IMPLEMENTING A MANUALIZED GROUP INTERVENTION FOR BEREAVED SIBLINGS: AN ANALYSIS OF FEASIBILITY AND BARRIERS

by

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Abstract

The current study, conducted in two segments, assessed the feasibility of implementing a manualized support group for siblings who had experienced the death of a brother or sister from cancer. Part 1 was carried out with a convenience sample of 10 children, aged 6 - 14 years, who attended the program. With respect to acceptability, retention rates, and treatment fidelity, positive outcomes were obtained. Results of standardized questionnaires completed by parents indicated significant improvements in overall, emotional, and social quality of life, and trend-level reductions in problem behaviours and distress symptoms. Outcomes of siblings’ self-report questionnaires reflected borderline decreases in problem behaviours. Part 2 of the investigation revealed significant recruitment barriers that impeded enrolment when rigorous sampling procedures were utilized. A qualitative analysis of phone recruitment interviews with parents yielded important themes explaining families’ participation declines, including impediments to enrolment, communication with surviving children, and coping with grief.
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Chapter 1: Introduction

1.1 Psychosocial Impact on Siblings When a Brother or Sister Dies of Cancer

When a child is diagnosed with cancer, families experience chronic strain that may tax coping resources, impact quality of life, and affect the psychosocial functioning of the entire family unit (Barrera, Alam, D’agostino, Nicholas, & Scheiderman, 2013; Buchbinder et al., 2011; Eilegård, Steineck, Nyberg, & Kreicbergs, 2013). Although treatment options and survival rates from childhood malignancies have increased in recent decades (Ness & Gurney, 2007), approximately 160 young people under 19 years of age still die from cancer every year in Canada (Canadian Cancer Society, 2013), triggering intense emotional distress in surviving parents and siblings. The death of a brother or sister, particularly when it occurs in childhood, is a unique and often devastating experience that can interfere with socialization and development (Davies, 1999) and run contrary to siblings’ expectations that the relationship will last a lifetime (Conidis, 2005). Moreover, the complexity of the sibling dynamic means that bereaved brothers and sisters have generally developed intense bonds with the deceased, while serving as their antagonists, role models, playmates, and protectors, resulting in strong feelings of loss when this relationship is terminated (Brody, 1998; Davies, 1999; Hogan & Greenfeld, 1991). Even prior to the death, healthy sibling have often already been emotionally affected by witnessing the physical deterioration of the ill child and experiencing changes and disruptions in family life, which may make survivors more susceptible to stress and negative psychological effects when the loss occurs (Barrera et al., 2007). Despite this, the literature to date has primarily focused on the psychosocial impact of adult bereavement, highlighting the importance of further research on bereaved children’s distinct challenges and vulnerabilities (Barbarin et al., 1995; Hogan & Greenfield, 1991; Kandt, 1994).
Following the death of a brother or sister, evidence suggests that grieving children may be at increased risk for disturbances in emotional, behavioural, social and academic domains (Brody, 1998; Davies, 1999; Fanos, Little, & Edwards, 2009; Hogan & DeSantis, 1996; McCowan & Davies, 1995; Weller, Weller, Fristad, & Bowes, 1991). Specifically, surviving siblings have been demonstrated to exhibit higher levels of depression and anxiety (Fanos, 1991), post-traumatic stress symptoms (Alderfer, Labay, & Kazak, 2003), sleep disturbances (Davies, 1993), somatic complaints, loneliness (Nolbris & Hellstrom, 2005), externalizing behaviours (Thompson et al., 2011), and poor school achievement (Balk, 1990). Interviews with bereaved siblings in a study conducted by Foster and colleagues (2011) revealed that personality changes including inhibition or fearfulness, as well as shifts in the dynamics of parent or peer relationships, are other common responses to the death of a brother or sister from cancer. In addition, bereaved siblings often experience altered attitudes toward schoolwork due to concentration difficulties, or loss of interest in activities that were previously enjoyed. Symptoms of anxiety, depression and guilt have been found by some researchers to persist well into adulthood, particularly for those who are adolescents at the time of the death (Fanos & Nickerson, 1991). This, coupled with the fact that social isolation in childhood is a risk factor for social difficulties later in life (Rubin, Bukowski, Parker, & Damon, 1998), underscores the need for early intervention.

1.2 Underlying Reasons for Negative Outcomes Observed in Siblings

Research on the underlying causes for intense psychological distress experienced by siblings during the illness trajectory has indicated that negative symptomatology typically results from observing the emotional and physical suffering of the ill child as well as from a personal loss of attention caused by the family’s preoccupation with the patient’s care (Shannon,
Barbarin, McManus, & Freeman, 1994). In fact, siblings have reported ‘feeling invisible,’ as friends and extended family members focus almost exclusively on the needs of the ill child, often overlooking the social-emotional needs of healthy siblings (Labay & Walco, 2004). Although young people of all ages may suffer adverse psychological effects following a sibling’s cancer diagnosis, younger children and adolescents typically experience distinct challenges during this stressful period. For instance, preschoolers express greatest difficulties associated with lengthy periods of separation from parents, while older children experience concern over the future and a sense of shame or embarrassment linked with the illness (Shannon et al., 1994). As well, impaired functioning in healthy siblings may, at times, stem from an exacerbation of a condition such as envy or sibling rivalry that has existed prior to diagnosis (Shannon et al., 1994).

Although there is limited research on the long term psychological effects resulting from a sibling death and the hypothesized mechanisms contributing to adverse outcomes following a loss, it is hypothesized that feelings of distress associated with living with a seriously ill brother or sister tend to persist, or potentially worsen, after the patient dies (Eilegård, et al., 2013). Moreover, parents who lose a child are often overwhelmed with personal feelings of grief, which may make it difficult or impossible to attend to the unique psychological and emotional needs of bereaved siblings (Auman, 2007). Parental inability to address the needs of healthy children may explain why surviving siblings have expressed high levels of dissatisfaction with the information and support provided to them prior to and immediately following the death (Nolbris & Hellstrom, 2005).

1.3 Psychological Gains in Bereaved Siblings

Despite research indicating increased levels of social-emotional impairments in bereaved siblings, surviving children have been observed to experience psychological gains as
well, including enhanced personal maturity, independence, empathy, self-satisfaction and growth (Kramer, 1981; Kramer, 1984; Sloper, 2000). It is hypothesized that heightened levels of positive traits may occur when siblings successfully fulfill obligations such as caring for younger family members and completing household chores in order to provide support for parents occupied with the care of the ill child (Horwitz & Kazak, 1990). A qualitative study by Foster and colleagues (2011) found that, in addition to viewing themselves as stronger and more capable following the death of a brother or sister, siblings experienced positive changes in their priorities and life perspectives. For instance, surviving children stated that they were less likely to take things for granted and were more appreciative of life. Although some siblings noted impaired relationships after the loss occurred, others expressed that their relationships with peers had strengthened, particularly when friends were able to serve as a source of support in the grief process. Closer relationships with family members were reported as well, given that parents were able to devote more time to their surviving children following the death of the ill child. Foster et al. (2011) hypothesized that the presence of stronger family relationships could be explained in part by bereaved siblings and parents sharing the intimate experience of the illness and death and therefore relying on each other for support. Other researchers have suggested that bereaved children may experience closer relationships with family members due to feelings of protectiveness and responsibility associated with caring for their grieving parents (Mahon & Page, 1995). Interestingly, the areas of positive change observed in bereaved children are consistent with previous research on posttraumatic growth, which has found similar gains in regards to sense of self, relationships and philosophy of life in a significant minority of adults following a trauma or loss (Tedeschi & Calhoun, 1995).

1.4 Function and Dysfunction of Continuing Bonds
There has been increasing attention in bereavement literature on the function of maintaining ongoing connections following the death of a loved one (Field, Nicholas, Holen, & Horowitz, 1999; Field, Gao, & Paderna, 2005; Klass & Walter, 2001; Klass, Silverman, & Nickman, 1996). The notion of continuing bonds, whereby bereaved individuals are emotionally sustained through the act of preserving relationships with the deceased (Field et al., 1999), has been noted to help those who have experienced a loss to work through and live with the death (Attig, 2001). Similar to a recent focus on posttraumatic growth, or positive changes that may occur following a loss, this represents a shift from viewing grief as a pathological process with purely negative consequences to a recognition that grief is a process that can involve ‘active coping’ and psychological gains (Attig, 2001; Packman, Horsley, Davies, & Kramer, 2006; Tedeschi & Calhoun, 1995). Some researchers, however, have noted that ongoing attachments with the deceased can become dysfunctional and result in maladaptive psychological consequences. For instance, when parents and other family members immortalize a dead child by overemphasizing his or her admired qualities or are overly preoccupied with enshrining the memory of the deceased (i.e., altars throughout the house, numerous photos of only the deceased child, daily visits to the graveyard), this may cause surviving children to feel unworthy and “not enough” to make their parents happy (Packman et al. 2006, p. 830). Similarly, when a relationship with a loved one was primarily conflicted or competitive prior to the death, continued connections with the deceased may be disturbing or frightening (Normand, Silverman, & Nickman, 1996; Packman et al., 2006).

The notion of continuing bonds with regard to sibling bereavement has not been well studied by researchers (Packman et al., 2006); however, some findings indicate that the unique sibling relationship means that the death of a child can have profound effects on surviving
brothers and sisters which, in turn, impacts the nature of their continuing bonds. For instance, siblings’ connections and shared history means that when one child dies, survivors essentially lose a part of themselves, which may explain the strong potential benefits for siblings who actively preserve the relationship by maintaining ongoing connections following the death (Davies, 2002). Unfortunately, sibling bereavement is often further complicated by covert and overt messages received from friends and relatives suggesting that the grief of brothers and sisters is naturally less intense and secondary to the sense of loss experienced by mothers and fathers (Devita-Raeburn, 2004; Horsley & Patterson, 2006). This may result in surviving children attempting to protect and remain strong for their parents by repressing and denying their grief and refraining from mentioning the deceased. Packman and colleagues (2006) suggest that parents and healthcare workers can play an important role in facilitating the creation and maintenance of continuing bonds in siblings, thereby counteracting surviving children’s common role as ‘forgotten or invisible mourners.’ Furthermore, continuing bonds can be beneficial in helping siblings to continually reprocess the devastating loss as they renegotiate the relationship with their deceased brother or sister at successive developmental stages in their lives (Devita-Raeburn, 2004).

1.5 Developmental Aspects of Grief

The notion of children’s grief undergoing a transformation with the advent of increased growth and maturity is consistent with research indicating that young people’s understanding of death changes over time in conjunction with natural shifts in cognitive development (Hunter & Smith, 2008). Although there is currently a dearth of knowledge on normal phases in the grief process of children, developmental theory such as Piaget’s (1959) stages of cognitive development can be useful in conceptualizing how changes in intellectual functioning at different
stages of development impact children’s ability to comprehend the concept of death. Specifically, Piaget’s work suggests that infants and young toddlers understand events in terms of direct experience, which means that even preverbal children are aware that a death or trauma has occurred when they sense the distress of adults surrounding them (Stuber & Violet, 2001). As well, very young children may suffer from negative psychological consequences and high levels of stress following the death of an adult with whom they have formed a strong attachment bond, particularly if the deceased was the primary caregiver (Willis, 2002). In regards to preschoolers, despite increased ability to understand death compared to infants, children at this phase of development often conceptualize the loss as a temporary or reversible state and may repeatedly question whether a deceased loved one will return (Stuber & Violet, 2001). As children experience further cognitive development following the preschool years, they typically understand that death is permanent; however, school-aged youngsters may not recognize the process as an intrinsic and natural part of life, resulting in difficulties with comprehending that death will happen to them personally. According to Piaget (1959), a final stage of intellectual growth occurs when older children who are capable of engaging in abstract thinking begin to hold an adult view of death as an inevitable, universal, final aspect of the life cycle for all living things, caused by the cessation of bodily function (Slaughter, 2005).

Given natural variations that exist in children’s ability to understand the concept of death at alternate stages of development, young people of different ages have been found to express grief in conjunction with their cognitive maturity (Hunter & Smith, 2008). For instance, infants may engage in intense crying or exhibit physical manifestations such as failure to thrive when experiencing prolonged or permanent separation from an attachment figure (Norris-Shortle, Young, & Williams, 1993). Toddlers’ grief, on the other hand, is often sporadic, with children of
this age appearing content one moment, and then angry and regressed the next (Christ, 2000; Stuber & Violet, 2001). Preschoolers are more likely to express their grief with regressions such as bedwetting, or asking to sleep in a parent’s bed, somatic complaints, repetitious questions regarding the deceased, separation anxiety, and tantrums (Christ, 2000, D’Antonio, 2011; Willis, 2002). As in the case of younger children, school-aged youngsters may experience physical symptoms or reversions to an earlier phase of development following the death, although advancements in language ability make it easier for this age group to articulate their feelings of sadness or anger associated with the death (D’Antonio, 2011). Losing a loved one in adolescence may result in unique grief symptomatology, with older children often experiencing survival guilt, global anxiety and sleeping difficulties that can impact interpersonal relationships (Fanos & Nickerson, 1991).

Knowledge of typical and atypical grief responses at different developmental stages is critical for clinicians and parents of bereaved children in order to ensure that children are adequately supported throughout the mourning process (D’Antonio, 2011). This is particularly important in light of commonly held misconceptions that children are incapable of experiencing true grief or recover from bereavement quickly (Auman, 2007; D’Antonio, 2011). Moreover, in addition to cognitive level of development influencing the grief process, factors such as individual traits, environmental circumstances and familial dynamics can impact young people’s ability to adapt to the death of a loved one at all stages of development (Norris-Shortle, Young, & Williams, 1993). This means that clinicians who work with bereaved children need to consider these dimensions in determining which interventions are appropriate for an individual child.

1.6 Important Characteristics of Bereavement Services

Findings indicate that a majority of young people typically benefit from support that
contains several important characteristics including an environment of trust and permission to engage in open dialogue (Tonkins & Lambert, 1996). These aspects of bereavement services are particularly important given that children who have experienced the death of a loved one need to feel safe while exploring their feelings and understand that anger, guilt, hopelessness, and fear are all normal grief responses (Birenbaum, 2000; DeMaso, Meyer, & Beasley, 1997). In addition to facilitating dialogue, open communication between clinicians, children, and parents can reduce isolation and withdrawal commonly experienced by bereaved family members and improve long-term bereavement adjustment (Eilegård et al., 2013; Martinson & Campos, 1991). Establishing an environment that is conducive to discussions on emotions and an understanding of the far-reaching effects of a loss is best accomplished by offering bereavement support to the entire family and not exclusively to surviving siblings or parents (Gibbons, 1992). This may allow mothers and fathers to experience greater comfort with engaging in open dialogue, which can facilitate emotional availability for sibling survivors, reduce behavioural disturbances, and help children learn to tolerate intense feelings (Gibbons, 1992). Furthermore, findings suggest that factual, developmentally appropriate responses to a death, rather than evasive explanations (e.g., Jack is in an eternal sleep) can facilitate better adjustment and provide reassurance to surviving children that they are not responsible for the loss (Gibbons, 1992). Moreover, children who have been encouraged to engage in self-expression may be more apt to communicate the extent that they wish to participate in events surrounding the end of life and death, including frequency of visits to a terminally ill sibling in the hospital, attending the funeral, and visiting the grave (Packman et al., 2006).

1.7 Scarcity and Inadequacy of Existing Interventions for Bereaved Siblings

Despite research indicating that bereaved children benefit from support throughout the
mourning process, efforts directed at developing psychosocial interventions for grieving children, and particularly those who have experienced the death of a brother or sister, are just emerging (Contro & Sourkes, 2012). Indeed, a survey of member institutions of the Children’s Oncology Group, comprised of over 200 leading hospitals and cancer centres around the world, revealed that only 59% had existing bereavement programs (Johnson et al., 2008). The dearth of current programming is particularly troubling considering that interviews with bereaved children indicate a strong desire to talk about the implications of the death and dissatisfaction with the professional support available (Nolbris & Hellström, 2005). For instance, in a qualitative study conducted by Nolbris and Hellström (2005), surviving siblings expressed that they regretted not having had the opportunity to meet others in the same situation and that they would have benefitted from special literature on children’s thoughts and feelings associated with death. Similarly, interviews with parents whose child had died from cancer acknowledged the need for sibling support and the inadequacy of current programming offered by hospitals (deCinque et al., 2006; Welch et al., 2012). In a questionnaire that asked bereaved parents to identify which topics they would choose to discuss in a home visit from hospital staff following their child’s death, siblings were the most commonly preferred topic (Welch et al., 2012). As well, parents noted that they were sometimes unable to meet the emotional and psychological needs of surviving children, and that comprehensive bereavement support would have filled this gap (Contro & Sourkes, 2012; deCinque et al., 2006). Moreover, parents described a lack of support and programming following their child’s death as highly distressing and indicative of having been abandoned by the hospital staff (deCinque et al., 2006; Welch et al., 2012). A number of mothers and fathers noted that they perceived oncology staff members who shared the experience of their child’s illness as ‘family’ or ‘community,’ which heightened expectations that doctors and nurses
would attend the funeral or remain in close contact during both periods of palliation and
bereavement (D’Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008; deCinque et al., 2006).

1.8 Current Interventions for Bereaved Siblings

Although limited, some therapeutic interventions have been developed for grieving
children, and particularly those who experienced the death of a brother or sister, in the hopes of
enhancing resilience, reducing negative symptomatology and promoting posttraumatic growth
(Little, Akin-Little, & Somerville, 2011; Paletti, 2005; Webb, 2010). Group work has been noted
to be a cost-effective option and therefore has been used in several programs designed to provide
bereaved children with the opportunity to mourn the death in a supportive environment (Potts,
O’Toole, & Farrell, 1999) and reduce feelings of isolation (Creed, Ruffin, & Ward, 2001). Some
examples of interventions for grieving siblings include camps and weekend retreats (Kramer &
Sodickson, 2002; Potts et al., 1999), weekly support group meetings offered by hospices or
pediatric palliative care programs (Davies et al., 2007; Kirk & Pritchard, 2012), and community
based peer bereavement programs guided by facilitators (Metal & Barnes, 2011). Specific
activities offered by supportive services have consisted of expressive arts or music therapies,
(Knapp & Contro, 2009; Pennells & Smith, 1995), the creation of memory boxes (Metal &
Barnes, 2011), and discussions designed to facilitate communication. In addition to helping
participants express and manage their grief and understand that others share similar feelings,
bereavement support groups can promote the development of continuing bonds and ongoing
connections with the deceased (Packman et al., 2006).

1.9 Evaluation of Existing Programs and Services

Despite the fact that researchers and clinicians both acknowledge the importance of
bereavement support for children, and maintain that hospitals and palliative care centres have an
obligation to provide bereavement follow-up care to the patient’s family (Heiney, Wells, & Ruffin, 1996; Johnson, Rincon, Gober, & Rexin, 1993), sparse evidence exists to support the effectiveness of any particular type of program (Metal & Barnes, 2011). In fact, an extensive review of various models of hospital-based bereavement services revealed a paucity of empirically based programs and limited utilization of the theoretical underpinnings of the grief process (deCinque, Monterosso, Dadd, Sidhu, & Lucas, 2004). In addition, conceptual frameworks used to develop hospital-based bereavement interventions often fail to incorporate feedback from parents and siblings regarding their support needs (deCinque et al., 2006). Even when formal evaluation of bereavement services for children does occur, methods for assessing effectiveness are diverse (e.g., case studies, qualitative interviews, and self-report questionnaires; Metal & Barnes, 2011), and post-intervention data exploring ‘what helped’ and ‘what changed’ are limited (Rolls, 2007). As well, given the highly individualized and developmental nature of the mourning response (Knapp & Contro, 2009), and the complexity of factors that may increase the likelihood of complicated grieving, screening procedures for targeting families at high risk for developing clinically significant grief symptoms have not been developed at the current time (deCinque et al., 2004). Moreover, with the single exception of a scale used to assess the specific domain of adolescent sibling grief, (Hogan & DeSantis, 1996), there is no well-validated measure of child bereavement available for clinicians or researchers to incorporate in their work with this population (Currier, Holland, & Neimeyer, 2007). Methodological differences across studies and a lack of valid measures for evaluating grief make direct comparisons difficult, and it has been argued that drawing conclusions from poor quality bereavement intervention research (e.g., lack of control groups or long term evaluation) is inappropriate (Schut, Stroebe, van den Bout, & Terheggen, 2001).
Adding to the complexity of the knowledge base on grief support service efficacy, several meta-analyses have produced conflicting results regarding the utility of bereavement interventions for children and adolescents. Specifically, meta-analyses conducted by Neimeyer (2000) and Currier and colleagues (2007) concluded that grief interventions do not generate the positive outcomes observed in other psychotherapeutic interventions and may, in fact, be harmful to bereaved children. On the other hand, a more recent review of 27 treatment studies indicated that bereavement services for children can be beneficial if offered in a timely manner, with larger effect sizes observed for interventions aimed at treating symptomatic or impaired participants compared to those without symptoms (Rosner, Kruse, & Hagl, 2010). At the current time, no meta-analyses have been conducted to assess the effectiveness of grief support programs exclusively targeting children who have experienced the death of a brother or sister or, even more specifically, the death of a sibling from cancer. Therefore, best practices for assisting families following the death of a child remains to be determined (Kazak & Noll, 2004). The existence of this significant gap in the literature as well as a general dearth of bereavement services for siblings underscores the importance of furthering empirical knowledge in this area. Efforts directed at the development of evidence-based programming will help to ensure that bereaved siblings are provided with the opportunity to participate in effective interventions that promote psychological well being.

1.10 Issues Pertaining to Recruitment and Participation in Bereavement Research

As researchers have started to acknowledge the critical need for a greater understanding of the grief experiences of siblings, unique methodological, ethical, enrolment, and logistical challenges in conducting research with bereaved children and parents are beginning to emerge (Akard et al., 2014; Meert et al., 2008). Recruitment in particular has served as a barrier to data
collection, as healthy siblings of children with life limiting illnesses have declined to participate in studies because they lacked interest or cited prior engagements (Stevens, Lord, Proctor, Nagy, & O’Riordan, 2010). In addition, gaining access to vulnerable youngsters can be difficult for researchers because of protective ‘gatekeepers’ such as parents who are reluctant to provide consent due to concerns that conversing about death or serious illness will have a destabilizing effect on their children (Stevens et al., 2010). Recruitment efforts may be further impeded by numerous call attempts to parents that include low rates of successful contact, with many families ultimately refusing participation (Akard et al., 2014). Researchers have noted that parents may choose to respond to recruitment calls with passive refusal (i.e., agreeing to be contacted at a later date and failing to respond to the phone call) owing to feelings of discomfort with saying “no” to researchers, particularly when a study is conducted through a child’s treating institutions (Akard et al., 2014). In addition, some families may find it difficult to participate in bereavement research during the first year of a child’s death (Akard et al., 2014). This poses ethical problems for investigators who strive to maintain a balance between protecting vulnerable human participants and ensuring that bereaved children are provided with the opportunity to participate in research and contribute to the existing knowledge base. Furthermore, low participation rates and small sample sizes resulting from poor recruitment rates can limit validity, generalizability and transferability, thereby impacting the quality of the results obtained (Horsley & Patterson, 2006; McPherson & Addington-Hall, 2004; Nolbris & Hellstron, 2005). Another factor that has been noted to impact research on sibling grief is the location of data collection (Stevens et al., 2010), particularly in the case of studies investigating the efficacy of bereavement interventions. For instance, although some families may experience positive feelings when attending services located in a familiar hospital or hospice (Davies et al., 2007; Potts et al.,
1999), others have reported feelings of distress associated with returning to the healthcare setting where their child died (Macdonald et al., 2005). This means that researchers and clinicians need to consider how a particular setting may be perceived by bereaved children and their parents in ensuring that study location does not act as a barrier to participation.

1.11 Rationale for the Current Study

A survey of the literature clearly reveals the inadequacy of current bereavement support for siblings (deCinque et al., 2006; Contro & Sourkes, 2012; Nolbris & Hellström, 2005; Welch et al., 2012), as well as a general dearth of evidence to support the effectiveness or specific benefits of any particular program (deCinque et al., 2004; Metal & Barnes, 2011; Rolls, 2007). Moreover, research with bereaved children has been demonstrated to present distinct challenges that impede participation, including barriers to the recruitment process and difficulties associated with program location (Akard et al., 2014; Macdonald et al., 2005; Stevens et al., 2010). Given the paucity of studies exploring the needs of grieving young people and contradictory findings on the utility of interventions designed to reduce emotional suffering, the present investigation was conducted to assess the feasibility of implementing a manualized support group intervention for bereaved siblings. In addition, an important objective in carrying out the study was to examine challenges associated with the recruitment process in pediatric cancer bereavement research, using qualitative methodology. Specifically, the group program was developed based on findings described above regarding the unique psychosocial needs of bereaved siblings, and was aimed at mitigating negative symptomology and enhancing psychological growth in children who had experienced the death of a brother or sister from cancer. Feasibility of the intervention was evaluated through an assessment of program acceptability, recruitment, retention, treatment fidelity, and preliminary evidence of outcomes. These criteria were developed by Kazak and
colleagues (2005) for the purpose of investigating feasibility in applied research, and have been used in other intervention studies designed for children diagnosed with cancer (Barrera & Schulte, 2009; Stehl et al., 2009). Primary outcomes explored were quality of life, grief, problem behaviour, stress symptomology and depression, as past findings have indicated the effects of sibling bereavement on these variables (Brody, 1998; Davies, 1999; Fanos et al., 2009; Fanos & Nickerson, 1991; Hogan & DeSantis, 1996; McCowan & Davies, 1995; Weller et al., 1991; Shannon et al., 1994). In conducting this study, it was hoped that further insights on effective practices for implementing child bereavement services would be obtained.

1.12 Objectives

The primary objectives of the current investigation were to:

I) evaluate the feasibility of running a manualized bereavement support group for siblings, and
II) identify and explore barriers to recruitment and implementation.

In order to achieve the study objectives, the investigation was conducted in two segments, with each aimed at addressing specific components of the overall goals. For Part 1, analyses of aspects of feasibility including program acceptability, retention rates, treatment fidelity, and preliminary analysis of outcomes were conducted. Considering that the first portion of the study was carried out with a small convenience sample comprised of families that were easily accessible to the supervising psychologist, feasibility of recruitment could not be adequately tested, as the group was not representative of the general population of bereaved siblings. In contrast, Part 2 was designed to assess recruitment and barriers to enrollment utilizing rigorous sampling procedures that consisted of inviting siblings to participate based on their inclusion in a hospital register of families with a child who died of cancer. In addition, it was hoped that the use of a larger and more representative sample would provide further support
for the results obtained in Part 1 and supply the statistical analyses with greater power to detect changes resulting from the intervention. However, given previous research documenting challenges in recruiting bereaved children for participation in research, we anticipated that a full assessment of feasibility utilizing quantitative methodology might not be possible for Part 2 in the event of a large number of participation declines.

In regards to Part 1, it was hypothesized that the program would prove to be feasible with respect to program acceptability, retention rates, and treatment fidelity, with preliminary outcomes indicating some gains in quality of life and reductions in problem behaviours, stress, grief symptomology, and depression. In conducting the second segment of the investigation, we expected to further document obstacles in the recruitment process through a qualitative analysis of data collected from enrolment phone interviews with a representative sample of bereaved families.

Chapter 2: Method

2.1 Part 1

2.1.1 Sample and Recruitment

Potential participants were recruited for the study following involvement in a similar group program for healthy siblings of cancer patients, or after the family had received treatment from a psychologist in the hematology/oncology program at the hospital. This meant that all participants had developed prior relationships with the supervising psychologist or other members of the research team prior to the commencement of the intervention. Inclusion criteria required that siblings were between the ages of 6 and 18 years, and had experienced the death of a brother or sister from cancer within the past three years. Children who presented with known cognitive or psychiatric impairments, or were unable to speak English, were excluded from the
study. Families that were identified as meeting the inclusion criteria were invited to participate by a familiar clinician, and then provided with written information that contained a brief description of the objectives of the study, details of the program and possible benefits for siblings. Interested families were then contacted by telephone and asked for verbal consent to proceed. If verbal consent was provided, recruiters verified eligibility, described the intervention in greater detail, and discussed potential starting dates and scheduling.

2.1.2 Procedure

The procedure and design for the investigation were approved by the Institutional Ethics Review Board. The intervention was located in a major pediatric hospital situated in a large metropolitan city in the province of Ontario. Participating parents and siblings were instructed to arrive 30 minutes prior to the first session in order to provide written consent/child assent and complete questionnaires on demographics and outcome measures (See Appendix A). Design for this portion of the study primarily consisted of a repeated measures method that explored differences between scores on quantitative measures completed at baseline and immediately following the final program session. Two groups of five siblings \((N = 10)\) participated in the program.

Clinically trained graduate or post-doctoral students implemented the intervention under the supervision of a registered psychologist. Training for facilitators included reading the manual, observing sessions conducted by other group leaders through a one-way mirror, and assisting facilitators prior to maintaining responsibility for running the program. In carrying out all session activities, group leaders were instructed to carefully adhere to the manual in order to optimize fidelity, while at the same time allowing for some flexibility in intervention execution to meet the individual and developmental needs of participants. As well, facilitators and the
supervising psychologist attended a debriefing following each session to allow group leaders to reflect on their feelings in a supportive environment and facilitate dialogue on changes that needed to be implemented in the future. In addition, group leaders completed logs that contained detailed information on participant engagement, cooperation, and activities carried out at each session. Session logs were subsequently analyzed by a member of the research team who was not involved in implementing the program for a) adherence to session outline, b) adherence to session theme, and c) engagement of participants in session activities.

2.1.3 Group Intervention

2.1.3.1 Conceptual Framework

Components of several conceptual frameworks were incorporated into the development of the program, with the general structure of the intervention based on a previous intervention for children with a brother or sister who had been treated for cancer (Barrera, Chung, Greenberg, & Fleming, 2002; Barrera, Chung, & Fleming, 2004; Chung, Miranda, Fleming, & Barrera, 2004). Cognitive behaviour theory, a model that emphasizes the significant role of cognitions in emotional and behavioural responses to life situations (Gonzalez-Prendes & Resko, 2012), served as the primary framework for the construction of the program design. Past research has provided empirical support for the efficacy of therapeutic approaches adapted from cognitive behaviour theory in treating children and adolescents who have experienced a trauma (Vernberg & Johnston, 2001) or the death of a loved one (Spuij, van Londen-Huiberts, & Boelen, 2013). In addition, therapies derived from cognitive behavioural theory, in conjunction with expressive approaches, have been used to provide bereaved children with a forum for communicating their thoughts and feelings (Pennels & Smith, 1995; Spuij et al., 2013; Webb, 2003). Another framework that was integrated into the structure of the program included the stress and coping
model (Lazarus & Folkman, 1984) linking an individual’s appraisal of a stressor and associated coping response with his or her previous experiences with similar stressors. As well, family systems theory (FST; Broderick, 1993), a model that views the family as a system in which each member is an essential component of the overall unit, and as a system functioning within a larger system (e.g., school, hospital), was used to conceptualize the experiences and needs of bereaved siblings within a variety of contexts including their home and school lives. Given that children’s understanding of death shifts with advances in maturity (Hunter & Smith, 2008), developmental theory was considered as well in the selection and planning of developmentally appropriate activities for participants of a variety of ages. Moreover, in light of empirical evidence supporting the link between positive group dynamics and intervention efficacy (Sampson & Marthas, 1981), facilitators received training on methods for establishing a group climate where participants felt comfortable conversing about sensitive topics including grief and anger. Most importantly, a focus on knowledge application and generalization was integrated into the program through problem solving discussions and role-play activities carried out by participants. Finally, in conjunction with the conceptual frameworks of the program, various therapeutic modalities including cognitive behaviour therapy (CBT) and expressive therapies (i.e., music, art, and drama therapy) were used in the creation of activities designed to reinforce session themes.

2.1.3.2 Program Design

The intervention consisted of eight 2-hour group sessions held on a weekly basis, with each session targeting a particular theme or goal. The program was supervised by a psychologist and facilitated by two clinically trained graduate students. Each session followed a specific structure, and commenced with a pre-activity designed to ensure that participants were occupied
upon arrival, as well as a concise review of activities carried out at prior sessions to reinforce previously acquired knowledge. This was followed by a brief mental set activity that focused on a particular theme, engaged participants’ attention, interest and motivation, and enhanced understanding of central concepts presented later in the session. Next, siblings were provided with healthy snacks, and encouraged to socialize informally and elaborate on relevant experiences that had occurred to them in the past week. At the conclusion of snack time, facilitators introduced the main activity, which was designed to directly address the specific goals and themes for that session and consolidate emerging skills. This was followed by the assignment of “funwork,” or homework consisting of a behavioural task that reinforced newly developed skills and promoted generalization of coping strategies. Finally, a deep breathing exercise was carried out to relax participants and counter any negative emotional responses that had occurred while discussing anxiety-provoking topics. Further details on session activities are contained in the manual created for the program (Barrera, Schulte, Jovcevska, Hancock, & Eaton-Russell, 2009).

2.1.3.3 Session Themes and Aims

Each session included activities associated with a specific theme or objective that was aimed at addressing the unique needs of bereaved siblings. A collection of theme-related activities targeted at different developmental levels and age ranges was detailed in the intervention manual, and facilitators selected those that were most appropriate based on the specific composition of the group. Objectives for initial sessions included the establishment of group rapport, the creation of a safe ambiance for participants, and the development of strategies for learning to cope with personal grief and death in the context of family life. Following sessions highlighted the overarching theme of relationships, and emphasized the development of
continuing bonds with the deceased sibling, relationships with family members, and interactions with peers. Latter sessions focused on the impact of the death on surviving siblings’ hopes and dreams for their personal lives through the incorporation of themes such as “All About Me” and “All About My Future.” Activities in these sessions were directed at fostering emotional and social growth, empowering participants, facilitating discussions on their plans for the future, and validating the magnitude of the effects of sibling loss. The final session focused on the consolidation of previously developed coping skills, and included a graduation ceremony that celebrated graduates’ accomplishments and reinforced newly formed friendships.

2.1.4 Feasibility Assessment

2.1.4.1 Retention Rates

Retention rates were evaluated by calculating the mean percentage of sessions attended by participants in both groups, as well as the total percentage of siblings who dropped out of the program.

2.1.4.2 Treatment Fidelity

Session logs completed by facilitators were analyzed by a member of the research team who was not involved in implementing the group for a) adherence to session outline, b) adherence to session theme, and c) engagement of participants in session activities. A five point Likert scale was used to rate each criterion, and scores for treatment fidelity were obtained by adding the totals from each session, averaging the totals across groups, and transforming the data into a percentage.

2.1.4.3 Program Acceptability

Group evaluation forms that were designed to assess acceptability, and had been utilized in previous intervention, were completed by siblings and parents upon termination of the
program (Barrera, Fleming, & Al-Khalili, 2004) (See Appendix B). Evaluation questionnaires consisted of nine items, including “How helpful was the group in helping you (your child, for parent version) deal with your (your child’s, for parent version) grief” and “What was the best part of being in the group?” Questions were rated on a Likert scale ranging from 1 (I don’t know) to 5 (Very Useful), and the percentage of parent and sibling responses corresponding to each level of the scale were computed for all items.

2.1.4.4 Preliminary Intervention Outcomes

Participating children and one or two of their parents completed the Pediatric Quality of Life (PedsQL) Generic Core Scale (Varni, Seid, & Kurtin, 2001), the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997), and the Child Behavior Checklist (for parents, CBCL; Achenbach, 2001) or Youth Self Report (for children aged 11 years and older; YSR; Achenbach, 2001). As well, siblings completed the Child Depression Inventory (CDI; Kovacs, 1992) and the Hogan Inventory of Bereavement (HIB; Hogan & DeSantis, 1996).

2.1.4.4.1 Quality of Life

Siblings’ functioning was assessed with the Pediatric Quality of Life Generic Core Scale, a multidimensional, 23-item measure designed to assess quality of life in healthy children. This scale includes a parent proxy form for children aged 2-18 years and a self-report for children aged 5-18 years. Four subscales representing different areas of functioning are included in the PedsQL (physical, emotional, social, and school), as well as an overall quality of life score. Items are rated on a scale of 0 (never a problem) to 4 (always a problem), depending on the rater’s perceptions of aspects of his/her (or his/her child’s) quality of life in the past month. Scores range from 0 to 100, with higher values indicating greater quality of life, and lower scores suggesting poorer quality of life. Validity of the PedsQL has been previously established for
healthy children and young people with acute and chronic conditions (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002; Varni et al., 2001). The internal consistency measure for the PedsQL was found to exceed the minimum reliability standard of .7 for both healthy children and those diagnosed with a serious illness (Varni et al., 2001).

2.1.4.4.2 Stress Symptoms

The IES-R is a 22-item self-report measure designed to assess the impact of a traumatic life event, and was used to evaluate stress symptomology in children who attended the program. The revised scale comprises three subscales measuring intrusion, avoidance, and hyperarousal. Items on the IES-R are rated on a five-point Likert scale, with higher scores indicating greater levels of stress-related symptomology. The IES-R has been demonstrated to have sound psychometric properties (Weiss, 2004), and is currently one of the most widely used measures for assessing posttraumatic stress symptoms (Elhai, Gray, Kashdan, & Franklin, 2005). High levels of internal consistency have been reported in previous research (intrusion: Cronbach’s alpha = .87 - .94, avoidance: .84 - .87, hyperarousal: .79 - .91; Creamer & Sourkes, 2003; Weiss & Marmar, 1997), and test-retest reliability, collected across a six-month interval, ranged from .89 to .94 (Weiss & Marmar, 1997). Given that the IES-R is a self-report measure, the current study used the standard version of the test for sibling participants and an adapted parent proxy version for mothers and fathers that was designed to elicit information on their perceptions of the magnitude of stress symptoms experienced by surviving children.

2.1.4.4.3 Problem Behaviours

The CBCL parent form is a standardized 118-item inventory completed by parents that yields a total, internalizing and externalizing behaviour composite score as well as three different competence scales (social, academic, and activities). For the current study, the total, internalizing
and externalizing scores were obtained to assess levels of problem behaviours exhibited by participants. Responses to items on the CBCL are rated on a three-point Likert scale ranging from “not true” to “often true” for the child. Raw scores on these scales are transformed into standardized *T* scores, with higher scores reflecting greater behavioural difficulties. Internal consistency reliability for the CBCL ranges from .57 to .71 for internalizing behaviours, .70 to .86 for externalizing behaviours, and .69 to .82 for total problem behaviours (Achenbach, 1991). Test-retest reliability calculated using Intraclass Correlation Coefficients has been found to range from .82 to .95 (Achenbach, 1991). The YSR (Achenbach, 2002) is a self-report version of the CBCL for youth aged 11 years and older, and was completed by adolescent participants. Reliability of the YSR has been found to range from .47 to .79 (Achenbach, 1991).

**2.1.4.4 Depression**

The CDI is a 27-item inventory for children between the ages of 6-17 that yields scores on five different scales (Negative Mood, Interpersonal Difficulties, Negative Self-esteem, Ineffectiveness, and Anhedonia), as well as an overall depression *T* score. In the present investigation, the overall score was used to assess siblings’ level of depression. Test-retest reliability for this measure has been evaluated over a two-week period and reported to be .82 (Finch, Saylor, Edwards & McIntosh, 1987). The internal consistency coefficients range from .71 to .89, and the test-retest coefficients range from .74 to .83 (Kovacs, 1992).

**2.1.4.5 Grief Symptomology**

The presence and severity of grief symptomology in participants was evaluated with the HIB, a 39-item self-report questionnaire adapted for children and adolescents. Each item on the questionnaire is rated on a scale from 1 (does not describe me) to 5 (describes me very well), as experienced by the child in the past two weeks. Two subscales are derived including grief
distress and personal growth, with higher scores on the grief scale indicating greater severity of bereavement symptoms, and higher scores on the personal growth scale suggesting greater levels of posttraumatic growth. This measure has been demonstrated to have good internal consistency and construct validity (Neimeyer & Hogan, 2001).

2.1.4.4.6 Statistical Analyses

Descriptive statistics were calculated for all outcome measures. For measures completed both by parents and children (i.e., IES-R, PedsQL), siblings’ self reports were compared to those of their mothers and/or fathers to evaluate discrepancies in perceived quality of life and response to the trauma. To assess intervention effect, a Wilcoxon signed-rank test was used to evaluate differences between responses to measures completed at baseline and post-treatment. As well, effect sizes, $r$, were calculated to evaluate the magnitude of the effect (Rosenthal, 1991). Considering the relatively small sample included in the study, it was expected that parametric assumptions would be broken, rendering the Wilcoxon signed-rank test an appropriate statistical technique for analyzing the current data set.

2.2 Part 2

2.2.1 Sample and Recruitment

Inclusion criteria for Part 2 were identical to Part 1 (see page 18 for a detailed description). A hospital register containing the names of all cancer patients who had died within the past three years was made available to members of the research team. Due to the fact that the database did not include information on siblings, healthcare professionals involved in the patient’s treatment (i.e., nurses, social workers) helped to identify which families had a surviving child between the ages of 6 and 18 years of age. A list of families with siblings in the target age
range was compiled, and their parents were sent a letter of invitation from the deceased child’s attending physician (See Appendix C). In the letter, parents were provided with a brief summary of the objectives of the program and a number to call if they did not wish to be contacted. This was followed by a telephone call to ascertain eligibility and interest in participating, as well as address any questions or concerns regarding the program (See Appendix D for interview script). Families that failed to answer the initial phone call were called again up to two additional times on a subsequent day of the week at a different time of day to heighten the likelihood that a parent would be home. If parents still could not be reached after a third phone call, a voicemail was left with information on how to contact the hospital and obtain further information about the study. Following three unsuccessful attempts that were not followed up with a response from parents, further recruitment efforts were halted. Families that chose not to attend the program were classified into two groups: active declines and passive declines. Active declines included parents and/or siblings who expressed a lack of interest in the program or could not attend due to scheduling difficulties. Passive declines consisted of families that did not answer phone calls or respond to voicemails, or indicated that they required additional time to decide before committing to the program and subsequently could not be reached. Extensive notes were taken on responses provided by parents during all phone conversations in order to facilitate the analysis of feasibility of recruitment.

**2.2.2 Procedures**

Given significant difficulties with enrolment that precluded the program from being offered for Part 2, a full assessment of feasibility utilizing quantitative methodology could not be carried out. Thus, the design for this portion of the investigation included a qualitative analysis of data collected from recruitment phone interviews that allowed for an in-depth evaluation of
enrollment challenges and common themes cited by families that actively declined to participate. This served as a valuable supplement to quantitative data obtained in Part 1 of the study, and provided further insights into the needs of bereaved siblings and their parents.

2.2.3 Recruitment Interviews

Phone recruitment interviews consisted of conversations with parents that included open-ended questions exploring their underlying reasons for declining participation (e.g., would you mind telling me a little bit about why (sibling’s name) would not like to participate in the program?). In this context, parents shared information regarding their bereavement experiences and provided suggestions that could be incorporated into the design of future interventions. Extensive interview notes from these phone calls were analyzed utilizing Interpretive Methodology (Thorne, 2008). Interviews ranged in duration from 10 to 30 min, depending on the parent’s level of engagement with members of the recruitment team ($M = 15$ min).

2.2.4 Data Analyses

Data collected from recruitment phone calls with parents were evaluated through content analysis, an interpretive approach for analyzing information obtained from open-ended questions (Foster et al., 2009; Thompson et al., 2011; Thorne, 2008). This method is used to enhance knowledge, offer new insights, develop practical guidelines for challenging situations, and provide direction for clinical recommendations (Foster et al., 2009). Content analysis was performed through repeated readings of transcribed phone conversations to gain a holistic sense of the data. Next, quotes were extracted and grouped together into preliminary categories. Quotes and existing categories were then reviewed and recoded multiple times by the primary investigator (i.e., category names were edited, new categories were explored, categories were combined, or categories were subdivided). These data were subsequently reviewed by a second
researcher for further reduction and revision of categories. Lower order categories that shared a common element were then grouped together to form broader, overarching themes. Researchers discussed these emerging themes and categories until a final consensus was reached and no new classifications emerged.

Chapter 3: Results

3.1 Part 1

3.1.1 Demographics

Out of a total of 15 siblings invited to participate, 10 children and adolescents (5 males, 5 females) met the inclusion criteria and attended the program. Surviving siblings’ mean age at enrolment was 11.30 years ($SD = 2.39$). Children in one group ranged in age from 9 to 13 years, and those in a second group were between the ages of 6 and 14 years. Fifty percent of siblings had three or more children in the family before the loss occurred. Time that had elapsed since the death ranged from 6 to 30 months, and average age of the deceased child at time of death was 10.15 years ($SD = 2.82$). Mothers and fathers ranged in age from 36 to 51 years. Parents of participants represented a diverse group, with a majority identifying as Caucasian, and several classifying themselves as African American or Jamaican Canadian. A majority of parents had attended some college or obtained a university degree. Ninety percent of parents were married, and 10% were divorced. Detailed demographic information on families is presented in Table 1.

3.1.2 Feasibility

3.1.2.1 Recruitment

A vast majority of families were recruited after receiving treatment from the supervising psychologist in hematology/oncology, or following participation in a similar program for siblings of cancer patients. In total, 15 families were invited to attend and 10 enrolled in the program,
representing a participation rate of 66.7%. Two families declined enrolment due to difficulties with commuting to the treating centre, which was located a significant distance from their place of residence. As well, three teenaged siblings stated that they were not interested in attending in the program. Not surprisingly, all parents who had discussed the need for sibling bereavement support with the supervising psychologist during the course of therapy sessions \((n = 5)\) consented to take part in the study.

### 3.1.2.2 Retention

There were no dropouts from both groups of siblings who participated in the intervention. Overall attendance for the eight sessions averaged 85.7%, and ranged from 71.4% to 100%.

### 3.1.2.3 Treatment Fidelity

Fidelity scores calculated for both intervention groups yielded 85% adherence to session outlines detailed in the manual, 95% adherence to session themes, and 77% participant engagement in activities.

### 3.1.2.4 Acceptability

Based on self-report responses to satisfaction questionnaires, 90% of siblings rated the group as “very useful” or “useful” for managing their grief and providing information on coping with bereavement. Seventy percent of participants found the group to be “very useful” or “useful” for helping to express feelings to parents, family members, and peers. Seventy seven percent of parents described the group as “very useful” or “useful” for providing siblings with information on how to express their thoughts and feelings to classmates. A majority of mothers and fathers stated that the intervention was “very useful” or “useful” for assisting their child to express feelings to other family members (85%) and facilitating dialogue on emotions with
parents (65%). When asked to name the most valuable feature of the program, 40% of siblings and parents cited the opportunity to meet other young people with similar experiences. However, remaining parents and children shared different perspectives, with a number of parents identifying the presence of a safe environment to express feelings (30%) or the opportunity to create positive memories within the hospital setting (20%), and 60% of siblings stating that group activities were most beneficial.

3.1.2.5 Intervention Outcomes

Means, standard deviations, and effect sizes for all outcome measures are displayed in Table 2. $P$ values of less than or equal to .05 were used to assess significance; however, given that this was a feasibility study, $P$ values of less than or equal to .11 were reported to represent borderline levels of significance.

3.1.2.5.1 Concordance between Child and Parent Measures

For measures completed both by parents and siblings (i.e., IES-R, PedsQL), a Wilcoxon signed-rank test was conducted to evaluate concordance between surviving children’s reports and those of their mothers and/or fathers. Given that data were collected from mothers and fathers of three siblings, while remaining participants had only one parent completing questionnaires, scores for the former group of children were run twice in the analysis in order to allow for comparisons between each parent’s report and his or her child. At baseline, no significant differences were found between parents’ and children’s scores on overall quality of life, or the subscales of emotional, physical and school functioning, as assessed by the PedsQL. As well, there were no significant differences at baseline between parents and siblings’ reports on the IES-R. Scores on the social functioning subscale of the PedsQL revealed significant differences, with parents ($Md_n = 85.00$) reporting poorer social functioning compared to
siblings’ self reports ($Mdn = 100.00$), $z = -2.46$, $p < .05$.

### 3.1.2.5.2 Parent Reported Quality of Life

Twenty-three percent of parent report scores obtained at baseline indicated at-risk status for impaired overall quality of life according to classifications proposed by Varni and colleagues (2003). However, the mean total PedsQL score was in the normal range. An analysis of parent report PedsQL total scores using the Wilcoxon signed-rank test yielded a significant effect and medium effect size, with higher overall quality of life reported by parents following the intervention ($Mdn = 88.00$) compared to baseline ($Mdn = 72.83$), $z = -2.13$, $p < .05$, $r = -.42$. Of the PedsQL subscale scores completed by parents, emotional functioning was significantly higher after the program ($Mdn = 80.00$) compared to baseline ($Mdn = 50.00$), with a medium to large effect size, $z = -2.34$, $p < .05$, $r = -.46$. Similarly, an analysis of social functioning scores obtained from parents yielded significantly higher results subsequent to the intervention ($Mdn = 95.00$) compared to baseline ($Mdn = 85.00$) and a large effect size, $z = -2.69$, $p < .01$, $r = -.52$. As well, school functioning as reported by parents was greater following the program ($Mdn = 85.00$) compared to baseline ($Mdn = 70.00$), with a medium effect size, $z = -1.83$, $p = .07$, $r = -.36$, but this effect was of borderline significance. On the other hand, no significant differences were found for physical functioning as a function of time, $p = .79$.

### 3.1.2.5.3 Parent Reports on Behaviour

Mean scores on the CBCL as reported by parents were in the normal range prior to and following participation in the program; however, 20% of siblings had total behaviour scores in the borderline clinical range and internalizing scores in the clinical range at baseline. An analysis of CBCL total $T$ scores using a Wilcoxon signed-rank test yielded a borderline effect for time, with improvements in siblings’ behaviour reported by parents following treatment ($Mdn = $
31.00) compared to baseline ($Mdn = 45.00$), and a large effect size, $z = -1.60, p = .11 \ r = -.51$. As well, CBCL externalizing behaviour scores decreased after the program ($Mdn = 34.00$) compared to baseline ($Mdn = 40.00$), with borderline significance and a large effect size, $z = -1.60, p = .11 \ r = -.51$. In addition, internalizing behaviours as reported by parents on the CBCL were reduced following the intervention ($Mdn = 39.00$) compared to baseline ($Mdn = 56.00$). Similar to scores of externalizing behaviours, these effects were of borderline significance and represented a large effect size, $z = -1.60, p = .11 \ r = -.51$.

### 3.1.2.5.4 Parent Reported Impact of the Trauma

A Wilcoxon signed-rank test of parent report scores indicated decreased stress-related symptomatology post intervention ($Mdn = 12.00$) compared to baseline ($Mdn = 18.00$), with a borderline effect and medium effect size, $z = -1.68, p = .09 \ r = -.42$. In accordance with categories for the IES-R established by some researchers (Asukai et al., 2002; Creamer et al., 2003), 50% of parent report scores obtained at baseline reflected a high probability of clinically significant post-traumatic stress symptoms, while the mean value was in the borderline risk range.

### 3.1.2.5.5 Self-reported Quality of Life

In contrast with parent reports, no significant differences were observed between siblings’ self reports of overall quality of life prior to and following the intervention, as evaluated by their total PedsQL scores, $p = .68$. Similarly, analyses of PedsQL subscale scores completed by participants revealed no significant time effects for physical functioning, $p = .48$, social functioning, $p = .72$, or school functioning $p = .53$. Emotional functioning was not found to be significantly different following the intervention compared to baseline, $p = .12$; however, a medium effect size was obtained, $r = -.35$. Although the mean total PedsQL self-report score
obtained at baseline was consistent with normal functioning, 20% of participant scores indicated at-risk status for impaired overall quality of life (Varni et al., 2003)

3.1.2.5.6 Self-reports on Behaviour

As in the case of parent responses on the CBCL, adolescent siblings’ total self report scores on the YSR yielded a borderline effect of time using a Wilcoxon signed-rank test, with greater overall problem behaviours reported at baseline ($Mdn = 46.00$) compared to following the intervention ($Mdn = 40.00$), and a large effect size, $z = -1.83$, $p = .07$ $r = -.58$. Conversely, an analysis of YSR subscales revealed no significant differences for externalizing, $p = .27$ and internalizing behaviours, $p = .28$; however, there was a medium effect size for both subscales, $r = .35$ (externalizing) and $r = .34$ (internalizing). Siblings’ scores on the YSR were not significantly different from normative values at baseline or following treatment.

3.1.2.5.7 Self-reported Impact of the Trauma

In contrast with borderline effects found for parent reports on the IES-R, an analysis revealed no significant time differences for siblings’ self report scores of stress symptoms, $p = .89$. However, 80% of sibling scores at baseline reflected a high probability of clinically significant post-traumatic stress symptoms in accordance with IES-R guidelines established by researchers (Asukai et al., 2002; Creamer et al., 2003).

3.1.2.5.8 Self-reports on Depression

Mean scores on the CDI were not significantly different from normative values at baseline or following treatment, with only one participant reporting symptoms of depression in the clinical range prior to attending the program. A Wilcoxon signed-rank analysis revealed no significant time differences, $p = .47$.

3.1.2.5.9 Self-reports of Grief Symptomology
A Wilcoxon signed-rank analysis revealed no significant time differences on the personal growth scale of the HIB as reported by siblings, \( p = .24 \). Grief symptomology was greater following the intervention (\( Mdn = 40.00 \)) compared to baseline (\( Mdn = 34.00 \)), with a medium effect size, \( r = .32 \). However, the results were not found to be significant, \( p = .16 \).

3.2 Part 2

3.2.1 Recruitment and Demographic Characteristics

Forty-four families included in a hospital register of patients who had died from cancer within the past three years, and identified by healthcare professionals as having a surviving sibling, were invited to participate. A majority of these families had not previously received psychological treatment from a psychologist in hematology/oncology or attended an intervention program at the hospital. Two families did not meet the inclusion criteria, as the surviving sibling was too young or too old, and one number was out of service. Fourteen parents did not respond to a voicemail message left by the recruiter, or initially indicated that they would think over the prospect of attending the program, and then failed to engage in further contact (passive declines). In addition to the 14 families classified as passive declines, 25 parents actively stated that they or their child did not wish to participate (active declines). The sample included for the qualitative analysis was comprised of 25 families that actively declined participation, as well as two families that initially provided verbal consent to participate but were subsequently informed that the intervention was cancelled. Demographic information such as ages, ethnicity, and educational backgrounds of parents and siblings was not listed in the hospital register, and is therefore unknown. Information on the eligibility of participants and the recruitment process is presented in Figure 1.

3.2.2 Qualitative Data Analysis
Content analysis of the interview transcripts revealed eight major themes, and these themes were grouped into three overarching categories that included 1) impediments to enrolment, 2) coping with grief, and 3) communicating with surviving children. Given the context of the interviews, all themes reflected underlying reasons for participant declines; however, only the first theme (impediments to enrolment) directly addressed factors impacting parents’ and siblings’ decisions not to participate. An additional theme also emerged that was conceptually unique and did not relate to challenges in the recruitment process. This theme, appreciation for available services, provided valuable insight into the perspectives and needs of bereaved families and therefore merited discussion as a separate entity.

3.2.2.1 Impediments to Enrolment

Impediments to enrolment were found in five subordinate themes expressed by 15 parents that described their hesitations associated with participating in the intervention. These included: a) seasonal barriers to attending, b) scheduling difficulties, c) concerns related to time frame, d) discomfort with the hospital setting, and e) sibling unwillingness to participate in bereavement/cancer related activities. Seasonal barriers to attending the program in the late spring/early summer were commonly cited by parents, some of whom expressed an interest in the study but not able to commit due to planned holidays or end-of-school-year activities for the sibling (e.g., exams). One mother advised that December would also be a poor time for offering a support group, considering that bereaved families are often emotionally taxed during the holiday season. In addition to seasonal concerns, several parents noted that time of week was an important factor in influencing their decision to participate. However, there was not a consensus on an optimal day or time, with some families, particularly those with older children, expressing a preference for weekday evenings or Sunday afternoons, and other families stating that they
were unavailable to attend a support group on weeknights due to potential conflicts with other activities (e.g., soccer practice). Additionally, the importance of time frame was alluded to by several parents who expressed reservations associated with having their child participate in a bereavement intervention due to the length of time that had elapsed since the death. For instance, one mother whose son had died 11 months prior commented, “I think my daughter is not ready yet,” while another parent whose child had died several years earlier stated, “I don’t want to bring (sibling’s name) back to that time. The ideal time would have been one year after the death.” Another significant impediment to participation noted by a number of families was the location of the program in the hospital where their child had been treated or died. For instance, one mother explained, “It’s horrible coming back to the hospital. I can’t even drive down the street.” Finally, a number of parents declined participation after expressing that the surviving child was not interested in attending bereavement or cancer related activities. Of these families, some parents noted that they believed the intervention would have been beneficial, and had in fact attempted to convince the sibling to participate (i.e., by having their paediatrician or another family member discuss the need for bereavement support), with unsuccessful results.

3.2.2.2 Coping with Grief

An important overarching theme often cited by families ($n = 11$) was coping with the loss, with a number of parents focusing on difficulties in this area and others on strategies for managing grief. Moreover, aspects of coping were often mentioned as indirect or secondary factors in parents’ decisions not to have their children participate in the group. For instance, in the case of families already experiencing significant challenges with managing their daily lives or going back to work following the loss, the prospect of attending a program was described as “too painful,” or overwhelming for parents. In addition to coping difficulties serving as an
obstacle to recruitment, families that reported using a variety of strategies to manage their grief often actively declined to participate as well. For example, one father stated, “I keep extremely busy. It’s okay as long as I don’t have to think about it. Otherwise, I would go crazy.” Other families reported engaging in constructive coping techniques such as enrolling a sibling in karate “to enhance her mental and physical strength” or keeping children occupied with school-related activities and studying. Furthermore, several parents noted that their surviving children had already received and benefitted from formal treatment from a psychologist, and therefore, were not in need of additional services. One parent poignantly described constantly alternating between coping and struggling to deal with the loss: “You need to negotiate between living life and living with a wound. Like you’ve been stabbed in the heart and then you have to sew it up and walk around and function…Sometimes it’s okay and sometimes I break down.”

3.2.2.3 Communicating with Surviving Children

Several (n = 4) parents expressed difficulties with conversing about the loss with surviving children, and some identified communication barriers as secondary factors in their decision to abstain from the program. A mother noted that she felt awkward discussing the possibility of attending the bereavement group with her daughter, as “she does not want to talk about the death with her parents.” Similarly, another parent stated that her teenaged son refused to engage in conversation regarding his brother’s death, which she felt was a reflection of his anxiety over the prospect of causing her or her husband to become further distressed. Moreover, this mother suggested that adolescents might be less apt to discuss bereavement compared to younger children, given the “high risk for teenagers to look different than their peers.” In addition to communication difficulties reported by families as originating from siblings’ discomfort with the topic of bereavement, some parents expressed the belief that discussing the
death could potentially result in negative psychological consequences for surviving children. For instance, one mother commented, “My daughter is strong. It’s better not to bring it up and go deeper.”

3.2.2.4 Appreciation for Available Services

Interestingly, and in spite of the poor response to recruitment, some families expressed strong feelings of gratitude for having been offered the opportunity to participate in a bereavement program. Several parents who were considered to be active declines explained that although their child would not be attending the group, they were pleased that support services were available for other families. Given that these parents’ responses extended beyond a cursory thank you, the notion of appreciation for the hospital’s efforts appeared to represent an important additional theme in the data.

Chapter 4: Discussion

In this discussion, results yielded in Parts 1 and 2 of the study have been integrated and interpreted in order to provide a comprehensive understanding of feasibility with respect to the provision of services for bereaved siblings. As well, barriers to program implementation are identified and discussed. Finally, recommendations for future research and practice are offered based on findings obtained in both segments of the investigation.

4.1 Feasibility

4.1.1 Acceptability, Retention, and Treatment Fidelity

The feasibility of implementing a manualized bereavement intervention for children who had experienced the death of a brother or sister from cancer was assessed utilizing criteria outlined by Kazak and colleagues (2005). In regards to acceptability of the program, siblings and parents consistently reported substantial benefits on satisfaction questionnaires, with a majority
of responses corresponding to ratings of “very useful” or “useful.” Similarly, retention rates were high, with no dropouts, and mean overall program attendance, at 85.7%, was satisfactory. Taken together, these program evaluation and attendance results suggest that the intervention was perceived as beneficial by parents and siblings. In addition, treatment fidelity was maintained, as scores of adherence and participant engagement ranged from 77% to 95%, indicating that facilitators were able to implement the program in accordance with manualized guidelines.

4.1.2 Recruitment

In contrast with positive outcomes obtained for some feasibility criteria, mixed results were yielded for recruitment rates, which, together with qualitative data collected during enrolment interviews with parents, ultimately provided important insights into the support needs of bereaved families. For Part 1 of the study, participation rate was 66.7%, and better than or comparable to rates of other interventions offered for parents and siblings of children diagnosed with cancer (Kazak et al., 2005). Not surprisingly, all parents who were informed about the program by their treating psychologist in hematology/oncology, and had previously expressed the need for sibling bereavement services, consented to take part in the intervention. On the other hand, families that were identified by a member of the deceased child’s healthcare team as potential candidates for the intervention, but had not obtained psychosocial support at the hospital prior to the child’s death, were less likely to participate (50%). In the case of Part 2 siblings recruited for the program, only two families, one of which had already accessed psychosocial services at the hospital, agreed to attend the group. Considering that 44 families in total were contacted, this reflected exceptionally low interest in participation, and provided strong additional support for the notion of recruitment as a significant barrier to bereavement research (Akard et al., 2014; Stevens et al., 2010).
Given the considerable challenges encountered in recruiting Part 2 parents and siblings who were unknown to the supervising psychologist, it seems that bereaved families may be more likely to consent to participate in grief studies or interventions when rapport has previously been developed with members of the research or clinical team. Trust has been found to be an integral aspect of bereavement care (Tonkins & Lambert, 1996), and families that have experienced the significant trauma of losing a child may find it difficult to commit to attending services offered by unfamiliar individuals with whom a relationship has not been established. This is consistent with previous findings indicating that parents caring for children with life-limiting conditions, or those whose child died following a chronic illness, commonly deferred decisions about healthy siblings’ study participation until after the family had met a member of the research team (Stevens et al., 2010). Similarly, a qualitative culture study exploring the palliative care and bereavement experiences of Chinese and Mexican parents noted that a lengthy rapport building process was crucial to establishing willingness to participate in research (Davies et al., 2009).

Moreover, in addition to the development of trust influencing participation outcomes, recruitment rates obtained in both segments of the current study suggest that enrolment may be higher for families that have previously initiated dialogue with mental health providers on their support needs during periods of treatment, end-of-life or bereavement, compared to those that have been identified by members of the healthcare team as requiring care but have not expressed an interest in accessing services. In fact, prior findings have indicated that bereaved individuals who do not perceive the potential benefits of treatment are often, understandably, reluctant to participate in intervention studies (Caserta, Utz, Lund, & deVries, 2010). This highlights the importance of ensuring that parents are not merely provided with lists or brochures that contain the names of bereavement services in their communities, but are educated by healthcare staff on
how various programs may enhance aspects of functioning. Interestingly, a meta-analysis of bereavement interventions revealed that studies using clients who had actively sought bereavement services yielded significantly larger effect sizes than investigations where participants were recruited by researchers, suggesting that outcomes are impacted by participant motivation to engage in treatment as well (Allumbaugh & Hoyt, 1999).

4.1.2.1 Themes Reflecting Barriers to Enrolment

During the course of recruitment interviews conducted in part 2 of the study, families provided rich information on their bereavement experiences that was grouped into several overarching themes including: impediments to enrolment, coping with grief, and communicating with children. Impediments to enrolment such as seasonal barriers, concerns related to time frame, scheduling difficulties, discomfort with the hospital setting, and sibling lack of interest were generally the primary and most commonly cited reasons for refusing participation. Conversely, the themes of coping and communication were alluded to less frequently, and often presented as impacting enrolment indirectly. For example, while an initial phone call with a parent revealed communication difficulties in the family and feelings of discomfort associated with discussing bereavement-related issues, a follow up phone call indicated that this mother had in fact relayed the program information to her adolescent daughter, who ultimately declined participation due to a lack of interest.

In regards to subcategories for the overarching theme of impediments to enrolment, a number of parents reported that the prospect of attending a program in the hospital where their child had died triggered strong feelings of distress. Although not universal to all bereaved families, as some have found solace in returning to the healthcare setting and rekindling relationships with staff (Potts et al., 1999), this theme merits special attention considering similar
findings in other studies (deCinque et al., 2004; Macdonald et al., 2005; Welch et al., 2012). In response to families’ apprehension around participating in a program offered in a hospital, efforts were made to find an alternate setting for the group and thereby ensure that program location did not act as a barrier to participation. However, despite being informed that the intervention site had changed, only one family that had initially identified location as a reason for declining enrolment agreed to reconsider their decision. This suggests that, although the prospect of attending a hospital based bereavement program may be upsetting for families, intervention site is only one of a number of factors in the delivery of services that may cause emotional trauma and deter participation. In fact, time frame was another subordinate theme expressed by parents that revealed fears of reawakening negative feelings associated with the loss. For instance, in considering the optimal time frame for the program, several mothers expressed concerns that allowing their child to participate either “too soon” or “too long” after the death could potentially result in negative psychological consequences. Thus, while some parents worried that the intervention could be harmful for children who appeared to have come to terms with the loss, others feared that participating would force siblings to confront their feelings too early in the grief process. The notion of a critical window of time when mourners are most responsive to formal support services has been documented by previous studies, with researchers conjecturing that interventions may be most effective when delivered within a 6-18 month period following the loss (Jordan & Neimeyer, 2003). In addition to parents’ concerns regarding time frame and the potential for reactivation of the trauma, it is possible that another subcategory, sibling unwillingness to enrol in the program, reflected surviving children’s personal fears that attending the intervention might cause distressing feelings to resurface. Indeed, several parents related that healthy siblings had refused to attend other “fun” activities offered for family members of cancer
patients (i.e., summer camp, trips for siblings), perhaps due to concerns that interacting with other children sharing similar experiences would result in the emergence of troubling emotions.

In addition to concerns over the possibility of further destabilising siblings previously traumatized by the death, logistical factors were other significant obstacles that explained families’ decisions to decline participation. Specifically, seasonal issues (i.e., summer holidays, exams) were demonstrated to be an unexpected and significant barrier to participation that, to our knowledge, has not been explored in the literature to date. Interestingly, several members of the healthcare team that had prior experience with arranging bereavement related activities for families anticipated that the time of year (late spring, early summer) might not be optimal for running a support group. This suggests that, although seasonal challenges have not been documented in studies on bereavement, some healthcare staff are aware of this phenomenon. As well as seasonal barriers impeding enrolment, parents often stated that scheduling challenges precluded participation in the program. This was not unexpected, considering that the group was offered on a weekday evening, and a significant number of families cited prior engagements or lived a considerable distance from the intervention site. Given the variations in responses related to scheduling concerns provided by parents with older versus younger children, it seems that evenings may be more suitable for adolescents than younger elementary-school aged children. However, the provision of several groups offered at different times of day might not be feasible for facilitators or parents due to limited resources and problems with arranging transportation for siblings during working hours, thereby highlighting the complexity of scheduling considerations in regards to the planning of intervention groups.

In the course of phone recruitment interviews, parents often alluded to coping difficulties they had experienced while dealing with the trauma of the death, as well as strategies for
managing their grief. One parent described oscillating between coping and failing to cope, and this is consistent with literature suggesting that grief is often a complex, nonlinear, and ongoing process (Arnold & Gemma, 2008; Barrera et al., 2007; Stroebe & Schut, 1999). In regards to the magnitude of coping challenges faced by families, many appeared to have adjusted to the loss and had resumed normal day-to-day activities (i.e., soccer or karate practice, taking healthy children to doctor’s appointments), despite regularly experiencing intense feelings of distress. Only a small minority of parents described exceptionally compromised functioning that interfered with their ability to return to work and maintain a normal schedule, possibly reflecting symptoms of complicated grief. As such, for most families, coping difficulties were not a direct reason for refusing participation, but rather, an illustration of the challenges posed by daily living during the mourning process, and therefore a secondary obstacle to attending the program. Other studies have found similar low rates of clinically significant psychological problems in bereaved parents, with a vast majority exhibiting “integrated grief” patterns that are suggestive of adaptive functioning (Barrera et al., 2007). In addition to the large proportion of well-adjusted families in the current investigation, the notion of parental and sibling resilience was supported as well by families’ reports on methods that they found helpful for managing negative emotions. These included a variety of strategies used by parents and siblings to distract themselves from focusing on the trauma, enhance mental and physical strength, and obtain psychological support. Specifically, a number of families reported that surviving children had engaged in ‘active’ coping techniques such as seeking individualized psychological services, participating in a sport, or keeping occupied with studying or school related activities, and therefore not requiring additional support. In contrast, some of the approaches described by a minority of parents reflected ‘avoidant’ coping, whereby family members reported the need to constantly immerse
themselves in carrying out chores or tasks in order to repress painful thoughts and memories. This is consistent with research indicating that mental escape is a common strategy employed by bereaved individuals, and may be beneficial if used to temporarily seek relief from stress, or in conjunction with more active coping strategies (Stroebe & Schut, 1999).

Another overarching theme that emerged in recruitment interviews with parents was communication style within the family. This was not surprising, given previous reports of high rates of communication problems between parents and bereaved siblings (Metel & Barnes, 2011), despite evidence signifying better long-term adjustment for those who are able to engage in open dialogue (Eilegård et al., 2013; Martinson & Campos, 1991). In explaining the reason for what one mother described as “feelings of awkwardness” associated with the prospect of conversing about the death, several parents suggested that communication barriers originated from siblings’ discomfort with the topic of bereavement. Indeed, one parent expressed that an adolescent son refused to talk about his brother’s death in order to protect her and his father from experiencing further emotional trauma. The notion of children refraining from discussing a sibling’s death in order to avoid upsetting parents has been well-documented in the literature, with 71% of parents in one study reporting that their surviving child had not displayed symptoms of distress at the time of bereavement and refused to elaborate on his or her grief (Metel & Barnes, 2011). Although a majority of parents who reported limited communication within the family attributed this problem to children’s uneasiness with conveying their emotions, it is possible that parents themselves were also reluctant to converse about the death and destabilise surviving siblings. In fact, this fear was expressed by a mother who suggested that her daughter might become negatively affected by attending the support group, as it could cause her to “go deeper” and ruminate about the death. Interestingly, despite the fact that previous research
identified communication problems as a primary factor in families’ decisions to seek out treatment (Metel & Barnes, 2011), in the current study, this theme was typically cited by parents to support their decision to decline participation (i.e., that it was too uncomfortable to discuss the intervention with their children). This apparent contradiction suggests that parents and siblings who self-identify the need for services and are ready to seek professional help with managing their grief may be more open to viewing the negative consequences of the death as a reason for pursuing treatment, rather than as an obstacle.

A final, and unexpected, topic that emerged in discussions with parents was gratitude for available services. Although this theme did not explain underlying reasons for enrolment declines, it appeared to be an important category that reflected the sense of comfort that parents experienced from knowing that other individuals, and particularly hospital staff, had acknowledged their emotional distress and bereavement needs. This is consistent with literature indicating that parents greatly appreciate support and sympathy received from members of the deceased child’s healthcare team, with families reporting feelings of abandonment when follow-up care is not offered after the death (deCinque et al., 2006; Macdonald et al., 2005). Thus, even when parents declined participation in the intervention, they seemed to receive some degree of consolation just from knowing that they had not been forgotten. Furthermore, the fact that many families provided unsolicited and personal information on their bereavement experiences that extended beyond responses to questions asked by interviewers suggests that the phone calls themselves were perceived by parents as a form of support offered by the institution. Engaging in prolonged conversation about the death and grief process appeared to be therapeutic for parents, who may have offered information under the assumption that members of the research team would empathize and serve as a source of comfort, given their affiliation with the hospital.
4.1.3 Preliminary Group Intervention Outcomes and Sensitivity of Measures

An important objective in conducting the present investigation was to assess the efficacy of the intervention. This was accomplished by conducting an in-depth analysis of preliminary outcomes utilizing quantitative data collected in Part 1. Variables that were explored included quality of life, depressions, behaviour, grief symptomology, and impact of the trauma. Responses on these measures yielded mixed results, with parents’ scores providing greater support for positive outcomes compared to children. Specifically, parents’ reports of their children’s functioning on the PedsQL indicated significantly higher overall quality of life as well as enhanced social functioning following the group intervention. Similarly, parents’ responses reflected improved school functioning; however, the results were only of borderline significance, likely due to the small sample size. In contrast, children’s quality of life self-report questionnaires did not reflect any significant changes post-intervention. Physical functioning was noted by both parents and children to remain constant between baseline and the last session, which was not unexpected, considering that this domain was not targeted by the program (e.g., difficulties in walking more than one block, lifting something heavy).

Interestingly, although children’s responses on the PedsQL were not suggestive of significantly enhanced functioning in any area following the termination of the program, both participants’ and parents’ responses on satisfaction questionnaires indicated that the program had produced beneficial effects and was well received by families. A comparable pattern indicating positive responses on children’s satisfaction questionnaires and minimal intervention effects on self-report standardized measures, as well as a lack of agreement between parent and participant outcome scores, has been found in another intervention study with pediatric brain tumour survivors (Barrera & Schulte, 2009). Given these discrepancies, it is possible that young people
may be less aware of personal psychosocial changes that have occurred over a relatively brief period of time, or that standardized self-report measures used to assess children’s quality of life are not sensitive to subtle shifts that emerge throughout the grief process. Alternatively, benefits of the program may have been masked by temporary increases in distress experienced by participants due to a reawakening of painful thoughts and memories brought about by program discussions on death and the deceased child. This hypothesis was supported by siblings’ unexpected reports of slightly increased grief symptomology on the HIB following participation, which, although not significant, reflected trend-level effects with a medium effect size. Furthermore, as in the case of quality of life measures, children’s self-reported stress-symptomology on the IES-R had not decreased after attending the program, in contrast to parent reports of their children’s stress-related symptoms that were suggestive of trend-level effects. This is also potentially indicative of painful emotions associated with revisiting the trauma influencing siblings’ scores on measures used for evaluating their feelings of distress. An additional reason for the discrepancy obtained between parents’ and children’s scores regarding intervention efficacy may have reflected the fact that mothers and fathers were simply not aware of the magnitude of the impact of the loss on surviving siblings. However, although the notion of cross-informant variance in some areas of quality of life has been documented in previous studies (Eiser & Morse, 2001), this explanation does not appear to explain the current findings, as baseline quality of life scores in a majority of domains were not significantly different for parents and participants.

In addition to quality of life, bereavement symptomology and feelings of distress, siblings’ behaviours and symptoms of depression were evaluated to determine whether any changes had occurred following participation in the program. Of note is the fact that mean
baseline scores were not significantly different from normative values for all behavioural domains assessed by both parents’ and participant’s reports, with a similar pattern of results obtained for baseline depression scores as well. These findings were somewhat surprising, as grieving children have been demonstrated to be at increased risk for disturbances in a variety of areas (Alderfer et al., 2003; Balk, 1990; Davies, 1993; Thompson et al., 2011). This provides additional support for the hypothesis that standardized measures may not be sensitive to unique behaviour and mood responses exhibited by bereaved children. Alternatively, it is possible that since the group was comprised of a non-representative sample of bereaved families that had previously benefitted from therapeutic services offered by the hospital, scores for measures completed prior to treatment were not reflective of true baseline values. Interestingly, despite baseline scores in the non-clinical range, results on CBCL questionnaires completed by parents indicated borderline effects, with improved overall behaviours, and decreased externalizing and internalizing behaviours as a function of time. Similarly, siblings’ self-report scores on the YSR yielded trend-level effects that suggested reductions in overall problem behaviours post-intervention. Although results were only of borderline significance, statistical analyses of both parent and participant reports of overall behaviours, as well as parent scores on externalizing and internalizing behaviours, yielded large effect sizes. Considering that the small sample size likely influenced the results obtained, the large effect sizes produced from the analyses provide additional support for intervention efficacy. However, given the exceptionally low rates of problem behaviours reported by mothers and fathers following treatment, the possibility that parents’ scores were reflective of a positive response bias cannot be ruled out without further research to clarify the issue. In fact, in conducting Part 2, we had hoped to include a larger number of participants and provide the statistical tests with greater power to detect intervention
effects, but this could not be accomplished due to recruitment barriers that impeded program implementation.

4.2 Recommendations for Future Research and Practice

Considering the promising, but inconclusive, trends and findings in the present study, there is clearly a need for further research to provide more definitive support for the results obtained and allow for further exploration of issues raised by the investigation. Specifically, a more in-depth analysis of intervention efficacy may be achieved with the inclusion of a larger sample size and wait-list control group, both of which were not incorporated into the current investigation and therefore served as significant study limitations. In addition, given the discrepancies between children’s responses on acceptability questionnaires and their reports on outcome measures, as well as the low levels of clinically significant symptoms found in siblings at baseline, it seems that standardized questionnaires do not sufficiently capture the multifaceted nature of young people’s bereavement experiences or subtle changes in the grieving process. Thus, it is recommended that future studies should employ a mixed method design that utilizes standardized measures in conjunction with qualitative data obtained from interviews with families in order to enhance the evaluation process. In fact, due to the complexity of the phenomena studied, it has been suggested that the integration of quantitative and qualitative approaches may be particularly useful in health science research (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011), and, based on the current results, this seems to apply to the study of bereavement service efficacy.

In exploring the feasibility of carrying out a bereavement support group for siblings, it is evident that the topic of enrolment merits its own focus, given the significant recruitment challenges encountered in Part 2 of the study. Indeed, it may be argued that, despite impeding
program implementation, the large proportion of enrolment declines and wealth of information obtained from parents who actively declined participation were perhaps the most valuable study outcomes with respect to enhancing current knowledge on barriers to the provision of services for bereaved siblings. For instance, considering families’ unwillingness to attend the program, it seems plausible that the establishment of trust between clinicians and parents may play a role in the implementation of effective bereavement interventions, possibly rendering recruitment by unknown individuals a less than optimal approach. This is consistent with research indicating the utility of healthcare bereavement service models that reflect a ‘continuity of care’ (D’Agostino et al., 2008), whereby families are encouraged to seek and access services from trusted members of the patient’s treatment or palliative care team immediately after, and even prior to, the child’s death. Ensuring that families are offered transitional bereavement care by familiar healthcare professionals, particularly within the first two years following the loss, can help to alleviate some of the emotional discomfort that has been reported by parents who return to the treating centre after a lengthy period of time has passed since the death. As well, a continuity of services may reduce parents’ sense of being abandoned by the hospital community after their child dies and provide families with the security of knowing that they have not been forgotten. Moreover, families may be more likely to participate in bereaved interventions provided by the treating centre if they are offered a variety of program options such as the flexibility to engage in individual face-to-face contact with a professional, receive treatment in a group setting, attend events carried out at the hospital, or access services at a different location. However, given that parents who declined to participate did not express a desire for transitional services provided by familiar and trusted healthcare professionals, further research is required to directly assess whether rapport between clinicians and bereaved families is indeed a critical factor in
influencing recruitment and intervention outcomes.

In addition to contributing to the knowledge base on practices that may potentially enhance enrolment and program implementation of future bereavement interventions for siblings, the current investigation has provided insights into which children are likely to reap the greatest benefits from participation. Firstly, length of time since the death appears to be a factor that needs to be considered in bereavement service design, with some parent reports suggesting that optimal timing ranges from more than six months to less than two years following the loss. In fact, previous studies indicate that this may be the period when complicated grief is diagnosable and prognostic of later difficulties (Ott, 2003; Prigerson & Jacobs, 2001), rendering support provided ‘too early’ or ‘too late’ in the mourning trajectory as ineffective. Furthermore, given that a majority of mourners are able to work through and integrate the loss relatively well, with only a small proportion experiencing symptoms of complicated grief, it is likely that most would demonstrate improvements without any intervention (Barrera et al., 2007; Ott & Lueger, 2002; Stroebe, Hansson, Stroebe, & Schut, 2001). This may explain why a vast majority of siblings in Part 2 of the study were reported by their parents to have adapted to life after the death of a brother or sister and resumed regular daily activities. As well, it is possible that children who attended the program were generally found to be functioning within normal limits at baseline due to a low prevalence of complicated grief in the sample, consistent with rates found in previous studies (Barrera et al., 2007; Ott & Lueger, 2002; Stroebe, Hansson, Stroebe, & Schut, 2001). These findings suggest that targeting all bereaved siblings included in a hospital register for participation is arguably a poor use of scarce resources, as well as potentially detrimental for children who may have responded well without treatment (Jordan & Neimeyer, 2003). Instead, it is recommended that families are provided with the opportunity to participate
in some type of screening process offered by palliative and bereavement care services that can help to determine which children are manifesting symptoms of complicated grief, and therefore, should be classified as high-risk mourners. Finally, in considering which families would benefit most from attending a bereavement program, it appears that those who self-identify the need for services are more apt to enrol and achieve the greatest gains, possibly due to greater motivation to deal with their grief, or the prevalence of higher levels of distress symptoms that require professional care in this population (Jordan & Neimeyer, 2003). In the current study, differences between self-identified participants and those who were referred could not be analyzed in depth given the small sample size. However, recruitment rates for Part 1 indicated that parents who had accessed services from a psychologist in hematology/oncology prior to the recruitment period and were aware of the benefits of treatment were most likely to respond favourably to attending the program. Conversely, those who had been identified by a member of the healthcare team as good candidates for the intervention but had never acknowledged the need for support were less likely to participate. This raises the question of whether families should be actively recruited for bereavement programs at all, or if parents should simply be informed and educated about the range of services offered by the hospital via email or letters, and then encouraged to initiate contact if interested in participating.

4.3 Conclusion

In summary, results obtained in Part 1 of the investigation yielded favourable outcomes for aspects of feasibility including acceptability, retention rates, and treatment fidelity, while preliminary intervention effects were mixed. Taken together, these data suggest strong evidence for the practicality of implementing a manualized bereavement program for grieving siblings, and promising, although inconclusive support for intervention efficacy. On the other hand,
outcomes for Part 2 of the study indicated exceptionally low recruitment rates that precluded the program from being offered, suggesting that difficulties encountered at the time of enrolment are a critical barrier to services experienced by parents and siblings and therefore a significant problem with respect to the feasibility of intervention implementation. Considering these findings, together with a general dearth of empirically based programs to address the needs of grieving families, there is clearly a compelling need for further research to provide more decisive evidence for intervention efficacy and a greater understanding of families’ needs. However, based on current results, it appears that the use a rigorous recruitment methodology that targets the inclusion of a representative sample of all bereaved siblings may not be possible, or even desirable, for intervention research aimed at servicing this highly vulnerable population.

In regards to clinical practice, themes that emerged during recruitment interviews with parents reflected challenges in the enrolment process, and were used to identify elements of hospital-based bereavement services that may be included to increase participation. Specifically, professionals involved in the implementation of bereavement care should be educated on which siblings are most likely to benefit from psychological treatment, with enrolment efforts aimed at griever with elevated risk for dysfunction, rather than children who display adaptive responses prior to, and following, the loss. At the same time, attempts to persuade families with heightened levels of psychosocial problems or grief symptoms to access care must be balanced with a supportive attitude that encourages parents and siblings to self-identify their own needs in the bereavement process and seek professional services as they see fit. Moreover, based on the large discrepancy in recruitment rates between families that were known to the supervising psychologist and those that were recruited by unfamiliar members of the research team, the relationship between trust and enrolment appears to be a factor in the provision of care that
merits further exploration. In reviewing the literature on bereavement service evaluation, it is evident that the scientifically demonstrated efficacy of formal interventions for mourning children is distressingly low, despite slowly increasing awareness of the unique and complex nature of sibling bereavement. It is hoped that integrating recommendations yielded from the current investigation into the delivery of bereavement care will increase program feasibility and minimize barriers to services, while most importantly, ensuring that insights gleaned from the experiences of bereaved families are used to guide the direction of future research and practice.
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Figures and Tables

Total number invited for participation

\[ n = 59 \text{ Families} \]

Part 1

- Group 1
  - Eligible \((n = 5)\)
  - Enrolled \((n = 5)\)
  - Declined Participation \((n = 0)\)

- Group 2
  - Eligible \((n = 10)\)
  - Enrolled \((n = 5)\)
  - Declined Participation \((n = 5)\)

Part 2

- Recruited by telephone \((n = 44)\)
  - Found to be ineligible \((n = 2)\)
  - Number out of service \((n = 1)\)
  - Active declines \((n = 25)\)
  - Passive declines \((n = 14)\)
  - Agreed to participate \((n = 2)\)

Figure 1. Flow chart summarizing eligibility and recruitment of participants for Parts 1 and 2 of the study
Table 1

*Sample Demographic Information*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling participant age (years; $N = 10$)</td>
<td></td>
<td>11.30 (2.39)</td>
</tr>
<tr>
<td>Deceased child’s age at time of death (years; $N = 10$)</td>
<td></td>
<td>10.15 (2.82)</td>
</tr>
<tr>
<td>Mother’s age (years; $N = 10$)</td>
<td></td>
<td>43.38 (7.39)</td>
</tr>
<tr>
<td>Father’s age (years; $N = 6$)</td>
<td></td>
<td>46.00 (6.57)</td>
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<tr>
<td>Sibling age (years)</td>
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<td></td>
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<tr>
<td>6</td>
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<td>9</td>
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<tr>
<td>14</td>
<td>2</td>
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<tr>
<td>Sibling gender</td>
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<td></td>
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<tr>
<td>Female</td>
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<tr>
<td>Time passed since death</td>
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<td></td>
</tr>
<tr>
<td>&lt; 12 months</td>
<td>4</td>
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<tr>
<td>12-18 months</td>
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<tr>
<td>24-36 months</td>
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<td>Second born</td>
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<tr>
<td>Youngest</td>
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<tr>
<td>Number of children in family prior to death</td>
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<td>Two Children</td>
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<tr>
<td>Three Children</td>
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Other 1

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<tr>
<td>African/Canadian</td>
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</tr>
<tr>
<td>Jamaican/Canadian</td>
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<th>Mother’s education level completed</th>
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<td>High school</td>
<td>3</td>
</tr>
<tr>
<td>Some college/university</td>
<td>0</td>
</tr>
<tr>
<td>University</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
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<table>
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<th>Father’s education level completed</th>
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<tbody>
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<td>High school</td>
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</tr>
<tr>
<td>Some college/university</td>
<td>2</td>
</tr>
<tr>
<td>University</td>
<td>3</td>
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<th>Parents’ marital status</th>
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<tr>
<td>Divorced</td>
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### Table 2

**Means, Standard Deviations, and Effect Sizes for Outcome Measures**

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<tr>
<th>Scale</th>
<th>N</th>
<th>Baseline M (SD)</th>
<th>Post-intervention M (SD)</th>
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<tr>
<td>PedsQL (Total, Parent)</td>
<td>13</td>
<td>74.66 (19.58)**</td>
<td>83.84 (10.61)</td>
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<tr>
<td>PedsQL (Emotional, Parent)</td>
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<td>58.85 (27.70)**</td>
<td>79.62 (13.14)</td>
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<tr>
<td>PedsQL (Physical, Parent)</td>
<td>13</td>
<td>83.65 (20.89)</td>
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<tr>
<td>PedsQL (School, Parent)</td>
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<td>66.92 (25.70)*</td>
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<tr>
<td>PedsQL (Social, Parent)</td>
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<td>83.85 (15.16)**</td>
<td>92.69 (12.35)</td>
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<tr>
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<td>45.20 (17.93)*</td>
<td>36.20 (11.78)</td>
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<tr>
<td>CBCL (Internalizing, Parent)</td>
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<td>42.80 (10.57)</td>
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<td>CBCL (Externalizing, Parent)</td>
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<td>38.20 (6.57)</td>
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<tr>
<td>IES-R (Parent)</td>
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<td>PedsQL (Total, Child)</td>
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<td>68.00 (21.63)</td>
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<td>PedsQL (Physical, Child)</td>
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<td>PedsQL (School, Child)</td>
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<td>78.00 (24.18)</td>
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<td>PedsQL (Social, Child)</td>
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<td>YSR (Total, Child)</td>
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<td>CDI (Child)</td>
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<tr>
<td>Measure</td>
<td>Mean (SD)</td>
<td>95% CI</td>
<td>Effect Size</td>
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</tr>
<tr>
<td>--------------------------------</td>
<td>-----------</td>
<td>--------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>HIB (Grief, Child)</td>
<td>10</td>
<td>38.00  (14.19)</td>
<td>47.20 (17.57)</td>
<td>-.32</td>
</tr>
</tbody>
</table>

CBCL (Child Behavior Checklist; Achenbach, 1991)
CDI (Child Depression Inventory; Kovacs, 1992)
HIB (Hogan Inventory of Bereavement; Hogan & DeSantis, 1996)
IES-R (Impact of Event Scale- Revised; Weiss & Marmar, 1997)
PedsQL (Pediatric Quality of Life Index; Varni et al., 2002)
YSR (Youth Self Report; Achenbach, 1991)

\[ p \leq .11 \] *  
\[ p \leq .05 \] **  
\[ p \leq .01 \] ***
Appendices

Appendix A: Parent Consent Form, Child Consent Form, Child Assent Form

CONSENT FORM

(Parent Form for Child)

Title of Project: A Feasibility Study of Group Therapy for Bereaved Siblings

Investigators:
Dr. Maru Barrera (416) 813-6784
Ms. Naomi Greenwald (416) 813-6784
Ms. Kelly Hancock (416) 813-4957
Ms. Ceilidh Eaton-Russell (416) 586-4800

Purpose of Research:
Children and adolescents who have experienced the death of a brother or sister from cancer are faced with a variety of problems that affect the way they live their lives. We developed a group program for bereaved siblings in order to reduce their grief and distress and find ways to make life a little more enjoyable. The main purpose of this study is to find out how this group will work best for young people like your child.

Description of The Research:
The study includes the following:

1) Parents and their children will be asked to complete questionnaires before and after the group program. The questionnaires ask about your child’s feelings and actions, how he or she gets along with others, and some general information about your family. Examples of some of the questions your child will be asked include whether it’s hard for her/him to pay attention in class, how often he/she feels sad, and whether he/she has trouble sleeping. The questionnaires take approximately 30 minutes to complete.

2) The group program consists of 8 sessions. Each session is held once a week for 2 hours. Specifically, the program will help siblings deal with their feelings and manage their relationships with the deceased child, other family members, and friends and classmates. The program will also focus on siblings’ present life experiences using creative activities, group discussion and games.

3) There will be approximately 24 participants between the ages of 8 to 16 in this study.
Potential Harms:
We know of no harm that taking part in this study could cause you or your child. You or your child may feel some discomfort when thinking about issues of grief and loss during group participation and while completing some questions. However, you or your child can decline to answer any question(s) that make you feel too uncomfortable. Additionally, if you or your child experiences severe distress during the course of the study, it will be addressed by the Registered Psychologist, Dr. Maru Barrera, who has many years of experience working with bereaved children and families. Moreover, should you experience any distress or discomfort at a later time from participating in this study, Dr. Barrera will assist you and your family in obtaining appropriate services. Also, if you would like, we will provide information about additional bereavement resources for you and your family.

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

Potential Benefits:
• Some children who participate in this study may benefit by participating in the group.
• The group is not proven therapy and, therefore, we cannot guarantee that participants will receive any benefit at all from this study.
• This group intervention program may benefit other children in the future who are grieving the death of a brother or sister.
• If families are interested in receiving general information about the study progress and a copy of the publication(s), we will provide them with the relevant materials at the end of the study. Families will not be receiving individual summary reports regarding their responses to the questionnaires as the data will be reported as group data.

Confidentiality:
We will respect your privacy. No information about the identity of you or your child will be given to anyone or published without your permission, unless the law requires us to do this. For example, the law requires us to give information about you (your child) if a child has been abused, if your child has 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.

Sick Kids Clinical Research Monitors, employees of the funder or sponsor of the study, or the regulator of the study may see your (your child’s) health record to check on the study. Additionally, the sessions in the study may be observed by an independent observer through a one-way mirror. If this happens we will let the children know that they are going to be observed and introduce them to the observer.

By signing this consent form, you agree to let these people look at your child’s records and observe the sessions. We will put a copy of this research consent form in your child’s research record. We will give you a copy for your files.

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. This could include external research team members. Following completion of the research study, the data will be
kept as long as required and then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.

The results of the tests we describe in this form will be used only for this study. If another health care professional caring for your child needs to see these results, you will have to give us your permission first. We will ask you to sign a form stating that you agree to have this person see your child’s results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

During the group meeting we will remind everyone that the information shared is private and should not be repeated outside the group. However, we cannot be sure that information about your child will be kept private. People in groups may share information about you with others outside the group.

**Reimbursement:**
We will reimburse you for parking expenses or provide you with the equivalent traveling expenses to participate in the study. Also, at the end of the sessions, children will receive a small gift.

**Participation:**
If you choose to let your child take part in this study you can take your child out of the study at any time. The care your child gets at SickKids will not be affected in any way by whether or not your child takes part in this study. New information from this study or other studies may affect whether you and your child want to continue to take part in the study. If this happens, we will tell you about this new information.

If your child becomes ill or is harmed because of study participation, we will treat your child for free. Your signing this consent form does not interfere with your legal rights in any way. The study staff, any people who gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

**Sponsorship:**
This study was originally funded by the Pediatric Oncology Group of Ontario (POGO) and is currently being sponsored by SickKids Hospital.

**Conflict of Interest:**
I, and the other research team members, have no conflict of interest to declare.

**Consent:**

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 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 ____________________________
Parent/Legal Guardian’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 Kelly Hancock (Project Coordinator) at
(416) 813-4957.

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.
CONSENT FORM  
(Child Form)

Title of Project: A Feasibility Study of Group Therapy for Bereaved Siblings

Investigators:  
Dr. Maru Barrera  (416) 813-6784  
Ms. Naomi Greenwald  (416) 813-6784  
Ms. Kelly Hancock  (416) 813-4957  
Ms. Ceilidh Eaton-Russell  (416) 586-4800

Purpose of Research:  
Kids who have a brother or sister who dies of cancer are faced with a variety of problems that affect the way they live their lives. We developed a group program for siblings like you in the hope that participating in the group will help reduce grief and sadness. The goal of this study is to find out if a group program for siblings whose brother or sister died of cancer is helpful to kids like you.

Description of the Research:  
The study involves the following:

1) Kids and their parents will be asked to complete questionnaires before and after the group program. The questionnaires ask about your feelings, actions, how you get along with others and some general information about your family. Examples of some of the questions you will be asked include whether it’s hard for you to pay attention in class, how often you feel sad, and whether you have trouble sleeping. The questionnaires take approximately 30 minutes to complete.

2) The group program consists of 8 sessions. Each session is held once a week for 2 hours. The group will help you to deal with your feelings and thoughts about your brother or sister who died, maintain healthy relationships with family members, friends and classmates, and learn how to focus on your present daily life. We will do those things by participating in creative activities, group discussions and games.

3) There will be approximately 24 participants between the ages of 8 to 16 in this study.

Potential Harms:  
We know of no harm that taking part in this study could cause you. However, you may feel some discomfort when thinking about issues of death and grief during group participation and while completing some questions. You can decline to answer any question(s) that make(s) you feel too uncomfortable. Additionally, should you experience severe distress during the course of this study, it will be addressed by the registered psychologist, Dr. Maru Barrera, who has
many years of experience working with bereaved children and families. Moreover, if you experience any distress or discomfort at a later time from participating in this study, Dr. Barrera will assist you and your family in obtaining appropriate services. Also, if you would like, we will provide information about additional bereavement resources for you and your family.

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

**Potential Benefits:**
- Some children who participate in this study may benefit by participating in the group.
- The group is not proven therapy and, therefore, we cannot guarantee that participants will receive any benefit at all from this study.
- This group program may benefit other children in the future who are grieving the death of a brother or sister.
- If families are interested in receiving general information about the study progress and a copy of the publication(s), we will provide them with the relevant materials at the end of the study. Families will not be receiving individual summary reports regarding their responses to the questionnaires, as the data will be reported as group data.

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

To check on the study, some research monitors from SickKids or employees of the funders of the study may see your health record. Also, the sessions in the study may be observed by an independent observer through a one-way mirror. If this happens, we will let you know that there is an observer in the next room.

By signing this consent form, you agree to let these people look at your records and for an observer to observe the sessions. We will put a copy of this research consent form in your research records. We will give you a copy for your files.

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. This could include external research team members. Following completion of the research study, the data will be kept as long as required and then destroyed as required by SickKids policy. Published study results will not reveal your identity.

The results of the tests we describe in this form will be used only for this study. If another health care professional caring for you needs to see these results, you will have to give us your permission first. We
will ask you to sign a form saying that you agree to have this person see your results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

During the group meeting we will remind everyone that the information shared is private and should not be repeated outside the group. But we cannot be sure that information about you will be kept private. People in groups may share information about you with others outside the group.

**Reimbursement:**
We will reimburse you for parking expenses or provide you with the equivalent traveling expenses to participate in the study. Also, at the end of the sessions, children will receive a small gift.

**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 or not you take part in this study. New information from this study or other studies may affect whether you want to continue to take part in the study. If this happens, we will tell you about this new information.

If you become ill or are harmed because of study participation, we will treat you for free. Your signing this consent form does not interfere with your legal rights in any way. The study staff, any people who gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

**Sponsorship:**
This study was originally funded by the Pediatric Oncology Group of Ontario (POGO) and is currently being sponsored by SickKids Hospital.

**Conflict of Interest:**
I, and the other research team members, have no conflict of interest to declare.

**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 do so.
6) I understand that no information about who I am will be given to anyone or published without first asking my permission.

7) I have read and understood pages 1 to 3 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 Kelly Hancock (416) 813-4957.

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: A Feasibility Study of Group Therapy for Bereaved Siblings

Investigators:
- Dr. Maru Barrera (416) 813-6784
- Ms. Naomi Greenwald (416) 813-6784
- Ms. Kelly Hancock (416) 813-4957
- Ms. Ceilidh Eaton-Russell (416) 586-4800

Why are we doing this study?
Kids who have a brother or sister who dies of cancer are faced with a variety of problems that affect the way they live their lives. The goal of this study is to find out if a group program for siblings whose brother or sister died of cancer is helpful to kids like you.

What will happen during the study?
The study involves the following:

1) To find out if this group is helpful, kids and their parents will be asked to complete questionnaires before and after the group program. The questionnaires ask about your feelings, actions, how you get along with others and some general information about your family. The questionnaires take approximately 30 minutes to complete.

2) The group program consists of 8 sessions. Each session is held once a week for 2 hours. During the group we will make arts and crafts, play games, have group discussions and most importantly, we will have fun together while we learn how to deal with your feelings, your thoughts and how to focus on your present daily life.

Are there good things and bad things about the study?
We know of no harm that taking part in this study could cause you. However, you may feel some discomfort when thinking about issues of death. Given the purpose of the group, you may feel some discomfort during group participation and while completing some questions. You don’t have to answer any questions that make you feel too uncomfortable. If you require any additional help, please contact the study coordinator: Kelly Hancock (416) 813-4957.

We are hopeful that kids who participate in this study will benefit from the experience. We also hope that this program will eventually help other kids in the future who are grieving the death of a brother or sister.

Who will know about what I did in the study?
If you are part of this study, your name and any other information about you will not be given to anyone. This will not be shared with anyone outside of the research/study staff. One exception is that if we feel your health may be in danger, we have to report that information to your parents or someone else.
Also, one of the study staff may watch the group from a one-way mirror in a different room. If this is going to happen we will let you know and let you meet the person who will be watching the group.

**Can I decide if I want to be in this study?**

It is your choice to take part in this study. You can stop at any time. If you decide not to take part, nobody will be angry or upset. We have talked to your parent(s)/legal guardian(s) about the study and, if you want to, you should talk to them about it too. Also, please ask us any questions that you have about the study. We will help you to understand.

**Assent:**

"I was present when ____________________________ read this form and said that he or she agreed, or assented, to take part in this study”.

________________________
Printed name of person who obtained assent

________________________
Signature & Date
Appendix B: Parent Satisfaction Questionnaires, Child Satisfaction Questionnaires

Melanie’s Transition Group Evaluation
(PARENT FORM)

Date: ___________________________ ID#: ___________________________

Below are some questions about the group your child participated in. We would like to know your views on the effect of the group on your child. Please select the responses that best represent your opinions.

1. How useful was the group in providing your child with information about coping with the loss of their brother/sister?

   Very Useful  Useful  Somewhat Useful  Not Useful at All  Don’t Know

2. How much do you feel your child’s involvement in the group has helped him/her to express his/her thoughts and feelings about the loss of his/her sibling to:

   a) friends/classmates?

      Helped Very Much  Helped  Helped Somewhat  Didn’t Help at All  D/K

   b) parents?

      Helped Very Much  Helped  Helped Somewhat  Didn’t Help at All  D/K

   c) other family members?

      Helped Very Much  Helped  Helped Somewhat  Didn’t Help at All  D/K

3. In your view, what was the best part of the group for your child?

   __________________________________________________________

   __________________________________________________________

4. In your view what was the most challenging part of the group for your child?

   __________________________________________________________

   __________________________________________________________
5. Do you have any additional comments or suggestions? (Please write on the back if necessary.)


Thank you for your assistance in completing this evaluation.
Melanie’s Transition Group Evaluation  
(CHILD FORM)

Date: ___________________________    ID#: ___________________________

Below are some questions about the group which you participated in. We would like to know how you felt about the group and whether it was helpful to you or not. Please check the answer that best represents how you feel about the group.

1. How useful was the group in addressing any issues related to losing your sister/brother?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful

2. How useful was the group in providing you with information about coping with the loss of your sister/brother?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful

3. How much do you feel the group helped you to express your feelings about the loss of your sister/brother to your friends or classmates?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful

4. How much do you feel the group helped you to express your feelings about the loss of your sister/brother to your family?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful

5. How useful was the group in helping you understand your new identity (example, only child, only girl, etc) within your family and at school?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful

6. How useful was the group in helping you accept your new identity within your family and at school?
   - Very Useful
   - Somewhat Useful
   - A Little Useful
   - Not Useful
7. What were your favourite parts about the group?

8. What were your least favourite parts about the group?

9. Do you have any advice for us?

10. Any additional comments?

Thank you for your cooperation.
Dear (name of parents)

I would like to express my sympathy to you and your family. Many of us here at the hospital were honored to work with (name of deceased child). I also wanted you to know that we are currently trying to learn more about how to help families when they have lost a child due to cancer, and we are particularly concerned about how to help siblings. Presently, there are limited services that focus only on the needs of bereaved siblings due to cancer. Indeed, many parents have told us of the need for resources here at Sick Kids for children and teens whose sibling has died from cancer. For this reason, we have developed an eight-week group therapy program for siblings of children who were treated by one of the teams in the haematology/oncology programs. We are assessing whether or not this group helps to reduce siblings’ grief and distress.

You and your children are under no obligation to participate in this project. You will be contacted in a few days by telephone with more details and to answer any questions you might have. If you would prefer that we not call you, please leave a message at 1-866-804-2921.

Thank you very much for considering participation in this special project. I believe this work will help grieving children deal with their sadness and every day life. We also hope that the results of this study will help us to provide comprehensive services for bereaved siblings in the future. My best wishes to you and your family.

Sincerely,

Dr. Maru Barrera, PhD, C. Psych
Department of Hematology/Oncology
Hospital for Sick Children
Appendix D: Recruitment Interview Script

Sibling Bereavement Group Recruitment Script
(families who received letter)

Hello, my name is __________ and I am calling from Sick Kids. I work with Dr. Barrera, a psychologist in the Hematology/ Oncology Program here in the hospital. I am calling about a letter you should have received a little while ago about a bereavement support group we are offering for children that will be starting in the next couple of weeks. Is this a good time to talk? It will take approximately 10 minutes.

Many parents here at SickKids have told us of the need for support services for siblings whose brother or sister died of cancer. We have developed a group for these children and are evaluating the program to see if people find it to be helpful. The purpose of my call is to invite (sibling’s name) to participate in this group.

The group will be held once a week for eight weeks and kids will get a chance to do a number of activities which we hope will help them with their grieving. They will get to talk about their experience with the death, express their feelings, and learn new ways to cope. The weekly group sessions will also give kids the opportunity to meet others who have been through similar experiences. We are planning on running the group on Wednesday evenings from 6:30 to 8:30, beginning on May 14 and concluding the first week of July.

Do you think this is something you and (sibling’s name) might be interested in? If you think (sibling’s name) might be interested in participating but would like to discuss it with him/her, I am happy to phone you again tomorrow after you have had a chance to speak with (sibling’s name) about his/her participation in this group. I am also happy to speak with (sibling’s name) myself and tell him/her a little more about the group if you would prefer. If parent wants us to call back the next day, schedule a time to call with them.

If YES TO PARTICIPATE:
Great, we are happy that you are interested. Let me get a little more information about (sibling’s name) and your family to make sure that this group is appropriate for (sibling’s name).

Screening Criteria
• How old is your son/daughter?
• Where do you live?
• Has your child been diagnosed with a learning disability?
• Does your child receive any special education services?
• Does your child have any medical conditions? (including mental health)
• Has your child received any counseling/therapy in order to help with the grieving process? If so, what services, frequency, when, etc.
• Is your child able to commit to the duration of the 8-week program?

The group will take place here at the hospital and, like I mentioned, will be held once a week for eight weeks. I should also let you know that we will be covering the parking fees for the weekly group meeting.
As part of the evaluation of the group, participating children and one of their parents will fill out some questionnaires. The first set of questionnaires will be completed on the first day we begin the group. This will take approximately 45 minutes to an hour. There will also be a short interview with the child and one of his/her parents on the first and last day of the group.

Do you have any questions? Thank you so much for speaking with me today and again we are pleased (sibling’s name) will be a part of this sibling group. We are looking forward to getting to know (sibling’s name) and will be calling you again in the near future to finalize group details.

**If NO:**
Would you mind sharing with me why you do not think this would be something (sibling’s name) would like to be involved in? Even though (sibling’s name) is not able to/doesn’t want to attend the group, I was wondering if you and your child would be able to fill out some questionnaires and participate in a short interview. The purpose of this is to help us evaluate the program and see if there are any differences in the grief process of children who do or don’t attend the program. Is that something you would be interested in doing?

**If parent says yes to questionnaires:** Great. There are two possible ways we can have you fill out the forms. Either we can come to your house and go over the questions with you and your child or you can come to the hospital and fill them out here. If you choose that option, we would pay for parking/transportation costs. The questionnaires and interview will take approximately an hour to complete. Would you prefer to come here or to have us come to you? (wait for response) Great. Then we will be calling you in the near future to finalize plans for having you fill out questionnaires.

Okay, well thank you for speaking with me today. I would like to leave you my phone number for you to contact me if you change your mind about participating in the program. If you prefer, I can also give you my email address. Please feel free to give me a call or send an email if you and (sibling’s name) become interested in participating.