maternal anxiety the greater the difficulties siblings had in adjusting to the new cancer situation (1994). This association between maternal distress and child’s intervention outcomes could have been examined. In addition to measuring maternal distress as a predictor variable for psychological distress, we could have examined the indirect outcome of the intervention on maternal distress.

Finally, the division of all cancers into brain tumour and other is somewhat arbitrary. Perhaps a better division would be to divide cancers into relatively good prognosis and relatively bad prognosis cancers, assuming that it is the prognosis that confers the extra stress on SCC.

**Direction for other Future Research**

Several recommendations can be made for future research in this field. To establish the efficacy of intervention programs as mentioned above, a randomized controlled or waitlist control designs could be used in future studies. Several researchers indicate that RCT studies are not feasible because of the small number of potential subjects available in the population; however, this could be overcome by conducting a multisite
collaborative study. Also, more follow up studies are needed to assess the sustainability of these intervention programs in the long run. Furthermore, since many factors influence intervention outcomes, the relationship between other variables (age, gender, diagnosis, maternal distress, social economic status, for example) should be further examined as mediating or covariate factors. Future studies should also compare different therapy settings (group, camp, individual for example) and explore which intervention settings are most beneficial and effective. Although post-intervention effects were evident at 8 weeks, potential studies may want to consider a longer duration than 8 weeks. Overcoming symptoms of depression or anxiety takes time. SibCT encourages SCC to face their problems, so these SCC may feel worse before they feel better. Such thought may reflect greater depression or anxiety symptoms following intervention. Considering siblings of children with brain tumours did not improve as much as the other subgroups, the group could be extended in order to spend more time on issues of prognosis, disfigurement, late behavioural problems, the main issues involved in brain tumours. Moreover, it may seem that females did not do as well because females open up more, if this is the case we could make suggestions for more male facilitators and male-type activities to help boys open up. Lastly, follow-up studies to evaluate the durability and sustainability of these changes over time should also be considered.

**Conclusion**

Siblings of children with cancer all react somewhat differently to the cancer experience. Some SCC are more resilient to the cancer experience than others. The objective of this study was to investigate the effects of a specialized intervention for SCC on more-resilient and less-resilient SCC. Such investigation prevents wasted valuable
resources on SCC who may not benefit from such intervention and highlights the importance of screening for SCC who are at risk and in need. It was hypothesized that less-resilient SCC would report significantly greater improvement following intervention compared to more-resilient SCC because the group intervention was specifically designed to increase resilience. As assumed, less-resilient SCC reported significantly greater improvement on symptoms of anxiety and depression following intervention. In the literature, age, gender, diagnosis and time since diagnosis and birth order relative to the ill child have been reported as variables that influenced SCC’s psychological distress. For this reason, in this study these five factors were tested as predictors of less-resilient SCC improvement following the therapeutic intervention. Gender was the only variable found to predict differences in improvement of anxiety (boys improved more than girls) and the diagnosis of brain tumour was the only variable that predicted differences in improvement of depression (the SCC’s depression was more likely to improve if their sibling’s diagnosis in NOT brain tumour). Furthermore, an interaction was found for gender and diagnosis on CDI (depression) differential scores. This showed that female SCC with a brother/sister with non-brain tumour cancers improved significantly more than all other categories. Furthermore, when the interaction between diagnosis and age was examined, a significant result was also found. Younger siblings of children with non-brain tumour cancers improved significantly more on symptoms of depression following the intervention than all other categories. These results suggest that the intervention that was provided may not have addressed the unique needs of siblings of children with brain tumours. This suggestion needs to be further investigated.
References


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APPENDIX A
Title of Project: Group Therapy for Siblings of Children with Cancer

Investigator: Dr. Maru Barrera 416-813-6784

Purpose of Research:
When a child is diagnosed with cancer, all family members are affected by the demands of treatment and the ensuing disruptions to family life. Children like yourself who have a brother or sister with cancer often experience changes in their care at because your brother or sister requires a lot of attention and care. It might be difficult to do things with your brother or sister because he/she does not feel well. Many children find it very difficult to deal with all of the changes, and with having to see their brother or sister sick a lot of the time. There might also be times when your parents have to go to the hospital and stay with your sick brother or sister and you cannot do the things that you would like to do. Or you may not get to see one or both of your parents as often as you would like.
The main objective of this study is to see if a group program for siblings of children with cancer helps you cope with these new and difficult experiences.

Description of the Research:
One way that staff have tried to help children like yourself deal with your brother’s or sister’s illness is by inviting them to meet with other children who also have a brother or sister with cancer. They can share their experiences and help each other to learn how to deal with the changes more effectively. In our group, we would like you to meet with other children who have a brother or sister with cancer for 8 weeks to share your thoughts and experiences and to learn how to deal with difficult situations. We want to know how well our program is in helping children deal with a brother or sister’s cancer.

What will happen in this study and during the group?
First, you and one of your parents will be asked to complete a few questionnaires about your thoughts and feelings. Then, about 8 weeks you will be asked to complete these same questionnaires one more time. The group has 8 sessions. You will come once a week for one and a half hours each. We will ask you to participate in activities such as drawing and games, and in discussions about topics related to your brother or sister’s illness, relationships with your parents, other family members, and your friends. Guest speakers will also be invited to talk to you for special sessions. After the group ends, we will ask you to answer the same questions about your brother or sister’s cancer, and about yourself and your family. Your answers will tell us how helpful you think our program is.
in helping you deal with all the changes that have occurred in your life since your brother or sister got sick with cancer.

**Potential Harms:**

We know of no harm that taking part in this study could cause you. Any concerns that may arise during the course of the program will be dealt with directly in the sessions. However, if specific issues cannot be resolved within the group, it will be recommended to you and your parents to request additional support by contacting the primary physician or primary nurse.

**Potential Inconvenience:**

You may experience some inconvenience by traveling to the hospital for the required assessments and 8 weekly group sessions.

**Potential Benefits:**

- Children who have a brother or sister with cancer and participate in the intervention group program may benefit from the educational and supportive nature of the program.
- The families of these children may also benefit from having some of their needs addressed which, in turn, may result in reduced family stress.
- The development of this group intervention program and establishing its effectiveness may benefit other siblings and their families in the future.

**Confidentiality:**

We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this.

SickKids Clinical Research Office Monitor, employees of the company funding the study [name] if any, or the regulator of the study may see your health record to check on the study.

By signing this consent form, you agree to let these people look at your records. We will put a copy of this research consent form in your/your child’s health record.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required by the SickKids “Records Retention and Destruction” policy. The data will then be destroyed according to this same policy.
Participation:
It is your choice to take part in this study. You can stop at any time. The care you get at SickKids will not be affected in any way by whether you take part in this study. New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

Consent:
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private. You will give no one information about me, unless the law requires you to.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to _____of this consent form. I agree, or consent, to take part in this study

________________________                      __________________________
Printed Name of Subject & Age                      Subject’s signature & date

________________________                      __________________________
Printed Name of person who explained consent                      Signature & date

________________________                      __________________________
Printed Witness’ name (if the subject/legal guardian does not read English)                      Witness’ signature & date

If you have any questions about this study, please call Dr. Maru Barrera at 416-813-6784

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at (416) 813-5718.”
PARENT CONSENT FORM

Title of Project: Group Therapy for Siblings of Children with Cancer

Investigator: Dr. Maru Barrera 416-813-6784

Purpose of Research:
When a child is diagnosed with cancer, all family members are affected by the stressors associated with the illness and the ensuing disruptions to family life. Healthy siblings of children with cancer often experience distress after diagnosis, during treatment, and/or post-treatment, which often lead to behavioural and/or socio-emotional problems. The main objective of this project is to evaluate the effectiveness of a group program for siblings of children with cancer in improving coping abilities and their psychological well-being.

Intervention: The intervention program will consist of 8 sessions that are 1 and 1/2 hours each. The program will provide children with accurate and age-appropriate information regarding different types of cancer, diagnoses and treatments. A guest speaker will be invited to talk to the children for some sessions. Children will have opportunities to express their feelings and experiences in a safe, supportive and fun environment and to learn how to cope with their feelings or difficult situations. They will also have the chance to meet other children who are experiencing similar difficulties. During the evaluation sessions, children will be asked to relate their knowledge about their brother’s or sister’s illness, their feelings, and how they try to cope with their circumstances.

Evaluation: For the evaluation of the program, we will ask you and your child to fill out some questionnaires about your child’s behaviour and moods, as well as answer some questions about your family. We will ask you and your child to complete these questionnaires when you enroll in the group, after 8 weeks (if you are in the waitlisted intervention group), during the first and last sessions of the intervention.
**Potential Harms:**
We know of no harm that taking part in this study could cause you. Any concerns that may arise during the course of the program will be dealt with directly in the sessions. However, if specific issues cannot be resolved within the group, it will be recommended to parents to request additional support by contacting the primary physician or primary nurse.

**Potential Inconvenience:**
You may experience some inconvenience by traveling to the hospital for the required 8 weekly group sessions.

**Potential Benefits:**
- Children who have a brother or sister with cancer and participate in the intervention group program may benefit from the educational and supportive nature of the program.
- The families of these children may also benefit from having some of their needs addressed which, in turn, may result in reduced family stress.
- The development of this group intervention program and establishing its effectiveness may benefit other siblings and their families in the future.
- The program is designed to help prevent emotional or behavioural difficulties in your child. If a child is found to have continued socio-emotional or behavioural difficulties, parents will be informed and suggestions for assistance will be provided.

**Confidentiality:**
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this.

For example, the law could make us give information about you
- If a child has been abused
- If you have an illness that could spread to others
- If you or someone else talks about suicide (killing themselves), or
- If the court orders us to give them the study papers

SickKids Clinical Research Office Monitor, employees of the company funding the study [name], or the regulator of the study may see your health record to check on the study. For example, people from Health Canada Health Products and Food Branch, U.S. National Institutes of Health, and U.S. Food and Drug Administration, if necessary, may look at your records.
**Participation:**
It is your choice to take part in this study. You can stop at any time. The care you get at SickKids will not be affected in any way by whether you take part in this study. New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of having my child take part in this study. I understand that I have the right to refuse to let my child take part in the study. I also have the right to take my child out of the study at any time. My decision about my child taking part in the study will not affect my child’s health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private. You will give no one information about my child, unless the law requires you to.
6) I understand that no information about my child will be given to anyone or be published without first asking my permission.

7) I have read and understood pages 1 to 3 of this consent form. I agree, or consent, that my child___________________ may take part in this study.

__________________________________________
Printed Name of Parent/Legal Guardian & date

__________________________________________
Parent/Legal Guardian’s signature

__________________________________________
Printed Name of person who explained consent

Signature & date

______________________________
Printed Witness’ name (if the parent/legal guardian does not read English)

Witness’ signature & date

If you have any questions about this study, please call Dr. Maru Barrera at 416-813-6784.

If you have questions about your rights as a subject in a study or injuries during a study, please call The Research Ethics Manager at (416) 813-5718
Title of Project: Group Therapy for Brothers and Sisters of Children with Cancer

Investigators: Dr. Maru Barrera 416-813-6784

Why are we doing this project?
Children like yourself who have a brother or sister with cancer often experience changes at home and at school because your brother or sister requires a lot of attention and care. It might be difficult to do things with your brother or sister because he/she does not feel well. Many children find it very difficult to deal with all of the changes, and with having to see their brother or sister sick a lot of the time. There might also be times when your parents have to go to the hospital and you cannot do the things that you would like to do. Or you may not get to see one or both of your parents as often as you would like.

One way that staff have tried to help children like yourself deal with your brother’s or sister’s illness is by inviting them to meet with other children who also have a brother or sister with cancer. They can share their experiences and help each other to learn how to deal with the changes more effectively. In our group, we would like you to meet with other children who have a brother or sister with cancer for 8 weeks to share your thoughts, concerns, and experiences. We want to know how well our program is in helping children deal with a brother or sister’s cancer.

What is the purpose of the group?
The group program may help you to learn about your brother or sister’s cancer, how to deal with difficult feelings and situations related to cancer. You will also have the chance to meet other children who are experiencing similar changes, and who can understand your feelings.

What will happen during the group?
We will ask you to join our group for 8 sessions. You will come once a week for 1 and 1/2 hours each. We will ask you to participate in activities such as drawing and games and to learn about topics related to your brother or sister’s illness. Topics will include relationships with your parents, your sick brother or sister, other family members, and your friends. Guest speakers will also be invited to talk to you for special sessions.

Before the group starts, during our first and last sessions, and after the group ends, we will ask you and one of your parents to answer some questions about your brother or sister’s cancer, and about yourself and your family. Your answers will tell us how helpful you think our program is in helping you deal with all the changes that have occurred in your life since your brother or sister got sick with cancer.

**Who will know about what you do in the group?**

If you are part of this group, your name and address will not be given to anyone. Only the staff and students working on this project will know what you and your parent did in this group. If we feel your health may be in danger, we may have to report your results to your doctor.

**Can I decide if I want to join the project?**

If you do not want to join the group, this is O.K. No one will be upset or disappointed. If you say yes now, but change your mind later, you can tell us, and that will be O.K. We are talking to your parent/legal guardians about the study and you should talk to them about it too. Ask them any questions that you do not understand from what you have read or heard. They will help you to understand. Please also ask us any questions, we will also help you to understand.

**ASSENT**

I was present when __________________________ read this form and gave his/her verbal assent. __________________________ Name of person who obtained assent

______________________________

Signature

______________________________

Date